Universidade do Minho
Escola de Economia e Gestão

Teresa Sofia Amorim Faria de Oliveira Lopes

Understanding and managing the holistic patient experience for improving healthcare services and well-being

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Understanding and managing the holistic patient experience for improving healthcare services and well-being

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Professora Doutora Cláudia Maria Neves Simões
e do
Professor Doutor Patrício Ricardo Soares Costa
e da
Professora Doutora Joana Pinto Leite César Machado

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THE STATEMENT OF INTEGRITY

I hereby declare having conducted this academic work with integrity. I confirm that I have not used plagiarism or any form of undue use of information or falsification of results along the process leading to its elaboration. I further declare that I have fully acknowledged the Code of Ethical Conduct of the University of Minho.

RESUMO – "Entendimento e Gestão da Experiência holística dos doentes para melhoria da entrega dos serviços de saúde e bem estar"

A presente tese tem por objetivo compreender como é que a experiência holística do doente se desencadeia ao longo da sua jornada e como é que os prestadores de serviços de saúde podem geri-la e melhorá-la eficazmente. A investigação reconhece que as experiências dos doentes são moldadas num ambiente de serviço complexo que envolve múltiplas partes interessadas, com os doentes ativamente envolvidos nos seus próprios cuidados de saúde e a importância de investigar as experiências dos doentes para melhorar os serviços, os resultados clínicos e o bem-estar dos doentes. No entanto, apesar do interesse crescente na experiência do doente, ainda é necessário um maior consenso relativamente à sua definição no âmbito da investigação em saúde. As definições da experiência do doente têm adotado principalmente a perspetiva do prestador de serviços de saúde, centrando-se nas dimensões da qualidade do serviço que moldam a experiência do doente e negligenciando-a como um fenómeno holístico. Para colmatar essa lacuna de investigação, a presente tese foi concebida, subdividindo-se em três principais estudos inter-relacionados.

O ponto de partida (Ensaio I) foi uma extensa revisão da literatura para sistemarizar as definições, bem como os métodos e as abordagens de investigação sobre a experiência do doente. Os resultados mostram que é necessário adotar uma visão holística da experiência, assumindo a perspetiva do doente no estudo da sua experiência, uma vez que esta engloba todas as interacções entre os doentes e os profissionais de saúde em vários pontos de contacto e canais ao longo da jornada do doente, ultrapassando as fronteiras das instituições de saúde. Foi proposto um modelo que mapeia e tipifica a experiência holística de um grupo de doentes com patologias crónicas. O modelo delineia as etapas (pré-, durante e pós-serviço) e os pontos de contacto mais relevantes ao longo da jornada do doente.

A segunda e terceira partes desta investigação (Ensaio II e III) constituem a componente empírica desta tese. No segundo estudo (Ensaio II), foi realizada uma netnografia, com análise de 186 tópicos de discussão de duas comunidades internacionais de saúde online para explorar as dimensões da experiência holística e do bem-estar reportadas doentes crónicos com diabetes tipo-1 (DT1) e Insuficiência Renal Crónica (IRC) em estadios avançados.

O terceiro e último estudo (Ensaio III) implicou a recolha de dados de 33 participantes, realizando-se um total de 40 entrevistas com múltiplos participantes, bem como a recolha de dados de outras fontes para efeitos de triangulação. Para a análise dos dados qualitativos do Ensaio II e III,

realizámos uma análise temática e uma análise de correspondências múltiplas (ACM) para explorar associações entre um conjunto de variáveis categóricas no Ensaio III.

Os resultados dos nossos estudos empíricos revelam as nuances específicas associadas a cada uma das doença crónicas estudadas, identificando grupos de pontos de contacto que moldam predominantemente as experiências dos doentes. Em particular, a investigação sublinha a presença de três categorias de pontos de contacto relacionados com a marca, com o doente e com a esfera social e que emergem como os influenciadores mais críticos das experiências dos doentes com Diabetes Tipo 1 e Doença Renal em Fase Terminal.

Ambos os estudos destacam alguns aspectos convergentes, tais como: (1) a necessidade imperativa de melhorar os processos de prestação dos cuidados de saúde e a importância do estabelecimento de uma relação de proximidade entre doentes e profissionais de saúde, enfatizando o supprte informacional e emocional (fatores diretamente controláveis pela instituição de saúde); (2) o papel dos doentes no autocuidado e na gestão e os seus esforços para se envolverem em actividades de co-criação de valor e ajustarem o seu estilo de vida à doença; e (3) a importância do suporte social (por exemplo, amigos, família, cuidadores), denotando-se aqui uma lacuna crítica no entendimento que as pessoas têm sobre estas doenças e de que forma é que se deve alavancar a literacia para a saúde. Estas conclusões convergentes sublinham áreas fundamentais para que as organizações de saúde criem uma forte orientação de resposta à experiência dos doentes e melhorando a sua gestão, promovendo a melhoria contínua dos serviços e gerando melhores resultados em saúde. Nas conclusões são discutidas as implicações teóricas, metodológicas e práticas, bem como as limitações inerentes à investigação e sugestões para futura investigação.

Palavras-chave: experiência do doente, jornada do doente, pontos de contacto, doenças crónicas, prestação de serviços de saúde, resultados em saúde.

ABSTRACT

The present thesis aims to understand how the holistic patient experience (PX) unfolds across the journey and how healthcare providers (HCPs) can effectively manage and enhance it. Research recognises that PXs are shaped within a complex service environment involving multiple stakeholders, with patients actively engaged in the care process, and the importance of investigating the PX to drive service improvements and health outcomes including well-being. However, despite increasing interest in PX, there still needs to be more consensus regarding its definition within research in healthcare. PX definitions have primarily adopted the healthcare provider perspective, focusing on service quality dimensions shaping the patient's care experience and overlooking PX as a holistic construct. The present thesis was conceived to fill this research gap and is subdivided into three main interrelated studies.

The starting point (Essay I) was an extensive literature review to sistematize the definitions, as well as the methods and approaches used in PX research. The results show that a clearer and more holistic view of the PX is needed, as it encompasses all interactions between patients and providers across various touchpoints and channels throughout the patient journey, extending beyond the boundaries of healthcare institutions. We proposed a model depicting a typical experience journey of a group of patients with chronic illnesses which outlines the main stages (pre-, during and post-service) and the most relevant points of contact along the patient's journey.

The second and third parts of this research (Esssay II and III) compose the empirical component of this thesis. In the second study (Essay II), a netnography was conducted, in which 186 discussion threads were analysed from two international online health communities – OHCs to explore the expressed dimensions of the experience and well-being of chronically ill patients with type 1 diabetes (T1D) and End-Stage Renal Failure (ESRF) throughout their journey.

The third and last study (Essay III) included collecting data from 33 participants and 40 interviews with multiple informants (patients, ICs and HCPs) as well as collecting data from other sources for triangulation purposes. For qualitative data analysis of Essay II and III, we conducted a thematic analysis and multiple correspondence analysis (MCA) to explore associations between a set of categorical variables within Essay III.

Both studies emphasise some convergent aspects, such as (1) the imperative need to improve healthcare delivery processes and the importance of establishing a close relationship between patients and healthcare professionals, emphasising informational and emotional support (factors

directly controllable by the healthcare institution/brand-owned touchpoints); (2) the role of patients in self-care and management and their efforts to engage in value-creating activities and adjust their lifestyle to the disease; and (3) the importance of social support (e.g. friends, family, carers), highlighting a critical gap in people's understanding of these diseases and how health literacy should be improved. These convergent findings underscore pivotal areas for HCOs to create a strong PX response orientation by enhancing the management of PXs and driving service improvements and health outcomes. In the final chapter, theoretical, methodological, and practical implications are discussed, along with the limitations inherent in the research and future research avenues.

Keywords: patient experience, patient journey, touchpoints, chronic diseases, healthcare service delivery, health outcomes

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ABBREVIATIONS

CKD – Chronic Kidney Disease

CX – Customer Experience

CMKF – Conservative Management for Kidney Failure

ESRF – End-Stage Renal Failure

ED – Emergency Department

GFR – Glomerular Filtration Rate

HbA1c – Glycated hemoglobin

HD – Hemodialysis

HCOs – Healthcare Organisations

HCPs – Healthcare Providers

LTC – Long-Term Conditions

IPA – Interpretative Phenomenologic Analysis

OHCs – Online Health Communities

MCA – Multiple Correspondence Analysis

PX – Patient Experience

PD – Peritoneal Dialysis

RRTs – Renal Replacement Techniques

SPSS – Statistical Package for Social Sciences

T1D – Type-1 Diabetes

TSR – Transformative Service Research

WOM – Word of Mouth

DOCTORAL PUBLICATIONS AND CONFERENCES

During the realization of the PhD thesis, different research outputs were prepared for submission to conferences and publications.

Proceedings at International Conferences:

- Amorim-Lopes, S., Simões, C.; Costa, P.; and Machado, J. (2023). "Understanding the patient experience for improving well-being and service delivery". *International Conference on Economics and Business Roads to Sustainability, ICBRS,* Faculty of Economics, University of Coimbra, 29 June – 01 July 2023.
- Amorim-Lopes, S., Simões, C.; Costa, P.; and Machado, J. (2022). "Understanding the patient experience for improving well-being and service delivery". *First Service Research Doctoral Workshop,* FEUP - University of Porto, 21 March 2022.
- Amorim-Lopes, S., Simões, C.; Costa, P.; and Machado, J. (2021). "Understanding the patient experience for improving well-being and service delivery". *Frontiers in Service Conference,* Fox School of Business - Global Institute for Artificial Intelligence & Business Analytics, 9-10 July 2021 (Virtual on Zoom).
- Amorim-Lopes, S., Simões, C.; Costa, P.; and Machado, J. (2020). "Understanding the patient experience for improving well-being and service delivery". *EMAC 2020 Annual Conference* (conference cancelled; accepted paper published in the conference proceedings).

Doctoral Colloquiums:

- Amorim-Lopes, S., Simões, C.; Costa, P.; and Machado, J. (2019). "Understanding patient experience throughout the patient journey to improve healthcare services and well-being". *32nd EMAC Doctoral Colloquium*, University of Hamburg, 27-28 May, Hamburg, Germany.

The realization of the PhD curricular component also originated two research outputs, including one communication at an international conference and one publication in a peer-reviewed international journal.

- Amorim-Lopes, S., Bernardes, J.; and Rodrigues, R. (2019). "Predictors of breast cancer patient experience - what really matters: evidence from public hospitals in England". *8th ICSR International Conference on Social Responsibility, Ethics and Sustainable Business*, University of Minho, 24-25 October, Braga, Portugal.
- Amorim-Lopes, S. and Alves, H. (2020). "Co-production and co-creation in public care services: a systematic review" *International Journal of Public Sector Management.* 10.1108/IJPSM-10-2019-0259.

Wisdom is not a product of schooling but of the lifelong attempt to acquire it.

— Einstein

1. CHAPTER I - INTRODUCTION

CHAPTER 1. INTRODUCTION

This introductory chapter (I) discusses the scope, research context, and this research's central questions and objectives. Then, it presents the methodology and summarises the main findings and contributions of this thesis's three essays. Lastly, it outlines the overall structure of this research (thesis synopsis).

1.1. Research scope

The significance of Patient Experience (PX) has been increasingly recognized in healthcare research and management worldwide (Deloitte, 2022). As PX gains prominence, patient-centric healthcare services become a focal point, emphasizing the centrality of patients' perspectives and active participation within the healthcare system (Black & Gallan, 2015). The attention to healthcare customers' (patients) experiences is particularly pertinent due to the heightened vulnerability of individuals in healthcare settings (Berry & Bendapudi, 2007), where patients often feel powerless and lack control over their physical and psychological well-being (McColl-Kennedy et al., 2012). Furthermore, PXs are shaped within a complex service environment involving multiple stakeholders, with patients actively engaged in the care process (Sweeney et al., 2015).

Despite increasing interest in PX, there is still a lack of consensus regarding its definition within healthcare (LaVela & Gallan, 2014; Wolf et al., 2014). PX can be conceptualized from two perspectives: the healthcare service provider and the customer (patient) perspective. Definitions of PX have primarily adopted the healthcare service provider perspective, focusing on service quality dimensions and shaping the patient's care experience (e.g., Ahmed et al., 2014; Bowling et al., 2012; Hewitson et al., 2014). Consequently, research on PX from an organisational standpoint often captures, through quantitative approaches, the patient's perceptions within specific healthcare interactions or settings (Manary et al., 2013; Russel et al., 2015) at a specific moment in time (static approach). It is also focused on designing PXs and internal processes to assist providers in enhancing the efficiency and effectiveness of care (Anhang Price et al., 2014; Rich & Piercy, 2013; Russel et al., 2015).

However, this perspective overlooks PX as a holistic construct (Ponsignon et al., 2018). To contrast, the holistic perspective of patients (e.g., LaVela & Gallan, 2014; Luxford & Sutton, 2014; Ponsignon et al., 2018; Silvera et al., 2017), considers PX as the culmination of patients' interactions throughout their entire journey. Indeed, according to this view, PX encompasses all interactions

between patients and HCPs across various touchpoints and channels, extending beyond the confines of healthcare organisation contexts. Patients engage with the healthcare system through numerous touchpoints across multiple channels, involving not only care provider-patient relationships but also interactions with friends, family, other patients, and communities (Ponsignon et al., 2018; McColl-Kennedy et al., 2018.

However, despite the increasing attention devoted to the view of PX as incorporating the patient's journey as a whole, there is still a call in the literature for a more consistent definition of PX, recognizing its holistic, multidimensional, and dynamic nature (Anderson et al., 2012; Ponsignon et al., 2018; Richardson et al., 2007; Silvera et al., 2017).

Moreover, there is still little empirical work on this domain (LaVela & Gallan, 2014). Most studies predominantly focus on the healthcare service perspective, mainly contributing to improving processes and service quality dimensions. Indeed, as patients' experiences in their healthcare journeys are not always well understood, it is essential to document patients' journeys across program and organisational boundaries (Jackson et al., 2012).

Even though some studies have adopted the patient's perspective and investigated the PXs from the lens of the patient journey, the majority of the research focuses on a single phase of the journey (Franck et al., 2017) especially during service encounters, therefore neglecting the totality of the PX, that is, all the interactions across all the stages. To achieve such goals, researchers can take advantage of multiple sources, such as qualitative methods, technologies, and comprehensive scales, to acquire a holistic view of PX (McColl-Kennedy et al., 2018).

1.2. Purpose, research questions and objectives

This thesis aims to build an in-depth understanding of how the holistic PX unfolds over time across the journey and how healthcare providers (HCPs) can effectively manage and enhance it to generate health outcomes such as well-being. Therefore, our two main research questions are as follows:

- (1) How does the PX occur throughout the patient journey?
- (2) How may the holistic PX be managed to enhance healthcare services and well–being outcomes?

The main objectives of this research are:

- To contribute to a more precise conceptualization of the holistic PX, highlighting the concept of PX within the patient's journey, specifying the domain of the PX construct and relevant dimensions that influence and result from the PX throughout the patient journey.
- To establish routes for healthcare organisations (HCOs) to develop a PX response orientation, that is, to specify guidelines for effective PX management while generating essential health outcomes, including well-being, for the overall healthcare system.

1.2.1. Research context

We conduct this research with chronically ill patients, a fruitful context to apply the study of PX across the journey. Chronic diseases are long-term conditions (LTCs) that have rapidly escalated to become a significant public health and medical challenge (Schneider et al., 2009). For patients with chronic conditions (e.g., cancer, diabetes, mental diseases, cardiovascular), the longevity of their illness and common multiple co-morbidities creates a more pronounced complexity. Therefore, they represent a high proportion of hospital admissions (Hewitson et al., 2014). and often require management by specialist hospital-based services (Campbell-Crofts & Stewart, 2018; Mechen & Andrews, 2019). Chronic conditions significantly impact individuals, their families and health and social care services (Hewitson et al., 2014).

Studies have shown that chronically ill patients whish to be involved in decisions about their care and access to information to help them make those decisions (Buljac et al., 2021). They perform various kinds of work not only during their time in hospital/medical consultations but also after discharge and at home by managing issues related to their treatment and condition (Brand & Pollock, 2018). Therefore, they want to be acknowledged by staff for their role in self-care and receive adequate support to help them self-manage their condition (Bayliss et al., 2008). Nevertheless, the literature points out that chronic patients are disappointed by today's healthcare availability or feel often neglected and not treated with compassion (Berglund et al., 2010; Wessel et al., 2012). Benham-hutchins et al. (2017) adds that most patients report experiencing a total lack of post-discharge care coordination, which leads to feelings of anxiety and uncertainty (Benham-hutchins et al., 2017).

Chronic health conditions pose therefore a significant challenge for modern public healthcare systems. Psychoeducational interventions and support from HCPs are crucial for alleviating psychological distress and improving coping strategies in patients with chronic diseases

(Theodoratou et al., 2023). Existing policies advocate for self-management support to alleviate pressure on healthcare services and enhance the health and well-being of patients. Indeed, patients' coping mechanisms play a pivotal role in shaping their quality of life and influencing the progression of the disease.

However, the study of the holistic experiences of chronically ill patients is still an overlooked research domain (Hewitson et al., 2014). Existing journey models have predominantly adopted a organisation-centric viewpoint, leading to insufficient insights, particularly concerning consumers' usage experiences in everyday contexts over extended periods (Nakata et al., 2019). It is imperative to gain a deeper understanding of the experiences of chronically ill patients throughout their journey (Maas et al., 2023). To bridge these gaps, our study aims to explore the holistic experiences of vulnerable consumers (chronically ill patients) as they navigate through their journey. Our overarching goal is to attain a comprehensive understanding of the factors that influence and characterize the journey undertaken by these individuals to drive service improvements and health outcomes.

In particular, this research is focused on two main chronic illnesses: Type 1 Diabetes – T1D and End-Stage Renal Failure – ESRF. Type 1 diabetes is a condition characterized by high blood sugar levels due to the lack of insulin production by pancreatic beta cells which results in the body's inability to use glucose for energy or regulate blood sugar levels (Gillespie, 2006). The disease is primarily managed by controlling blood glucose levels, with hemoglobin A1c and blood glucose measurements being key diagnostic and management tools (Kahanovitz et al., 2017). The global prevalence of T1D is on the rise, with a significant increase in recent years (Bodke et al., 2023). The experiences of patients with T1D are multifaceted and require a holistic approach to care. Freeborn et al. (2013) emphasizes the importance of understanding the challenges and perspectives of people with T1D, including the need for autonomy, social acceptance, and effective diabetes education. Wiley et al. (2014) further underscores the need for patient-centered diabetes education, with a focus on enhancing health literacy and incorporating peer-led support. These studies collectively underscore the importance of addressing the unique experiences and needs of patients with T1D to improve their overall well-being and health outcomes.

Similarly, there has been a notable increase in the incidence of ESRD over recent decades (Hsu et al., 2004). This is attributed to several contributing factors, including population ageing, the heightened prevalence of diabetes and hypertension, and improved survival rates among ESRD patients, as corroborated by Hostetter (2001). Similarly, Portugal has observed a notable rise in

the incidence of ESRF, with research indicating substantial regional disparities in dialysis prevalence, as reported by de Almeida et al. (2021) .This trend underscores the pressing need for heightened preventive measures and enhanced patient management strategies to tackle the escalating burden of ESRF in Portugal. Furthermore, the multifaceted experiences of ESRF patients necessitate comprehensive care approaches. Lin & Chu, (2022) emphasizes the pivotal role of healthcare professionals in offering guidance and support, particularly in urgent dialysis scenarios. Other authors underscore the necessity for (1) enhanced support for family caregivers, who often grapple with substantial caregiving burdens (Maddalena et al., 2018), (2) the importance of personalized treatment plans that consider patients' preferences and social support networks (Dimkovic et al., 2009); and (3) the implementation of specialized end-of-life care for ESRF patients, recognizing the unique care needs within this population (Greaves et al., 2009). In summary, literature underscores the importance of addressing the experiences of individuals with ESRF to ensure the provision of comprehensive and effective care.

1.3. Methodology

This research aims to provide an in-depth understanding of how the holistic PX unfolds over time across the journey and how HCPs can effectively manage and enhance it. The overarching objective is to improve service delivery and promote well-being outcomes within the healthcare system, particularly for patients and their families. To address the research questions, we adopted a qualitative approach seeking to develop a complex picture of the phenomenon under study (the PX) by reaching multiple perspectives, such as patients, informal caregivers (ICs), and healthcare providers (HCPs) and identifying the many factors involved in a situation (Creswell, 2013; Hatch, 2002; Marshall & Rossman, 2011). The exploratory nature of this research is justified by the research questions that begin with "how" and the limited theoretical development of the issue under investigation. Key features of this research strategy include (1) a focus on qualitative data collection and analysis, (2) employing an inductive approach to explore the relationship between theory and research, and (3) viewing social reality as an evolving construct shaped by individuals' interactions. This approach aligns with constructivist perspectives, wherein reality is socially constructed by individuals' perceptions and experiences within their broader social context (Bryman, 2014; Wahyuni, 2012).

To develop the research while addressing the research questions, we developed three interrelated Essays, further described in the following subsections.

1.3.1. Essay I

The essay I (Chapter 2) was conceptual. The aim was to promote a deeper understanding of PX and delineate/establish its realm. The main research question (RQ1) was defined as: How is the realm of PX delineated from a holistic perspective? The literature review was conducted by using the three-step analytical procedure consistent with MacInnis (2011) typology of conceptual contributions: (1) summarizing, (2) integrating, and (3) delineating. The initial step — summarizing — involved condensing existing PX knowledge from academic and practitioner literature. Scientific databases, including Scopus, Web of Science, JSTOR, Proquest, and Google Scholar, were considered, covering publications from 1999 to mid-2024. Adopting an interdisciplinary approach, we integrated perspectives from healthcare services and business management to gain a multidimensional understanding of PX. Additionally, we examined prominent journals in healthcare (e.g., Patient Experience Journal, BMJ Open) and business management (e.g., Journal of Service Management, Journal of Service Research) domains. We supplemented our search by screening reference lists and practitioner literature, such as research reports and white papers from global communities of practice. The second step — integrating — aimed to draw connections between elements identified in the literature. We explored drivers for expanding PX and examined two main theoretical perspectives: healthcare organisation and customer/patient viewpoint. By synthesizing insights from both perspectives, we strived for a holistic conceptualization of PX that acknowledges its complexity and provides a foundation for further discourse in the field. The last step — delineation — focused on delineating PX from related concepts (e.g., patient satisfaction, patient engagement) and outlining its boundaries and critical components. We propose a three-stage cyclical journey capturing the development of the experience of chronically ill patients over time. Furthermore, we identified critical areas and strategies for effectively managing PX, creating a roadmap for understanding PX processes and their connections to other conceptual entities.

1.3.2. Essay II

The essay II (Chapter 3) was empirical and aimed to examine the expressed experiences and well-being dimensions of individuals with chronic illnesses (T1D and End-Stage Renal Failute - ESRF) within online health communities (OHCs). Three research questions were defined: (RQ1) How do chronically ill patients express key PX dimensions in OHCs?; (RQ2) How do chronically ill patients

express key well-being dimensions in OHCs?; and (RQ3) How do PX and well-being relate to the patient journey?

To achieve this objective, a netnography was employed. Netnography, a qualitative research methodology, adapts traditional ethnographic techniques to study cultures and communities formed through computer-mediated communications. In marketing research, netnography leverages publicly available information on online platforms to identify and comprehend relevant consumer groups' needs and decision-making factors. Unlike conventional ethnography focused on markets, netnography offers advantages in terms of time efficiency and complexity reduction. Additionally, netnography distinguishes itself by its potential for unobtrusive observation, although it can be conducted with varying levels of intervention. Compared to focus groups and personal interviews, netnography is less intrusive, providing insights from authentic consumer behaviours within naturally occurring contexts. Moreover, it offers a cost-effective and timely means of gathering data. Netnography grants marketing researchers access to genuine consumer behaviours, including information-seeking activities and communal discussions, offering a unique opportunity to understand consumer dynamics. Its naturalistic and unobtrusive nature enables ongoing engagement with participants within specific online social settings, potentially fostering valuable relationships between researchers, consumers, and marketers (Kozinets, 2002).

A total of 186 discussion threads were analysed from two international OHCs and a thematic analysis with the support of NVivo software was conducted to identitfy the main reported experience and well-being dimensions by chronically ill patients.

1.3.3. Essay III

Lastly, essay III (Chapter 4) was also empirical and aimed to investigate the experiences of chronically ill patients (with T1D and ESRF) throughout their journey. Three research questions were delineated: (RQ1) RQ1. How do the experiences of chronically ill patients unfold throughout their journey? RQ2. How do different touchpoints influence the experience of chronically ill patients throughout the journey? and RQ3. How can the experience of chronically ill patients be managed to generate service delivery improvements and well-being outcomes? To understand the phenomenon of PX from different perspectives (patients, ICs and HCPs), we used an Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research methodology used primarily in psychology and related fields to explore the lived experiences of individuals through the use of mixed methods research design. IPA is particularly suited for investigating how people make sense

of their personal and social worlds as it involves an in-depth examination of individuals' subjective experiences, focusing on how they interpret and understand significant events, relationships, or phenomena in their lives (Smith & Osborn, 2004). Essay III incorporated in-depth interviews, focus groups, and patient diaries. This was supplemented by additional data triangulation from various sources, including text-based document analysis and non-participant observation. A total of 38 participants were included in the study and 40 interviews were conducted. A thematic analysis was conducted with the support of NVivo software. Additionally, Multiple Correspondence Analysis (MCA), a statistical technique was used to explore the relations among multivariate categorical variables (Hoffman & Franke, 1986). This technique provides many benefits, especially the graphical map, which allows the visualization of the associations between categorical variables (Doey & Kurta, 2011). The MCA was carried out to in this study to identify salient relationships among qualitative variables (sociodemographic, clinical, lifestyle and experience variables).

1.4. Main findings and contributions

1.4.1. Essay I (Chapter 2)

The first essay of this thesis aimed to explore the realm of PX from a holistic perspective and makes significant contributions to the academic field of PX research by examining PX as a comprehensive phenomenon occurring throughout the patient journey. We argue for PX as a distinctive construct and show how many other established domains (e.g., patient satisfaction, patient management, service quality) contribute to the understanding of PX. We also propose a model depicting a typical experience journey of vulnerable healthcare consumers, such as those suffering from chronic conditions. Chronic illnesses are escalating globally, and the journeys of chronically ill patients are becoming increasingly complex, encompassing multiple interactions and touchpoints. In particular, our proposed journey process model clarifies the PX domain by defining and describing the different touchpoint types chronic patients encounter throughout their journeys. In the second part of the Essay, we focus on managing the PX, drawing on customer experience management literature (CXM) insights. As PX is dynamic and multidimensional, it requires organisation-related capabilities and extended service delivery networks. We also highlight many challenges to conducting future research in this area while suggesting a future research agenda for stimulating research on understanding and managing the PX.

1.4.2. Essay II (Chapter 3)

The second essay of this research aimed to empirically explore the expresssed experiences and well-being dimensions of chronically ill patients within OHCs, contributing to recent theoretical discussions in services marketing literature regarding the need to move beyond service-dominant logic to understand services with minimal service-provider interaction. Main findings show that experience and well-being dimensions emerge throughout three main stages of the patient journey: the pre-service encounter stage (''What is happening to me?''), service encounter stage (''What is this disease? What treatments do I need to do?'') and post-service encounter stage (''How do I live with this condition?''). In the initial pre-service encounter phase, individuals report to want more about their symptoms (patient-owned touchpoints). Then, patients commonly search for OHCs to gather information about and discuss their symptoms with peers and comprehend and effectively manage them. During the service encounter stage, participants report the processes of diagnosis and treatment, involving interactions with healthcare processes and professionals (brand-owned

touchpoints). Thus, T1D/ESRF patients predominantly report their needs and negative experiences during these encounters on OHCs, such as seeking increased technical competence from HCPs at various levels (informational and emotional) and expressing the necessity for enhanced care effectiveness (e.g., through multidisciplinary team collaboration). This stage overall underscores the significance of the patient-practitioner relationship, information exchange, and communication in shaping the PX, highlighting the importance of support delivery and multidisciplinary approaches. Finally, regarding the post-service encounter stage, participants reported engaging in self-management activities over time (patient-owned touchpoints) while seeking social support from peers, family, and ICs (social-owned touchpoints). Patients often express dissatisfaction with the low level of social understanding and support, emphasizing the necessity for increased awareness and support from others in managing their condition.

1.4.3. Essay III (Chapter 4)

The third essay of this research aimed to empirically investigate the experiences of chronically ill patients (T1D and ESRF) throughout their journey. It offers substantial contributions to the literature on patient experience management (PXM) and healthcare service management and also enables HCOs to transition from conventional, episodic care approaches towards a more integrated and continuous patient-centric continuum. Overall, findings suggest that PXs unfold social dynamics and evolve throughout the patient's journey. Our investigation underscores the holistic and dynamic nature of these experiences, spanning three distinct stages: pre-service encounters, during-service encounters, and post-service encounters. Throughout this journey, the interactions are influenced by numerous stakeholders and touchpoints, highlighting the interconnectedness and complexity inherent in PXs. Moreover, we introduce two tailored patient journey models specific to the chronic conditions under investigation (T1D and ESRF). These models deepen our comprehension of PXs and offer invaluable insights for future research. Our empirical findings reveal crucial insights into PX dynamics across multiple dimensions, including the brand, patient, social, partner, and external spheres, traversing each journey stage. During pre-service encounters, patients identify symptoms and seek care (patient-owned touchpoints). During the service encounter stage, the study particularly highlights the pivotal role of interactions with processes and health staff (brand-owned touchpoints). Improving the efficacy of care delivery, including timeliness, access, and communication, is imperative for nurturing positive PXs. Additionally, healthcare professionals play a crucial role in shaping PXs by fostering meaningful relationships and providing support across

emotional, technical, and psychosocial domains. In the post-service phase, patients deal with the challenges of managing daily disease-related issues and adapting their lifestyles to accommodate chronic illness. They engage in activities promoting physical and mental well-being, augment knowledge, and develop coping strategies (patient-owned touchpoints). Moreover, they often encounter a lack of support from social circles due to prevalent misinformation and stigma surrounding these diseases (social-owned touchpoints).

1.4.4. Overall contributions

This research contributes to the literature and healthcare practice in several ways. From a theoretical perspective, this study contributes to broadening the understanding of PX throughout the patient journey by proposing a framework that highlights the variables that may influence and result from PX. Also, it contributes to the development of PX research while addressing a holistic perspective of the phenomenon, which confers some novelty potential. The second strand of contributions pertains to the healthcare service literature. This research widens the knowledge in the healthcare service strategy and management by highlighting the main challenges and capabilities that HCOs need to address the PX from a holistic standpoint. Lastly, by exploring the holistic PX throughout the patient journey to enhance the well-being of patients and relatives, this research can also contribute to the transformative service research (TSR), which focuses on the integration of consumer and service research to drive changes and improvements in the well-being of individuals' communities and the ecosystem (Anderson et al., 2012).

Regarding the practical contributions, this research is likely to have a solid social impact since a practical PX approach may contribute to creating valuable well-being outcomes, such as mental and physical health (Anderson et al., 2012; Rosenbaum, 2015) for patients and their families. Moreover, this investigation offers HCPs valuable insights into comprehensively understanding the holistic PX, mainly guiding organisational strategies towards fostering robust PX. Indeed, this study provides insights for HCPs to understand the holistic PX better and draw insights into how those organisations can: (a) shape their service strategies bearing in mind the creation of a strong PX and (b) establish further a set of capabilities and comprehensive measures to manage PX across multiple touchpoints and journey stages. This research enables organisations to transition from conventional, episodic care approaches towards a more integrated and continuous patient-centric continuum (Luxford & Sutton, 2014; Wolf et al., 2021).

In Table 1.1 we describe the research design, data collection methods, data analysis procedures utilized in each of this thesis's essays and the main findings.

Table 1. 1. Global view of the research

Global research questions	RQ1. How does the holistic PX occurs throughout the journey? RQ2. How can the holistic PX across the journey be managed to enhance healthcare service delivery and generate well-being outcomes?		
Research strategy	Qualitative approach		
Title of each Essay	ESSAY I (CHAPTER 2) Understanding and Managing the Patient Experience throughout the Journey: A Literature Review	ESSAY II (CHAPTER 3) Online Health Communities (OHCs) and Chronic Illnesses: Capturing perspectives on Experiences and Well-being	ESSAY III (CHAPTER 4) Understanding and Managing the Experience of Chronically Ill Patients throughout the Journey: What really matters? Insights from participants
Research questions for each Essay	RQ1. How is the realm of PX delineated from a holistic perspective?	RQ1. How do chronically ill patients express key PX dimensions in OHC? RQ2. How do chronically ill patients express key well-being dimensions in OHC? RQ3. How do PX and well-being relate to the journey stages?	RQ1. How do the experiences of chronically ill patients unfold throughout their journey? RQ2. How do different touchpoints influence the experience of chronically ill patients throughout the journey? RQ3. How can the experience of chronically ill patients be managed to generate service delivery improvements and well-being outcomes?
Methodological approach (data collection and data analysis)	Integrative literature review. Three-step analytical procedure consistent with MacInnis's (2011) typology of conceptual contributions (1) summarizing, (2) integrating, and (3) delineating. Selection of articles on the PX collected between 1999 and 2024 from different journals and fields (e.g.,	Netnography. The study followed the steps described by Kozinets (2002): (a) preparation for entry into the field, (b) data collection, and (c) data analysis. One hundred eighty-six (n=186) discussion threads were collected and analysed from two international online health communities (OHCs) focused	Interpretative Phenomenological Analysis (IPA). — Total of 38 participants recruited from the Hospital of Braga (public hospital at the North of Portugal). — Individual in-depth interviews with T1D/ESRF patients (n=19); HCPs (n=10) and ICs (n=4). — One focus group with HCPs (nutritionists) (n=5)

	business/management; healthcare—medicine, Nursing, Health research).	on specific chronic conditions (T1D and ESRF). Thematic analysis was used to analyse data with the support of Nvivo software.	—Six diaries developed by T1D (n=3) and ESRD patients (n=3) discussed in post-diaries follow-up interviews. Data sources for triangulation: — Non-participant observation (n= 3h) (nephrology service). — Text-based document analysis (n=20) Additional sources of data for generating managerial implications: — Best practices collection — Netnography. Thematic analysis was used to analyse qualitative data with the support of Nvivo software. Multiple correspondence analys (MCA) was used to explore salient relationships through qualitative variables using IBM SPSS Statistics V.29
Main contributions	This article provides a more robust understanding of PX and its journey in an era of increasingly complex service contexts and patient paths. PX is proposed to have a holistic scope involving complex, social, and dynamic interfaces and natures throughout the journey. A specific PX journey model for chronic conditions is developed. Critical domains of patient PX management are discussed, and critical areas for future research on this vital topic are proposed.	The study provides a basis for HCOs dealing with people with chronic conditions and being able to channel their voices and improve their experiences and well-being.HCOs can utilize the results of this study to identify relevant OHCs and engage in information sharing to ensure relevant and accurate information is disseminated to patients as they seek out information concerning their health conditions. HCPs can design more effective treatment modalities, improve services, and interact more meaningfully with their patients.	The study underscores the holistic and dynamic nature of PXs spanning three distinct stages across the journey: pre-service encounters, during-service encounters, and post-service encounters. We propose two tailored patient journey models specific to the chronic conditions under investigation to deepen our comprehension of PXs and offer invaluable insights for future research. This study assists HCPs in establishing comprehensive capabilities and measures to effectively manage PXs across various touchpoints and stages of the patient journey.

1.5. Structure of the thesis

This thesis comprises five main chapters. Chapter 1 introduces the thesis topic, scope, context, research questions, and objectives. It also provides an overview of the three essays in the thesis, summarizing their purpose, methodological approaches, findings, and critical contributions. The chapter also outlines the structure of the thesis.

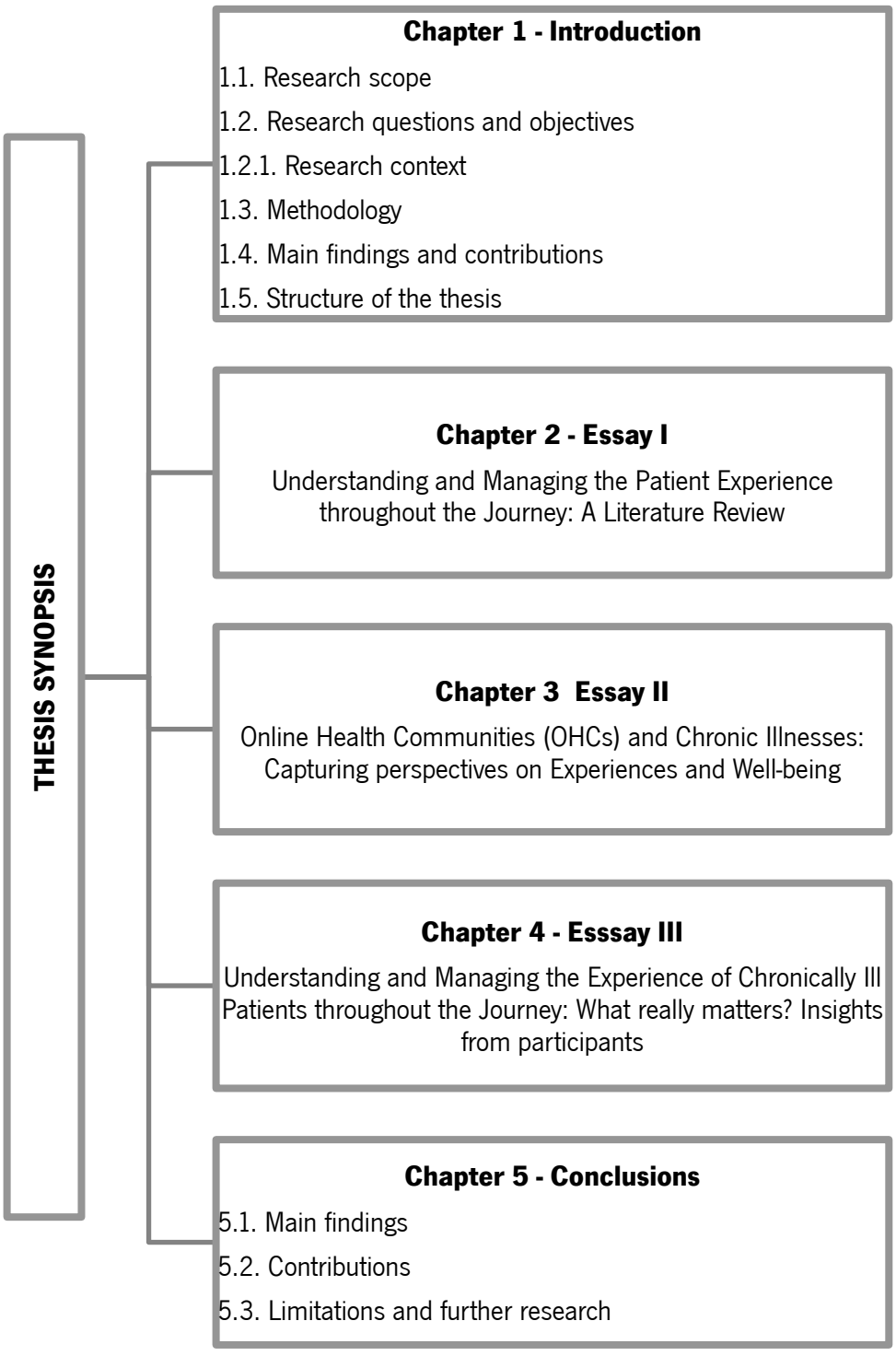
Chapter 2 focuses on the first essay, which entails an extensive literature review that identifies research gaps in PX research and establishes the foundational aspects of PX, including its main principles and dimensions. The contribution was synthesizing various approaches reported in existing literature and proposing a conceptual integrated model for understanding and managing PX across the journey, particularly in chronic conditions.

Following the introductory work, Chapter 3 presents the second essay, which empirically investigates the PX across the journey among chronically ill patients with T1D and ESRF. We conducted a netnography, analyzing expressed experiences and well-dimensions from two disease-focused online health communities. The study contributes methodologically by offering insights into chronically ill patients' experiences within a naturalistic setting and practically by providing HCOs with critical dimensions and touchpoint interactions influencing the experiences of these vulnerable consumers.

Chapter 4 builds upon the preceding chapters by conducting an empirical qualitative investigation that comprehensively examines the holistic experiences of individuals with chronic illnesses, specifically T1D and ESRF, throughout their journey. The research integrates the perspectives of patients, ICs, and HCPs, significantly advancing healthcare service research and PX literature by elucidating how touchpoints shape the experiences of chronically ill patients and proposing patient journey models tailored to the specific chronic conditions under investigation.

Finally, Chapter 5 summarizes each essay's main findings and contributions, and the overall research identifies limitations and suggests future research directions. Figure 1.1 provides an overview of the collation of all chapters.

Figure 1. 1– Thesis synopsis



2. CHAPTER II (ESSAY I)

Understanding and Managing the Patient Experience throughout the Journey: A Literature Review

CHAPTER 2. UNDERSTANDING AND MANAGING THE PATIENT EXPERIENCE THROUGHOUT THE JOURNEY: A LITERATURE REVIEW (ESSAY I)

2.1. ABSTRACT

Understanding patient experience (PX) is an important research focus and leading management objective across healthcare organisations (HCOs). PX definitions predominantly take the healthcare service provider perspective, with services mainly elaborating on service quality dimensions and crafting an experience of care for the patient. Such a perspective neglects patients' interactions with care providers and through a myriad of touchpoints in multiple channels beyond the boundaries of the healthcare organisation context. Experiences occur within a complex setting, connecting multiple actors involved in the service provision and the patient, who plays an active role in the process. These changes require HCOs to adopt new organisational models and tools and invest in capabilities and external partnerships to create and deliver positive PXs. This study develops a deeper understanding of PX in the increasingly complex service context and establishes its outcomes. Building on existing PX definitions and conceptualizations and drawing on recent customer experience (CX) literature, we delineate the realm of PX. PX has a holistic scope and occurs throughout the patient journey, involving complex, social and dynamic interfaces and natures. The "journey" encompasses multiple interactions between patients and touchpoints that occur over time inside and outside the context of the healthcare organisation. Such touchpoints are clusters of experiential elements that shape and foster PXs, some outside the service provider's control. The patient journey emphasizes the PX extending beyond the care provider-patient dyad to capture additional value networks and resources, such as friends, family, other patients and communities. We further develop a model of Patient Experience Journey for Chronic Diseases which delineates the most relevant stages and touchpoints, spanning each phase of the patient journey. Creating a PX orientation and driving PX improvements may create valuable outcomes for the overall healthcare system. Such outcomes may include service improvement, patient loyalty, a better reputation, and impacting patients' lives and well-being. From a managerial perspective, addressing the PX more comprehensively and holistically can be challenging for HCOs, given the high interdependencies within patient journeys. Focusing on the holistic PX is critical to crafting practical care delivery approaches and providing positive PXs.

Key words: patient experience, patient journey, touchpoints, patient experience management

2.2. INTRODUCTION

Understanding patient experience (PX) is an important focus area for research and a leading management objective across healthcare organisations (HCOs) (Beattie et al., 2015; Danaher & Gallan, 2016; Trenchard et al., 2019). The rapid growth of the PX has been driven by the emergence of a new consumer mindset (Wolf et al., 2014). Indeed, the experience is considered extremely important to the new consumers and "anchored in an individual's desire to be acknowledged and identified as a critical driver for healthcare decision-making" (Wolf, 2018b, p.1). The shift from the industrial economy view to a modern view that considers that the experience is what the customer receives at the end of a service encounter (Pine & Gilmore, 1998) may also be central to the expanding global dialogue on PX in healthcare (Luxford & Sutton, 2014).

Despite the proliferation of writing on PX and its expansion as a field of study and practice, there still needs to be stated alignment around PX (LaVela & Gallan, 2014; Wolf et al., 2014). PX definitions predominantly take the healthcare service provider perspective, with care services mainly elaborating on service quality dimensions and crafting an experience of care for the patient to receive (e.g., Ahmed et al., 2014; Bowling et al., 2012; Hewitson et al., 2014). Hence, research on PX from an organisational standpoint typically concentrates on patients' perceptions regarding a specific healthcare interaction or interactions occurring within a healthcare facility or practice (Manary et al., 2013; Russell et al., 2015). Studies have also explored, for instance, the design and improvement of healthcare service delivery and operations (Rich & Piercy, 2013) to improve process efficiency through optimising patient flows and resource utilisation (Russell et al., 2015). Overall, research on PX from the service provider/organisational perspective focuses on ways to design PXs and underlying internal processes to help providers improve the efficiency and effectiveness of care (Anhang-Price et al., 2014).

However, this perspective neglects the PX as a whole (Ponsignon et al., 2018), that is, all the patients' interactions with care providers through a myriad of touchpoints in multiple channels beyond the boundaries of the healthcare organisation context (McColl-Kennedy, Snyder, et al., 2017). Patients now interact with the healthcare system through myriad touchpoints in multiple channels. PX extends beyond the care provider-patient dyad to capture additional value networks and resources, such as friends, family, other patients and communities. Therefore, the literature calls for a more consistent PX definition, while considering its holistic, multidimensional, and dynamic nature (Anderson et al., 2012; Ponsignon et al., 2018; Richardson et al., 2007; Silvera et al., 2017).

This study addresses such calls by developing a deeper understanding of PX in the increasingly complex service context and patient behaviours. Our research questions are as follows:

RQ1. How is the realm of PX delineated from a holistic perspective?

Building on customer experience (CX) definitions and conceptualisations (see Appendix II) we delineate the realm of PX. We propose the notion of PX as having a holistic scope, involving complex, social and dynamic interfaces and natures (Lemon & Verhoef, 2016, McColl-Kennedy, 2015) and occurring throughout the patient journey. Indeed, PX encompasses the multifaceted cognitive, affective, emotional, social, and physical reactions showed by patients in response to direct or indirect interactions with healthcare service providers at various touchpoints throughout their journey. The journey encompasses multiple interactions and relationships between patients and touchpoints that occur over time inside and outside the care context (Danaher & Gallan, 2016b; Wolf et al., 2014).

From a managerial perspective, given the high number of interdependencies within patient journeys, addressing the PX more comprehensively and holistically can be a challenge for HCOs. However, focusing on the holistic PX is critical to crafting effective care delivery approaches and providing positive PXs. To successfully manage PXs, HCOs must identify a set of critical changes in terms of their structure, organisation, channels, people, resources and capabilities to create a strong PX response orientation. The focus on the holistic PX will be essential to improve healthcare services delivery and generate critical outcomes for patients and families, such as well-being (Anderson et al., 2012; Ponsignon et al., 2015, 2018; Rosenbaum, 2015).

To conclude, this work details the specific grounds of PX, argues for a clear, multidimensional and holistic understanding of PX and thus informs the management and improvement of healthcare systems in a meaningful, patient-centric way.

This article is structured as follows: in the next section, we outline the methodological approach; in the third section, a literature review on PX is conducted, capturing what is currently known about PX theoretical perspectives and management. The subsequent sections report the future research agenda, contributions to research and practice, and concluding thoughts.

2.3. METHODOLOGICAL CONSIDERATIONS

In this study, we utilize a three-step analytical procedure consistent with MacInnis's (2011) typology of conceptual contributions (1) summarizing, (2) integrating, and (3) delineating. In the step 1 - summarizing - the objective is to assess existing knowledge and condense it into a concise set of essential insights (MacInnis, 2011). This research aims to provide an integrative perspective of the marketing and healthcare literature discussing PX.

To assess the state of PX research, we sought out and analysed studies published in several scientific databases, such as Scopus, Web of Science, JSTOR, Proquest and Google Scholar. The search parameters focused on international academic journal papers (both conceptual and empirical), reviews, books, chapter books, conferences, and practitioner publications. The records identified the first article as being published in 1999, and papers were considered until the middle of 2024. For more information about the search strategy see Appendix I.

We adopted an interdisciplinary stance to yield a more comprehensive view of the PX (Gioia & Pitre, 1990). Specifically, we looked at writings on customer/consumer experiences across the domain of Health Sciences Services, Business and Management. The three journals from the healthcare domain with the most publications are in the specialised areas of PX, medicine and nursing: Patient Experience Journal, BMJ Open and the Journal of Clinical Nursing. In the business and management domain, the two journals which comprise the majority of publications are in the more specialised areas of services marketing: Journal of Service Management and Journal of Service Research. In addition, snowballing searches (e.g., reference lists) were conducted across the included scientific articles.

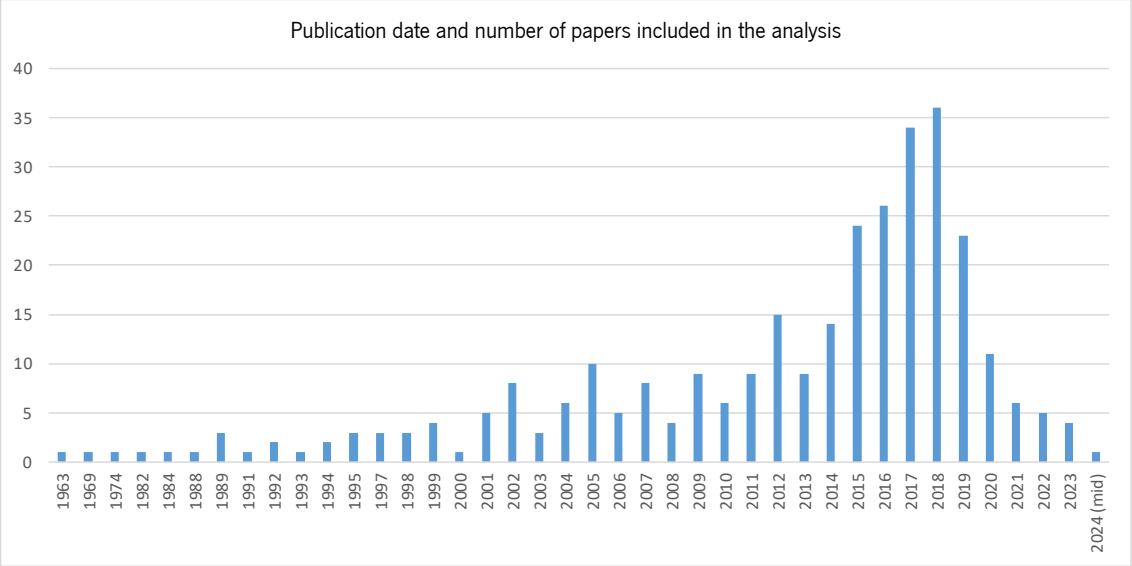
This review is not limited to academic inquiry but also considers the practitioner discourse, thereby enriching our examination of PX. To identify relevant practitioner literature, we carefully screened the Internet for research reports and white papers stemming from major global communities of practice doing research on PX (e.g., The Beryl Institute[1]).

An Excel workbook was prepared to archive the most relevant data relative to the selected scientific articles and practitioner publications. For each individual scientific article or practitioner publication, the following information was inserted in the database: i) study overview (author/year/journal/title); ii) type of paper; iii) method/sample; iv) keywords; v) objectives/purpose, main findings and contributions. Therefore, our review allowed us to identify

1. The Beryl Institute is a global community focused on improving the PX in healthcare.

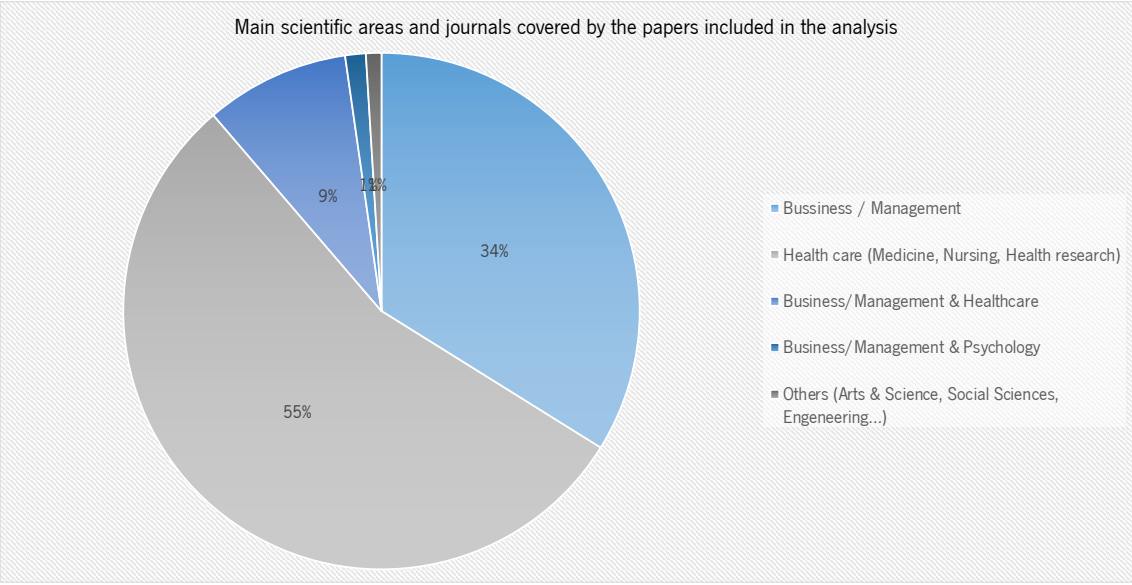
key dimensions that readily capture the PX conceptualisation and serve as input for the next analytical step. Figure 2.1. presents the number of papers included in the analysis per year, while Figure 2.2. shows the main scientific areas and journals of the included papers.

Figure 2. 1 - Synthesis of the literature on PX: publication date and number of papers included in the analysis



Sources: Author's elaboration

Figure 2. 2 – Main scientific areas and journals covered by the papers included in the analysis



Sources: Author's elaboration

The step 2 - Integrating - aims to draw connections between what is previously known, finding a novel, higher-order means of perceiving connections between multiple themes and elements in the literature (Mele et al., 2014). It involves synthesis, creating a bigger whole from the diverse parts available. In doing so, integration addresses complexity, offering a simple perspective of a specific phenomenon (MacInnis, 2011). In this research, we integrate the findings from the summarization step, in which we explore the drivers for the rapid expansion of PX and the two main theoretical perspectives on PX: the healthcare organisation and the customer (patient). Collecting insights from both perspectives can contribute to a better understanding of what constitutes PX. Then, we stand for a holistic understanding and conceptualisation of PX that accommodates its complexity and provides a basis for further discussion on the field.

Lastly, the step 3 - delineating - entails depicting a specific construct and showing how it relates to the broader conceptual world around it. The goal is to improve comprehension of a focal construct by understanding its relationship with other concepts, hence stipulating its boundaries and identifying what should be considered in its study. Delineation results in the creation of a roadmap that permits a greater understanding of the processes that underlie an entity and details how it connects to other conceptual domains (MacInnis, 2011). With respect to our research, delineation allowed: (1) discerning PX from other highly related concepts in the literature (e.g., patient satisfaction, patient engagement, patient-centred focus), (2) specifying a three-stage cyclical journey (pre, during- and post-service encounters) that captures the development of PX over time, and (3) identifying the critical areas and ways and to effectively manage PX.

2.4. UNDERSTANDING PATIENT EXPERIENCE

2.4.1. Drivers for the emergence of patient experience as a fertile research field

The healthcare sector has been identified as an essential context and fertile ground for various service research priorities (Anderson et al., 2012, Danaher & Gallan, 2016; Ostrom et al., 2015). Healthcare services have been recognized as a significant and worthwhile field to study from a services marketing perspective, offering the potential to substantially contribute to the field (Berry & Bendapudi, 2007). All consumers interact with healthcare services at some point in their lives, and healthcare services directly impact both consumers' daily and long-term quality of life (Berry & Bendapudi, 2007; Danaher & Gallan, 2016). No other service sector affects the quality of life more than healthcare (Padma et al., 2009). The healthcare sector offers a fascinating context for studying emerging theories and concepts in marketing and consumer research, such as consumer (patient) experience (Dodds et al., 2018). PX is, therefore, emerging as an essential focus area for research and a leading management objective across healthcare globally (Beattie et al., 2015; Danaher & Gallan, 2016; Ostrom et al., 2015). Service researchers have a tremendous opportunity to apply, expand, and develop PX as a new theoretical lens to assess and improve service in healthcare (Danaher & Gallan, 2016).

Three main factors have driven the rapid expansion in the use of the PX term: the challenging roles and complex conditions of patients, the development of new technologies, and the resource pressures faced by HCPs. Those factors are explained below.

2.4.1.1. Patients: challenging roles and complex conditions

There is a fundamental shift in healthcare consumpion, where patients are becoming increasingly well-informed, actively engaged in their own healthcare, and exhibiting higher expectations (Padma et al., 2009). Overall, they want to perform an active role in their own care and treatment decisions and in co-producing the service with healthcare professionals, which is more evident in chronic conditions (Berglund & Westerlund, 2016; McColl-Kennedy et al., 2017c). It implies that rather than being passive recipients of market offerings, patients can adopt a significantly more active role in their care by contributing to various personal resources such as information and knowledge. They can also participate in various activities independently and collaborate with multiple stakeholders to enhance their health and well-being (McColl-Kennedy et al., 2017c; Ostrom et al., 2015). Therefore, in health services, the perspective of individuals, families, and communities is

adopted, and these actors are seen as active participants or co-creators, as well as beneficiaries, of the health system (World Health Organization, WHO 2016)

Patients' expectation levels are growing faster (Samal et al., 2017). The healthcare consumers are becoming more demanding at different levels: i) they are looking towards the optimal levels of value for the money spent; ii) have more intolerant levels towards waiting times at various procedures and are requiring better quality and quantity of food, privacy in rooms, easy accessibility, convenient parking, connectivity, cleanliness, friendliness, comfortable and relaxing environment; iii) the power of social media exposures has given them a new weapon for complaining on a real-time basis; iv) they expect someone to guide them towards various services. They have a greater demand for the provision of physical (e.g., in-room facilitates, equipment, parking), financial (e.g., handling of money) and emotional security (e.g., accessibility, responsiveness, courtesy, caring, respect, compassion, knowledge of the doctors, nurses and other staffs) (Samal et al., 2017). Such context leads to the idea of PX as essential to patients. The Beryl Institute's recent study on "Consumer Perspectives of Patient Experience" reveals that experience is anchored in an individual's desire to be acknowledged and identified as a critical driver for healthcare decision-making (Wolf, 2018a). It also suggests that healthcare decisions are driven mainly by the stories and recommendations that patients receive (Wolf, 2018a).

Importantly, patients are under complex conditions. Healthcare interactions can generate experiences characterized by uncertainty, vulnerability, helplessness, and sometimes even guilt (Galarza-Winton et al., 2013; Tallandini & Scalembra, 2006) Patients are potentially vulnerable because healthcare is a service people do not necessarily want (Berry & Bendapudi, 2007). They are often ill, sometimes out of control of their own body (Anderson et al., 2018) and in physical or psychological discomfort when they consume health services (Padma et al., 2009) which makes it more difficult to create a solid positive healthcare experience (Kennedy, 2017).

Patients also elicit strong emotional responses (Berry et al., 2015), and their loved ones are also involved at an emotional level when receiving the services (Park et al., 2017). Healthcare is, therefore, characterized by a complex emotional context fuelled by fear, pain, and anxiety due to both illness and treatment (Kash et al., 2018; Kemp et al., 2014). This is especially true due to consumers needing more familiarity and control, the high-level consequences associated with the services, and the complexity and duration of the services (Berry et al., 2015).

Overall, it is crucial to recognize that healthcare services embody a consumer journey characterized by often disjointed, confusing processes unfolding over time (Danaher & Gallan, 2016). Patients'

demographic heterogeneity also amplifies the complexity of their conditions (Sofaer et al., 2005). Healthcare professionals can provide the same service, but the patient may experience it differently due to their condition (Vogus & Mcclelland, 2016).

Finally, patients can be at a knowledge disadvantage. One can argue that the knowledge asymmetry between provider and patient results from the highly educated, professionalized, and specialized healthcare workforce (Makarem & Al-Amin, 2014). Such a knowledge gap is often exacerbated by the emotionality and vulnerability felt by patients and their families as they cope with health problems and manage complex disease processes (Dempsey et al., 2014). Prior studies corroborate that patients often feel helpless due to their lack of medical knowledge (Adams et al., 2016). As a result, they rarely challenge physicians' recommendations that influence their decisions about their health (McGlynn et al., 2003). They can judge the clinical quality of services less (Berry & Bendapudi, 2007). Hence, due to the higher vulnerability of patients and their complex conditions, a much deeper and broader understanding of the experiences of patients is needed to deliver the best possible service (Danaher & Gallan, 2016).

2.4.1.2. Ever-advancing technology in healthcare context

In healthcare services, the majority of the design of medical services is driven by technology and standardized care (Malone, 2003). Technology and standardization not only create physical distance between caregivers and patients, but they also create emotional distance. They can disrupt the caregiver-patient relationship as caregivers become excessively focused on the efficient and effective utilization of technology, neglecting the human-centred aspects of care (Galarza-Winton et al., 2013). In other words, caregivers no longer 'get to know' the patient (Malone, 2003) and patient care becomes task-oriented and diminishes caregivers' ability to respond therapeutically to patients (Galarza-Winton et al., 2013). This leads to the urgent need to adopt the customer focus in healthcare by addressing their perspectives, perceptions, feelings and experiences (Anderson et al., 2018; Danaher & Gallan, 2016)

2.4.1.3. Pressures faced by healthcare providers (HCPs)

The rise in the number of providers and the resource pressures experienced by private and public providers underscores the necessity of gaining a deeper understanding of consumer value in healthcare and their experiences (Dobele & Lindgreen (2011). Globally, healthcare is failing since patient care is of low quality and healthcare system costs are progressively increasing (Hillary et

al., 2016). This results in pressure on HCOs, especially Hospitals, to ensure cost-effective procedures and improvements in delivery approaches. Some authors have discussed how to deal with the new healthcare environment. For example, Orszag (2011) and Thorpe (2005) highlight the value of care as the most promising approach by recommending focusing on the quality of the services provided instead of quantity. This has remarkably enhanced the need for creating a value-based care (VBC) system (Agwunobi & Osborne, 2016; Hillary et al., 2016; Porter, 2014; Porter & Lee, 2013). It means that delivering and improving value may be healthcare's fundamental purpose and the only solution for reforming healthcare versus cost shifting to patients, restricting services, or reducing provider compensation (Porter, 2014). Instead of focusing on the financial success of system participants, the value is focused on patient success (Porter & Lee, 2013). In order to move to a Value-Based Competition, HCPs need to focus on assessing PX (Porter & Teisberg, 2006). In response to increased patient access to health information via the Internet and digital media, rising service expectations from patients, technological advancements, and the escalating cost of care, the healthcare industry has undergone significant changes in healthcare service delivery (Frow et al., 2016; Lee, 2011). In the current healthcare landscape dominated by transparency and consumerism, HCPs must explore the experiences of patients and their families within their facilities and beyond, understand their perceptions of healthcare services, and identify the factors influencing these perceptions. This understanding is essential to meet and surpass patients' expectations and needs (Lee, 2011). As such, PX as a topic has been and will remain a crucial indicator of future viability for HCOs ((Wolf, 2018b; Wolf et al., 2014). One could argue that the experience economy that considers that what a customer receives at the end of a service encounter is the experience (Pine & Gilmore, 1998) traced the emergence of a new business model for providing personalized service in the context of the healthcare industry (Prahalad & Ramaswamy, 2004). Indeed, healthcare services can be redesigned using psychological principles to deliver more positive experiences (Chase & Dasu, 2014; Luxford & Sutton, 2014). In the wake of this new perspective, the consumer term has been used to recognize that the patient relationship has changed dramatically some years ago (Van Fleet & Peterson, 2016). The patient is called the ultimate medicine customer (Lexa, 2006). This is consistent with the current trend toward patients actively participating in their care, including in shared decision-making with their care providers (Brook et al., 2017). Table 2.1 summarizes these ideas.

Table 2. 1. Drivers for the emergence of PX as a fertile research field

Drivers for the emergence of PX	PX fertile research area
I) <u>Patients: challenging roles and complex conditions</u> *Patients better informed and with a new mindset* — Informed patients: Patients are better informed and have greater access to health information through the Internet and social media. — Active role: patients want to be involved and active in their own care, treatment decisions, and in co-producing the service with healthcare professionals (more evident in chronic conditions). — Higher expectations: Patients have expectation levels that are growing at a faster rate regarding the provision of physical, financial and emotional security. *Complex conditions of Patients:* — Vulnerability: Patients are potentially vulnerable, usually in physical or psychological discomfort. The patient's loved ones are also involved at an emotional level. — Demographic heterogeneity: The demographic heterogeneity of patients amplifies the complexity. Patients may experience healthcare services differently as a function of their condition and background. — Knowledge gap: Patients are at a knowledge disadvantage and are less able to judge the clinical quality of services.	— Healthcare services are a crucial and fertile field for service research. Service researchers have a strong opportunity to apply, expand, and develop PX through new theoretical lens to assess and improve service in healthcare. PX is a critical differentiator and indicator of future viability for HCOs. — Healthcare services can be redesigned using psychological principles to deliver positive experiences.
II) <u>Ever-advancing technology in healthcare context</u> — Technology and standardization of care interrupt the caregiver–patient relationship as caregivers become overly focused on efficient and effective use of technology and ignore human-centered aspects of care.	
III) <u>Pressures faced by care providers</u> — Healthcare is failing since patient care is of low quality, and the healthcare system's costs are progressively increasing. This results in pressure on HCOs to ensure cost-effective procedures and improvements in delivery approaches.	

Sources: Author's elaboration based on the following works: Anderson et al., 2012, Danaher and Gallan 2016, Ostrom et al., 2015; Padma et al., 2009; McColl-Kennedy, Synder et al., 2017; Samal et al., 2017; Wolf, 2018b; Wolf et al., 2014, Galarza-Winton, et al., 2013; Berry & Bendapudi, 2007; Dobele and Lindgreen, 2011; Dempsey et al., 2014; Sofaer & Firminger, 2005; Brook et al., 2016; Malone et al., 2013; Porter, 2014; Hillary et al., 2016.

After understanding the emergence and the overall importance of PX for the healthcare system, it is relevant to further analyze how the approaches to PX have evolved.

2.4.2. Perspectives on patient experience research

While there has been increasing interest in the PX topic, there still needs to be a consistent view and a commonly used definition of PX in healthcare (LaVela & Gallan, 2014; Wolf et al., 2014). Throughout the development of the PX construct, research has advanced on two opposing theoretical lenses: organisational/service provider perspective and the customer (patient) perspective. Inspired by Kranzbuhler et al. (2018), we frame and describe these two perspectives by examining their features. Table 2.2 summarizes the two views.

Table 2. 2– Perspectives on PX

	Organisational / service provider perspective	Customer (patient) perspective
Central theories	Behavioral theory of the firm (Cyert & March, 1963), and the customer value creation (Srivastava & Shervani, 1999)	Experienced utility (Kahneman et al., 1997a), Service-dominant logic (SDL) (Vargo & Lusch, 2004), and model of environmental psychology
Key Assumptions	Experiences can be designed; Stimuli/elements of care will be perceived by patients	Value is idiosyncratic, experiential and contextual in nature; HCOs cannot deliver value (patient is always co-creator of value)
Focal constructs	The service landscape (e.g., servicescape/hospital/healthcare environment, patient-care services interactions, organisational culture and context, processes)	The customer (patient) across the journey (e.g., environmental and personal factors, cognition, affect, senses, behaviors)
Unit and level of analysis	Mainly meso level (hospital, care units/departments....) and static	Mainly micro-level (individual/patient) and dynamic
Definition of PX (e.g.)	PX as a service quality pillar.PX can be conceptualized both as patients' experiences of care and as feedback received from patients about those experiences with domains/elements of care (Ahmed et al., 2014)	PX as holistic, dynamic and occurring across the journey. The PX happens throughout the patient journey, which begins from the first time they consider where they are going to get their care. This extends to not only the onsite visits but also to where they pick up their prescriptions, how they are going to manage their care at home and how each of their care encounters plays a

		part in their overall health (Luxford, Karen and Sutton, 2014)
Empirical predisposition and predominant research methods	Inside hospital/clinical care boundaries view: describing the impact of healthcare dimensions/features on PX. Predictive - know what (e.g., "What are the impact of the hospital-dimensions on PX") Mostly empirical (quantitative - surveys; Other methods: theoretical/conceptual approaches.	Outside hospital/ clinical care boundaries view: describing the "lived experience" of patients across multiple touchpoints throughout their journey. Prescriptive - know how (e.g., “How do patients experience the interactions with multiple actors throughout their jouney?”). Mostly empirical (qualitative - interviews; critical incident technique, diaries registration). Oher approaches: theoretical/conceptual approaches.

Source: Author's elaborations are based on the Framework of Kranzbuhler et al. (2018)

2.4.2.1. Organisational /service provider perspective on patient experience (PX)

Research from the organisational perspective focuses mainly on PX as an integral aspect of care quality (Doyle et al., 2013; Farr & Cressey, 2015; Luxford & Sutton, 2014; Weech-Maldonado et al., 2012) alongside clinical effectiveness and patient safety (Doyle et al., 2013). Quality refers to how services attain the desired health outcomes for individuals and populations (Institute of Medicine, 2001). Three main healthcare quality elements have been identified: structure (e.g., infrastructure, technology staffing, funding), process (caregiver and patient interaction), and outcome (e.g., health status, mortality rate, patient satisfaction) (Narang et al., 2015). Care providers are increasingly interested in understanding how PXs are associated with measures of structures, processes, and outcomes since such knowledge could help providers improve the efficiency and effectiveness of care (Anhang-Price et al., 2014; Hendriks et al., 2009).

The organisational/service provider perspective has been particularly prevalent in approaching PX, which may be explained by the fact that healthcare systems are highly complex; government and other funders demand benchmarks, measurements, and efficiency, thereby encouraging standardized practices that enhance predictability but may decrease responsiveness to individual patient needs. In addition, there is the idea that providers seek significant degrees of influence, advancing a false conclusion that the care delivery system reflects what is best for patients (Goudy et al., 2015). Central theories can be applied to understand this perspective such as the

behavioural theory of the firm (e.g. Cyert & March, 1963) and the creation of customer value (Srivastava et al., 1999). The behavioral theory of the firm emphasizes the premise of efficiency in all firm actions. The creation of customer value consists of three main vital processes: (1) service or experience development management (e.g. Patrício et al., 2008, 2011; Zomerdijk & Voss, 2010); (2) customer relationship management (e.g. Payne & Frow, 2005); and (3) partner network management (e.g. Patrício et al., 2011; Tax et al., 2013).

The organisational/service provider view is based on the critical assumption that HCOs can design and thus determine PXs. That is, stimuli created by HCOs are generally perceived similarly by patients/service recipients. PX is associated with quality domains and patients' subjective perceptions regarding the elements of care (Wennberg et al., 2009; Withers et al., 2018).

Overall, the PX research taking the organisational perspective is often analysed at a meso-level. From a meso-level standpoint, PX arises from the broader alignment of multiple actors directly and indirectly engaged at various times and locations within a healthcare service system (Chandler & Lusch, 2015). That is, indirect service-for-service exchanges are a concern, which is realized through triadic relationships between dyads of actors (Tsiotsou, 2016). This type of analysis is focused on the optimal design of environments, processes, and systems within healthcare boundaries. Indeed, research that adopts the organisational angle of PX typically addresses the role of healthcare service attributes on PX (e.g., Dagger & Sweeney, 2007), such as the organisational culture (e.g. (Sorra et al., 2012), servicescapes (e.g. Mitra, 2016) and health-staff (e.g. (Pemberton & Richards, 2013; Rodriguez & King, 2014).

However, even though predominant research occurs at the meso level, scholars have adopted more macro-level approaches to move beyond care service boundaries and identify the impact of service delivery networks of organisations on customer perceptions of healthcare services (e.g., (Makarem & Al-Amin, 2014; Palumbo et al., 2017b). Indeed, at the macro level, relationships rely on complex synergies between multiple actors, who comply with specific norms and rules to establish a vivid and co-creating environment (Rozenes & Cohen, 2017). With the terms of value constellation (Patrício et al., 2011a) service ecosystem (Akaka & Vargo, 2015; Chandler & Lusch, 2015) and service delivery network (Tax et al., 2013), the investigation has moved away from the notion of purely dyadic organisation–customer relationships. Relevant studies posit that HCOs must analyze and assess the effects of the entire service network on PX (e.g., Lombarts, 2018; Palumbo et al., 2017a).

PX research adopting the organisational/service provider perspective approaches the creation and assessment of PX mainly on the static level. The investigation of static PX deals with how patients experience service encounters and factors/touchpoints that are directly controllable by the HCOs. The static approach to PX is constrained in its applicability to continuously provided services, where the service experience unfolds across multiple consumption episodes, and customers are prone to updating their perceptions throughout the experience (Gronroos, 1993; Rust & Oliver, 1994). Service production and consumption often unfold over several consumption episodes (Bolton & Lemon, 1999). Likewise, services such as healthcare require the customer to engage in multiple service encounters over time. As service encounters accumulate, marketers need to understand the service attributes that drive positive service outcomes at different stages of the consumption process. A process-based perspective is most relevant because this approach allows researchers to examine the effect of the consumption stage on service perceptions (Mittal et al., 1998, 1999). Therefore, scholars have adopted more dynamic approaches that account for PXs among multiple channels within the same company, offline and online (Dhebar, 2013; Patrício et al., 2008; Sweeney et al., 2015). A practical tool for this is the service experience blueprint, which systematically incorporates customers' desired experiences and needs at every touchpoint (Patrício et al., 2008). Blueprinting was initially used to draw flow charts of dependencies and tasks in computer systems and industrial engineering (Fliess & Kleinaltenkamp, 2004).

Similarly, blueprinting in healthcare is used in service design as a mapping technique to visualize all the processes involved in delivering a service that is internal or externally visible to the patient, including respective execution times and costs (e.g., Elrod & Fortenberry (2018). In addition, the 'care pathway' is a term used to describe the process of healthcare service delivery. The concept of care pathways has its roots in the management mentioned above theories: Critical Path Method (CPM), Lean Six Sigma, Business Process Redesign (BPR) and the Theory of Constraints (ToC) (bottlenecks). All the approaches relate to the Health Operation Management (HOM) perspective (Schrijvers et al., 2012). Care pathways are typically more generic and outlined from an organisational standpoint, prioritizing the convenience of care providers rather than that of patients. The timing, location, and manner of interactions between patients and HCPs are often dictated by provider preferences, such as convenience, routine, and cost-efficiency, rather than patient preferences, as highlighted by (Grocott, 2019). For clinicians, care pathways are integrated management plans that outline a sequence and timing of actions required to achieve a

standardized care process and optimal efficiency (Panella et al., 2003). They are the clinical management tools that help care workers understand their workflow (Grocott, 2019).

PX is often conceptualized as a multidimensional construct representing both patients' experiences of care and feedback received from patients about those experiences with domains/elements of care, including, for example, respect, information and communication, physical comfort, emotional support, convenient and punctual appointments, the ability to choose hospitals/doctors, helpful reception staff, knowledgeable doctors, clear and understandable communication, respectful and dignified treatment, involvement in treatment decisions and access to care (Ahmed et al., 2014; Bowling et al., 2012; Hewitson et al., 2014). The World Health Organization recommended greater engagement with the PX to inform and improve the quality and safety of patient care (WHO, 2016). The recommendations have added momentum to the development of the person-centred healthcare paradigm (Webster et al., 2019), with the personal aspects of the care experience being the focus (Frampton, 2012). In this regard, the healthcare experience should be structured primarily around the needs of patients and a more personalized, humane, and demystified PX is required (Charmel and Frampton, 2008). Researchers taking the organisational perspective on PX also stress the importance of meeting patients' basic emotional needs throughout the healthcare procedure and maximizing their social, mental, and physical health and wellness (Needham, 2012). To support this effort, it is suggested to personalize medicine, empower healthcare employees, collaborate closely with patients (Needham, 2012) foster enduring relationships with them (Pemberton & Richards, 2013; Staniszewska et al., 2014) provide personalized and effective care coordination, and establish environments that address the clinical and technological requirements of hospitals and health centres. Simultaneously, these environments should cater to the human need for comfort, familiarity, and autonomy, while ensuring cost-effectiveness (Frampton, 2012). The real challenge lies in conceptualizing PX as a means to alleviate suffering and anxiety throughout the entire continuum of care, spanning from the initial phone call to discharge (Stempniak, 2013). Moreover, high levels of compassion and empathy (kindness) toward patients, families, and colleagues should be considered (Padilla, 2017). Additional aspects are highlighted, such as the need to involve the relatives in care if they and the patients wish (Pemberton & Richards, 2013)) and promote the continuity of care (Staniszewska et al., 2014; Staniszewska & Bullock, 2012). The underlying idea is that individuals are living with their condition and experiencing it uniquely, that family and broader life need to be considered and that all these aspects of lived experience can affect self-care (Staniszewska et al., 2014).

The conceptualization of PX from an organisational perspective has also evolved from service quality to service brand experience. Brakus et al. (2009, p.53) conceptualize brand experience "as subjective, internal consumer responses (sensations, feelings and cognitions) and behavioural responses evoked by brand-related stimuli". In healthcare, scholars adopt a multidimensional view stressing that PX includes emotional, social and personal fulfilment during the various touchpoints involved in a service (Park et al., 2017; Weiss & Tyink, 2009). For Meyer & Schwager (2007), PX is defined as patients' internal and subjective responses to any direct or indirect contact with an organisation, encompassing every aspect of the organisation's offerings. PX is driven by what happens at many touchpoints between patients and the organisation (e.g., calling for an appointment, checking in at the reception desk, communicating with the physician and nurse, or receiving test results). These points of interaction are "moments of truth" at which patients form the most perceptions and decide to return or recommend the healthcare organisation (Kennedy et al., 2014). These definitions highlight the relevance of touchpoints, which are individual interactions between the service provider and the customer (patient) at distinct points in the care experience (Homburg et al., 2015; Schmitt, 2003). A summary of contributions for PX definition from the organisational/service provider angle is shown in Table 2.3.

Table 2. 3 – Definitions of PX from the organisational/service provider perspective

Viewing PX as a service quality pillar	
Source	Definition
Wennberg et al. (2009)	PX is associated with quality domains, patients' perceptions of the elements of care, and patients' ratings of their hospital experiences.
Doyle et al. (2013)	PX is recognised as one of the three pillars of quality in healthcare alongside clinical effectiveness and patient safety. Patients' direct experience of care process through clinical encounters can provide valuable insights into every-day care.
Anhang Price et al., (2014)	PX is an integral aspect of care quality and users are increasingly interested in understanding how PXs are associated with measures of structures, processes, and outcomes. Such knowledge could help providers improve the efficiency and effectiveness of care.
Ahmed et al. (2014)	PX is a multidimensional construct encompassing a number of elements of care (e.g.,cleanliness of facilities, waiting times, the information provided, and interactions with staff including receptionists, healthcare assistants, nurses and doctors). PX can be conceptualized both as patients' experiences of care and as feedback received from patients about those experiences with domains of care.

Hewitson et al. (2014)	PX is described as patients' self-reports of their experience of inpatient care. Their assessment include: staff-patient interactions, information provisions, involvement in decisions and support for self-care (shared decision- making and self-care management support).
AHRQ - Agency for Healthcare Research and Quality (2016)	PX is assumed as an integral component of healthcare quality, including several aspects of healthcare delivery that patients value highly when they seek and receive care, such as getting timely appointments, easy access to information, and good communication with HCPs.
Nottingham et al., (2018)	PXs have been identified as a key indicator for evaluating and improving internal processes and the overall quality of care.
Viewing PX as a service/brand experience	
Source	Definition
Meyer & Schwager (2007)	PX is defined as the internal and subjective responses that patients have to any direct or indirect contact with an organisation, covering every aspect of the organisation's offering.
Kennedy et al. (2014)	PX as a series of complex healthcare processes, each comprised of numerous critical points of interaction between patients and the organisation (e.g. calling for an appointment, checking in at the reception desk, communicating with the physician, and receiving test results)

Source: Author's elaboration

In terms of empirical predisposition, much of the PX research that adopts the organisational/service provider perspective is quantitative. PX insights are often gained through surveys. Studies typically measure healthcare perceptions using traditional survey-based instruments such as SERVQUAL (Curry & Sinclair, 2002; Curry & Stark, 2000). General service quality dimensions measured in the SERVQUAL are "tangibility", "reliability", "responsiveness", "assurance", and "empathy" (Parasuraman et al., 1985). In hospital service quality, these dimensions are defined as physical environment, functional quality and diagnostic accuracy, communication, trustworthiness and exactness, keeping promises, accurate records, timeliness, excellent and relevant specialized knowledge, politeness, sympathy, reassurance, willingness to help and ability to reflect patients' needs (Furrer et al., 2000; Polsa et al., 2013). More recently, other instruments have been used to collect and reflect the care experiences of patients, which might provide a more representative summary of selected aspects of care quality (Isaac et al., 2010). For instance, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) was created by the Agency for Healthcare Research and Quality (AHRQ) in collaboration with the Centers for Medicare & Medicaid Services in 2002 in the United States of America (USA)

(Werder, 2015). HCAHPS represents a standard survey instrument and data collection methodology for measuring patient's experience of their hospital care inside the hospital (Isaac et al., 2010). HCAHPS data allow us to gain critical insights into patients' experiences in the hospital and how these experiences relate to other aspects of care (Jha et al., 2008). The HCAHPS instruments assess the following core domains of care: nurse and physician communication (e.g., regarding medication) and interactions (e.g., the respect shown for the patient), staff responsiveness and timeliness of care, and overall quality ratings, including ratings for providers and the likelihood of recommending the facility. It also asks about demographic characteristics (Jha et al., 2008).

Overall, PX survey tools assess patients' experiences with care from the moment they connect with the hospital until the moment they leave the hospital (Worlu et al., 2016b). PX is always considered within the hospital/clinical boundaries. PX survey tools used to monitor patient feedback focus on the general experience with the service rather than an experience related to a specific disease. Thus, these instruments or tools have revealed positive associations between patient satisfaction and safety and are a reliable measure of how well a hospital can provide good quality service (Smith & Weldring, 2013). In this regard, patient-reported experience measures (PREMs) serve as a comprehensive report of the patient's or person's perspective, providing evidence on improvement areas or the humaneness of care. It includes aspects such as whether the patient is treated with dignity and respect, the involvement of the patient's social environment in the treatment process, and the coordination of care, including transitions between sectors and waiting times (Klose et al., 2016). Despite the frequent use of PX survey tools, other approaches can be used, such as qualitative interviews (e.g. Osei-Frimpong et al. 2015) and mixed methods (e.g. Dagger & Sweeney, 2007). Another group of studies approaches the phenomenon of PX conceptually, often in an interdisciplinary way, by integrating, for instance, insights from healthcare operations research and marketing (Anderson et al., 2018). A sample of PX studies taking the organisational perspective is presented in Table 2.4.

Table 2. 4– Studies of PX adopting the organisational/service provider perspective

Source	Methodological approach	Study's purpose	Main findings
Wilde-Larsson & Larsson (2009)	Empirical - Quantitative (survey)	It explores the relationship between patients' care experiences and their attitudes towards visiting the same healthcare provider again.	Care experience impacts general health status. Detailed knowledge about the relationship between patients' experience and patient post-care-episode attitudes and behaviours can provide important clues about how these linking processes may work. Patients' service experiences appear to affect outcome variables like hesitation about continuing to visit the same care provider.
Park et al. (2017)	Conceptual	It proposes a quality assessment framework for healthcare services based on patient expectations and perceived quality of service through their personal experience with the healthcare provider, across the various touchpoints during patient care.	The framework generates a quality score which is a measure of the degree to which the patient's expectations were met or exceeded.
Kumar et al. (2018)	Empirical - Mixed (stage 1 - qualitative interviews; stage 2 - quantitative - survey)	It aims to propose and empirically test a new, improved customer-based brand equity (CBBE) creation framework, which advocates marketing activities to create CBBE through PX.	The proposed framework is in contrast to extant literature suggesting marketing activities directly create CBBE in healthcare. The results suggest that PX is the focal mediating variable for the relationship between marketing activities and CBBE. This study adopts the 7Ps marketing mix – along with the ethical dimension (social responsibility) – as the most exhaustive and unambiguous to capture hospitals' marketing activities that impact PX. Such dimensions that provoke effects on PX are physical environment (physical evidence), interpersonal care activity (people), technical process and administrative procedure (process), core service (product), service communication (promotion), service charge (price), access convenience (place) and social responsibility (ethical dimension).

Mitra (2016)	Empirical - Quantitative (survey)	It seeks to understand the relationship between customers' servicescape perceptions, self-image congruity, and attitude in the healthcare context.	The results show that favourable servicescape perceptions help customers form image congruence in terms of symbolic and functional elements, strengthening their attitude. Servicescape accentuated image congruence has varying effects on customers' attitudes depending on patients' prior experience. This study emphasizes the role of servicescape on self-image congruity formation and customer attitude in healthcare. Favourable servicescape perceptions may encourage customers to form image congruence and attitude. Managers should make efforts to signal desired servicescape perceptions in order to retain existing customers and attract new ones.
Hamdan et al. (2016)	Empirical - Quantitative (survey)	It explores the impact of creating a child-friendly hospital environment on pediatric cancer patients and their families.	Several interventions were applied, such as wall posters, play rooms designated for certain age groups, quiet patient rooms for families to rest, an attractive waiting room, and plasma televisions with kid channels. A hospital or healthcare setting needs essential tools continuously improve the quality of care for their patient population to enhance comfort for the patient and the entire family. A small initiative to address the patient's emotional needs brings a huge difference in their health condition, thus giving positive health outcomes and an excellent on PX.
Makarem & Al-Amin (2014)	Empirical Quantitative (survey HCAHPS)	It proposes a comprehensive model of PX and satisfaction that moves beyond the service process to incorporate organisational and market factors that affect customer experiences directly and indirectly through their influence on the service process.	Three organisational and market factors lie at the centre of the healthcare debate: physician ownership, hospital specialization, and market competition. Physician ownership, specialization, and market competition positively affect patient ratings. Dimensions of the service process act as a mediator between organisational and market factors and patient ratings. This study provides new insights into the importance of including both organisational and market factors and service process dimensions when examining customer ratings and offers implications for governance and strategy in service organisations.

Source: Author's elaboration

2.4.2.2. Customer/patient perspective on patient experience (PX)

The customer perspective adopted in the healthcare focuses on understanding consumer (patient) behaviour and explaining underlying psychological processes (Kranzbuhler et al., 2018). Central theories can be used to better understand PX from this angle, such as experienced utility (Kahneman et al., 1997) and service-dominant logic (SDL) (Vargo & Lusch, 2004; Vargo & Lusch, 2008), emphasizing the subjectivity and context specificity of experiences and the resulting perceived utility. Furthermore, the Mehrabian & Russel (1974) model of environmental psychology is used to explain the impact of consumers' surroundings and their sensory reactions, as well as the cognitive theory, which suggests that in a healthcare service encounter, even where a patient regularly sees the same doctor, the service outcome changes depending on the patient. Hence, a patient's active participation is essential to achieving a successful service outcome (Kim, 2018). In this context, the extensive exchange of information and empathy deepens the relationship between physician and patient.

According to customer (patient) perspective, value is highly idiosyncratic, experiential, and contextual. Thus, the consumer perspective acknowledges that organisations cannot deliver value by themselves or determine how consumers perceive their own experiences (Kranzbuhler et al., 2018). Therefore, the PX research adopting the patient's perspective is mostly developed at the micro-level, which is focused on the patient's encounters with the system at different times of need. The micro-level context involves the individual (patient) level service exchange, concentrating on the dyadic relationship between the provider and the patient. Although PX is inherently individual and cannot be directly induced by the provider (Prahalad & Ramaswamy, 2004), providers can employ various experience-facilitating factors to create conditions that enable desired experiences to occur (Zomerdijk & Voss, 2010). At the micro level, studies focus on understanding individuals' cognitive, affective and sensory reactions towards stimuli during service encounters and how value is co-created (e.g., Kim, 2018; Osei-Frimpong et al., 2015). For example, Osei-Frimpong et al. (2015) explore value co-creation processes from the focal dyad of the patient and the physician, examining how their experiences in the consulting room influence the value that is created. The study identifies three critical areas influencing the co-creation process, along with corresponding elements or activities to be taken into account during the service encounter: social context, beliefs and perceptions, and partnership between the focal dyad. First, the actors' experiences are influenced by the social context within which the encounter occurs. It is also influenced by the

actors' social skills, which allow them to communicate with each other and create an enabling environment for the service exchange. Beliefs and perceptions of the actors also drive their emotional appeal and their level of trust and assurances that impact the co-creation process. In this respect, creating a PX in a service encounter depends mainly on the relationship between the actors. Finally, partnerships require both actors to understand each other and provide greater clarification about their respective roles and responsibilities. It allows for active participation or involvement and orientation of the actors in the consultation process.

PX research adopting the patient's perspective is mostly dynamic, as it deals with how patients experience sequences of touchpoints throughout their journey and how outcomes are generated (e.g., satisfaction, well-being) (Doherty et al., 2009; Lapsley & Groves, 2004). This customer's view or perception of touchpoints (Zomerdijk & Voss, 2010) constitutes dynamic experiences (Patrício et al., 2011). Applying the concept of the customer journey (Lemon & Verhoef, 2016) in healthcare, the process of consuming healthcare services can be characterized as a sequence of events in which patients have a series of touchpoints with the HCOs starting in the search phase or even before and involving every moment that they interact with the organisation. For Manchaiah & Stephens (2012), the term 'patient journey' refers to the experiences and processes a patient undergoes during their disease and its treatment. Kuo et al., 2015) add that the journey captures diagnosis, management and interactions with HCPs. LaVela & Gallan (2014, p.29) suggest that PX incorporates the patient's journey as a whole and explicitly adopts Beryl's Institute[2] definition: "the sum of all interactions, shaped by an organisation's culture, that influences patient perceptions across the continuum of care." According to this perspective, patients' experience expands in the space, reaching beyond the facets of a clinical/hospital encounter. Indeed, it occurs in all facets of the healthcare system, in all encounters, settings, and services (Wolf et al., 2014). The HCOs and patient may co-produce service during the patient journey. According to this view, the PX of health goes beyond the organisation-patient dyad to involve cognitive and emotional resources and resources from friends, family, and other customers/organisations and the community (McColl-Kennedy et al., 2012). The PX is also defined as an individual's cognitive, affective, and sensory evaluation of a series of individual interactions with an organisation at different points in time (Ponsignon et al., 2018). The Table 2.5 provides exemples of PX definitions.

[2] Global community of practice committed to transforming the healthcare

Table 2. 5 – Definitions of PX from the patient´s perspective

Source	Definition
McColl-Kennedy et al. (2012)	— PX extends well beyond the organisation-patient dyad to involve their own cognitive and emotional resources as well as resources from friends, family, and other customers and from other organisations and the community
Manchaiah & Stephens (2012)	— The term 'patient journey' refers to the experiences and processes a patient undergoes during the course of their disease and its treatment.
Wolf et al. (2014)	— PX as an idea crosses the continuum of care and is not just limited to a specific care setting or just the clinical encounter of care but to all touchpoints through which one encounters a HCO. It transcends the boundaries of care settings, encompassing all points of interaction with a healthcare organisation. — Experience goes beyond quantitative metrics or survey responses, encompassing every interaction with a healthcare organisation and its impact on individuals, families, and care partners. Experience is shaped by the expectations and perceptions of those involved, with each encounter being unique due to individuals' beliefs and experiences. — Experience is personalized, requiring actions and processes that respect the uniqueness of each individual's encounter, even amidst efforts to streamline processes and enhance efficiency. — Experience is much more than patient satisfaction. Satisfaction is an indicator of moments of time, but experience captures all someone encounters, the perceptions they take with them and the stories they tell.
Luxford & Sutton (2014)	PX happens throughout the journey, which begins from the first time patients consider where they are going to get their care. This extends to not only the medical appointments but also to where they pick up their prescriptions, how they are going to manage their care at home and how each of their care encounters plays a part in their overall health.
Purcărea (2016)	PX occurs across the continuum Journey. It provides an holistic assessment of the healthcare services' and experience attributes, acting on feedback and reaching healthcare service excellence, providing a better understanding of all the touchpoints with their patients and improving the quality and consistency of all these touchpoints. All these objectives are achieved by employees, who must be truly connected to the healthcare business.

Walker et al. (2017)	PX is taken to refer to a wider concept than linearly measured satisfaction or narrowly focussed outcomes, to attempt to learn about how the patient subjectively feel about their condition and whole of the care episode in a holistic manner including 'affective' or emotional responses.
Barton et al. (2019)	The idea of a client journey has become widespread as the prevalence of chronic illnesses has increased in frequency. Patient journey differ from 'integrated care pathways' and 'care pathways', which outline an agreed plan developed by a multidisciplinary team and may include client or carer involvement of anticipated care or client satisfaction feedback.
Wolf et al. (2021)	— PX encompasses a rich tapestry of human interactions spanning clinical and non-clinical settings across the care continuum and into the communities served by HCOs globally. This comprehensive understanding must consider the experiences of both healthcare professionals and the communities they serve, encompassing interactions with HCOs and systems at large. The essence of experience remains centered on the individual, while also acknowledging the pivotal roles played by their family and healthcare team. It recognizes the profound impact of these relationships and underscores the commitment necessary to serve the communities in which these connections thrive. The fundamental definition of PX mirrors the broader human experience in healthcare. — The layers that constitute the depth of experience in healthcare emphasize the broader human experience within the healthcare realm. — While the core tenets of PX (all interactions, organisational culture, perceptions, and the continuum of care) initially defined served as a framework, they were never intended to be confined solely to direct recipients of healthcare. The healthcare ecosystem is profoundly influenced by all its constituents, including organisations, healthcare professionals, patients, family members, care partners, and the communities it serves. Together, these elements encapsulate the human experience of healthcare.

Source: Author's elaborations

Next, we examine in detail the "journey" concept and its significant components and touchpoints while applying it to the healthcare context.

Patient journey conceptualization: stages and touchpoints

Transposing insights from customer journey literature to healthcare, the patient journey represents a map of the steps a patient takes as he/she progresses through different stages of a disease, often capturing diagnosis and management and interactions with health professionals (Barton et al., 2019). Patient journeys serve as valuable tools designed to gather comprehensive insights into patients' experiences across various medical domains, including those affected by chronic diseases. They offer a straightforward means to illuminate the collective needs of patient communities, complementing the clinical perspective on a particular disease if desired. Patient journeys facilitate the exchange and exploration of information between patients and clinicians, going beyond medical aspects to encompass emotional, psychological, social, and other pertinent factors influencing daily life. This fosters the identification of unmet needs and the formulation of strategies to address them, encompassing both common challenges shared by groups of patients with a specific diagnosis and unique concerns associated with individual syndromes (Webb et al., 2022).

Recently, patient journey mapping has been defined as a patient-centered initiative aimed at gaining deeper insights into the barriers, facilitators, experiences, interactions with services, and outcomes encountered by individuals, as well as their caregivers and family members, throughout their engagement with one or more healthcare services. This process involves documenting various elements of the patient journey to create either visual or descriptive maps. Unlike studies focused solely on tracking patient flow, demand, and movement within healthcare systems, patient journey mapping emphasizes a clear patient-centered perspective (Bulto et al., 2024). As a fundamental principle, patient journey mapping projects prioritize the capture of patient perspectives and experiences through the lens of patients and consumers. By doing so, these projects offer valuable evidence that can inform the development and implementation of responsive, context-specific strategies to enhance patient healthcare experiences and outcomes. Such improvements may manifest at the level of individual patient care, care models, or within the broader healthcare system (Bulto et al., 2024).

In summary, there has been a change in the way people interact with healthcare services, from relatively short and sharp encounters to more people commencing journeys that may take years or decades of care (Barton et al., 2019). Likewise, Jackson et al. (2012) argue that it is essential to document patients' journeys across program and organisational boundaries. It means assessing

the PX from the perspective of the continuous journey rather than as distinct episodes of care received from a specific program, service, or provider (Richardson, 2015).

In healthcare, a patient journey consists of patient interactions with healthcare professionals and other actorss distributed over three stages: pre-service, service encounters, and post-service period (Maas et al., 2023).

— Pre-service encounter. The patient's journey begins with individuals first noticing a symptom and becoming familiar with a troublesome body (Schildmeijer et al., 2018) until the moment they consider where to get care (Luxford & Sutton, 2014). Accordingly, research has examined how cancer patients notice their first physical symptoms and seek a healthcare provider to obtain a diagnosis (e.g., Abhyankar et al., 2019; Graffigna et al., 2017; Namukwaya et al., 2017). For example, Leydon et al. (2003) highlight some of the challenges experienced during the complex journey towards a cancer diagnosis, including the fear of potential findings. Their study also suggests that pre-diagnostic moments on the illness journey are essential to people with cancer and can influence levels of satisfaction with subsequent care. Hence, scholars underscore the impact of family dynamics on decisions to seek care from a primary care practitioner, as well as the significance of an individual's gender in shaping perceptions of health-seeking behavior (Leydon et al., 2003b; Martin, 2017). Family, friends and acquaintances are significant sources of WOM-related health information and advice (de Cruppé & Geraedts, 2011; Friedman et al., 2012; Geana et al., 2011). Research investigating the pre-consumption stage of the patient's journey has been extended into digital environments (Maas et al., 2023). Patients often search for answers and the cause of their symptoms or frequently rely on information from the internet. (e.g., Goldstein et al., 2019). Also, they are showing a growing interest in comprehensible Internet healthcare information (Berry & Bendapudi, 2007; Niehues et al., 2012) for decision-making about where to get care (e.g., (Dickerson et al., 2011). In this context, Hinz et al. (2012) emphasize that the most crucial sources of information comprise personal experiences, referrals, healthcare provider information, and recommendations conveyed through electronic word-of-mouth (eWOM) channels (Maas et al., 2023; Martin, 2017). This frequently allows patients to gain authentic information from other consumers who have already dealt with the healthcare provider and medical treatment (Swan & Oliver, 1989).

— During service encounter. In healthcare service research, much emphasis has been placed on the patient's care experience in hospital settings (e.g., Osei-Frimpong et al., 2015; Osei-

Frimpong & Owusu-Frimpong, 2017). In particular, studies provide a comprehensive overview of the contextual elements that influence patient care service experiences, including the physical environment (e.g., Lee, 2011), health staff/ employees (e.g., Brook et al., 2017), and the customer value co-created in healthcare service delivery process (e.g., Kim, 2018). The article by Kim (2018) focuses into the co-creation of customer value in healthcare service delivery and its impact on patients' perceptions of well-being. The findings suggest that physicians contribute significant affective and cognitive resources to patients during the medical encounter process. These collaborative activities result in heightened experiential value and perceived well-being among patients. Patients are actively involved in problem-solving, while service providers contribute resources such as professional expertise and effective care.

— Post-service encounter. In healthcare, research on the post-consumption of care services has been placed on the discharge of patients from the hospital (e.g., Granero-Molina et al., 2019; Kang et al., 2020; O'Gara et al., 2018) and the recovery of patients (e.g., Olsson et al., 2018). Discharge from the hospital can signify the beginning of an uncertain journey, attributed to the influence of critical illness on health-related quality of life (O'Gara et al., 2018). For example, studies have explored adult general surgical patients' perceptions of and satisfaction with discharge education provided by HCPs (Kang et al., (2020) and described the experiences of mothers of extremely preterm infants during the initial 20 months at home after being discharged from a neonatal intensive care unit (Granero-Molina et al., 2019). Studies have also explored patients behavior after the service encounter experience, mainly how they interact with peers/patients through online communities (OCs) and forums (e.g., Keeling et al., 2013; Samal et al., 2017).

  Online rating platforms for physicians and hospitals worldwide are gaining influence, with e-WOM growing exponentially (Goyette et al., 2010) in the healthcare sector (Martin, 2017). On such platforms, patients and relatives share recommendations and anonymous reviews about their experiences, which have a potentially larger audience than traditional WOM reviews because they are published online (Drevs & Hinz, 2014, p.230). Hence, internet healthcare rating has become a viable tool for guiding patients in making health decisions (Niehues et al., 2012).

  Significantly, patient characteristics (e.g., age, health status, ethnic background, education, insurance status or patient values), impact the likelihood of patients' recommendations on

such online communities (e.g. Ferguson et al., 2010; Klinkenberg et al., 2011). For example, persons over 65 years were more likely to respond 'definitely yes' for willingness to recommend (Klinkenberg et al., 2011, p.354). Moreover, people with perceived good or excellent health were more likely to participate in positive WOM. White participants would also more often recommend a healthcare provider than members of another racial group. Patients with a higher education were more willing to recommend (Klinkenberg et al., 2011, p.354). Lastly, patients who choose a hospital themselves write more positive online reviews than those with another directed choice (Drevs & Hinz, 2014, p.223).

As previously mentioned, patient journey consists of patient interactions, so-called touchpoints, with healthcare professionals and other actorss distributed over three stages. The term touchpoint, commonly used among practitioners, was introduced relatively recently into the academic literature (Bitner et al., 2008) often as a substitute for service encounter (Surprenant & Solomon, 1987). Terms like contact point (Stauss & Weinlich, 1997), service event (Lillrank, 2009), a moment of truth (Carlzon, 1989) and service moment appear as synonyms for touchpoints (Kumar et al., 2018). Zomerdijk & Voss (2011) characterized touchpoints as moments of contact between the customer and the organisation, whereas Kumar et al. (2018) define a touchpoint as a communication between a customer and a service provider. Touchpoints can also be conceptualized as "episodes of direct or indirect contact with the brand" (Baxendale et al., 2015, p.236). Others define touchpoints as clusters of experiential elements that facilitate product or service experiences (Berry et al., 2006; Dubberly & Evenson, 2008; Zomerdijk & Voss, 2010) or as the verbal or nonverbal incidents that an individual perceives and consciously associates with a particular organisation or brand (Baxendale et al., 2015).

The touchpoint must meet the following criteria: (1) it must be noticeable to the customer, implying that if the customer does not encounter it in any way, it cannot be classified as a touchpoint; (2) it must be a distinct event that can be pinpointed in time; and (3) it must involve communication or interaction between the customer and a service provider (Kumar et al., 2018).

Lemon & Verhoef (2016) have classified touchpoints based on the subject that manages and controls them: the company itself, a business partner, the customer, or external factors (e.g. a peer, the environment). They specifically identify four categories of experience touchpoints: brand-owned, partner-owned, customer-owned, and social/external touchpoints. Similarly, other researchers have made the distinction between organisation-initiated and customer-initiated touchpoints (e.g Anderl et al., 2016; de Haan et al., 2015). In this scenario, brand-owned and

partner-owned touchpoints would be initiated more by the organisation, whereas customer-owned and social/external touchpoints would be initiated more by the customer/third parties. The customer might interact with each of such touch point categories in each stage of the experience. Overall, depending on the nature of the product or service and the customer's journey, the strength or significance of each touchpoint category may vary at each stage. Once identified, organisations must determine how key touchpoints can be influenced. Next we attempt to define each touchpoint type within the healthcare context.

— Brand owned touchpoints entail customer interactions during the experience under the organisation's control (e.g. designed and managed by the organisation) (Lemon & Verhoef, 2016). They include all brand-owned media (e.g., websites) and brand-controlled marketing mix elements (e.g., service dimensions). In the pre-consumption of healthcare services, an example would be the use of internet tools, more specifically, the use of advertising, websites, search engines and social media platforms to influence potential future patients in seeking care in a precise medical unit (Azimi et al., 2017; Purcarea, 2019) and ensure the probability for them to recommend the health facility further (Wilde-Larsson & Larsson, 2009).

  During the service encounter stage, the influence of direct touchpoints during the service encounter stage has been studied extensively, as well as its impacts on WOM and patient behaviours (Martin, 2017), overall experience and satisfaction (e.g., Hamdan et al., 2016; Ojiako et al., 2010; Osei-Frimpong & Owusu-Frimpong, 2017). Research has also emphasized the importance of servicescapes (i.e, physical surroundings that influence patients' and employees' behaviour in a service setup (Mitra, 2016) in influencing the overall PX (Anderson et al., 2018; Trueblood & Bonk, 2019). Literature has adopted a broad approach by identifying marketing activities that affect the experience, such as physical environment (physical evidence), interpersonal care activity (people), technical process and administrative procedure (process), core service (product), service communication (promotion), service charge (price), access convenience (place) and social responsibility (ethical dimension) (Kumar et al., 2018). Despite the large number of studies that focus on the brand-owned touchpoints during the care service encounter stage, the understanding of the effects of brand-related touchpoints on patients' health outcomes (e.g. well-being) needs deeper insights (Ugalde et al., 2019).

  In the post-consumption stage, research has focused on the role of long-term psychosocial support provided by providers (e.g. Granero-Molina et al., 2019; Mechen & Andrews, 2019; O'Gara et al., 2018). Such advice may be particularly pertinent in helping chronic patients (e.g., with longer-term

cancer) adjust their lives and improve their psychological well-being (Graham-Wisener & Dempster, 2017).

— Parner-owned touchpoints refer to customer interactions during the experience that are collaboratively designed and managed by the organisation and one or more of its partners. Partners can include marketing agencies, multichannel distribution partners, multivendor loyalty program partners, and communication channel partners (Lemon & Verhoef, 2016). Hospitals establish partnerships with medical insurance companies in healthcare, making it more affordable for patients to see a medical specialist. Insurance coverage stands out as a primary determinant for hospital selection among both inpatients and outpatients (Mosadeghrad, 2014; Vu et al., 2016). Collaborations and partnerships with other healthcare entities, locally and nationally, have been established to strengthen the ability to provide coordinated and efficient access to care and improved PX (Vu et al., 2016). For example, the Regional Trauma Network is the Cleveland Clinic's partnership with Metro Health Medical Center on the Northern Ohio Trauma System (NOTS), which connects the community's Level I and II adult trauma centres by sharing quality data and clinical best practices to improve patient outcomes (Porter, 2014; Porter & Lee, 2013).

  Overall, healthcare networks are needed to expand geographic reach through the development of affiliations with community providers (Gentry & Badrinath, 2017; Hillary et al., 2016; Porter, 2014; Porter & Lee, 2013). The line between brand-owned and partner-owned touchpoints may sometimes blur (Lemon & Verhoef, 2016). For example, a healthcare organisation/system may create its smartphone app, typically a brand-owned touch point, designed to work well on both the Google Android and Apple iOS platforms at a specific time. Updates and improvements in functionality by Apple and Google may require updates by the organisation to its functionality and design, suggesting that partners may also influence some brand-owned touchpoints (Lemon & Verhoef, 2016). For example, Spat et al. (2012) offer insights into the development process of a Google Android-based tablet PC system tailored for in-hospital glucose management treatment of acutely ill patients with type 2 diabetes (T2D). The system provides decision support for insulin dosing and aligns with the Medical Device directive for software. Other apps are also designed to be used by patients over time, that is, across their illness journey, especially after medical encounters. This is the case of the "My Cancer Diary" app, which is a tool for cancer patient self-management that provides general information about cancer (e.g., anticancer drugs, severe symptoms, frequently asked questions about cancers); a patient assistance tool (e.g., symptom management), and healthcare professional assistance (e.g., cancer education) (Park et al., 2015).

Overall, the experience effects of partner-owned touchpoints are unclear, and studies on this topic are scarce.

- Customer owned touchpoints. These touchpoints refer to customer actions that are integral to the overall CX but are not influenced or controlled by the organisation, its partners, or other entities (Lemon & Verhoef, 2016). In the healthcare context, an example would be patients first noticing a symptom, thinking about their health needs, and seeking to attend a healthcare provider (e.g., Briggs & Flemming, 2007; Leydon et al., 2003; Namukwaya et al., 2017). In this stage, patients often try to find the cause of their symptoms by analyzing their habits and routines and frequently turn to the Internet for possible causes, further information/education, and coping strategies (Bettoli et al., 2016; Goldstein et al., 2019). Also, individuals actively sought online clinics when searching for a particular interest service provider, such as treatment (Myburgh et al., 2016).

- Patient-owned touchpoints are most critical and prevalent during and after care consumption. During such stages, the healthcare organisation and the patient may co-create service, but the patient's experience extends well beyond the organisation-patient dyad to involve their own cognitive and emotional resources (McColl-Kennedy et al., 2012; Sweeney et al., 2015). Building on previous work on value co-creation activities (e.g., McColl-Kennedy et al., 2012), Sweeney et al. (2015) explore value co-creation in healthcare, identifying a hierarchy of activities representing varying levels of "patient" effort from complying with essential requirements (less effort, more manageable tasks) to extensive decision making (more effort, more challenging tasks). The most common co-creation activities are as follows: compliance with requirements, proactive seeking, managing the practicalities of life, emotion regulation, and relationships with family and friends (Bagdoniene et al., 2019; Sweeney et al., 2015).

- Social/external touchpoints - Throughout the experience, customers are surrounded by external touchpoints (e.g., other customers, peer influences, and environments) that may influence the process. Peers may exert influence, solicited or unsolicited, in all three stages of the experience (Lemon & Verhoef, 2016). External touchpoints are important in enhancing the PX. PX extends the care provider-patient dyad to involve value networks (Ostrom et al., 2015) and resources from friends, family, other patients or the community (McColl-Kennedy et al., 2012; Sweeney et al., 2015). In particular, family and friends may influence a patient's decision to attend a primary care practitioner/provider (Leydon et al., 2003). Patients also consider their friends' or relatives'

recommendations if they do not have previous experience with admission to a specific hospital (Mosadeghrad, 2014).

Other patients can also influence patients and families, especially during the experience of care (e.g., Egan et al., 2016; Wong et al., 2015). For example, the relationships between families in the ICU may provide a source of social support or cause further emotional distress (Wong et al., 2015). Family and friends influence patients' experience after the care experience (e.g., O'Gara et al., 2018; Walker et al., 2017). For example, peer information may provide an illness trajectory that other patients can use as a guide to prepare for their cancer journey. Experiential information is accessible and holds the potential to identify overlooked information and supportive care needs. It may also have potential use in delivering psychological support to other patients (Graham-Wisener & Dempster (2017).

Third-party information sources such as online health communities (OHCs) and social media influence patients.For example, Keeling et al. (2013) examined how participants in the online forum discussed their experience with healthcare services and related pharmaceutical products. The findings indicate that the value of peer-to-peer online interactions goes beyond simple tangible or informational resources, encompassing experience, including hedonic value (e.g. enjoyment from extended discussion of health) and sociability value (e.g. a sense of belongingness), and building of social capital (Mathwick et al., 2008; Nambisan & Watt, 2011). Others suggest that patients increasingly use OHCs to satisfy complex needs that healthcare professionals leave unmet, including the creation of cure-oriented (i.e., functional, informational, cognitive content) and care-oriented value (i.e., emotional, affective support) (Van Oerle et al., 2018). For example, on the online health community - PatientsLikeMe.com – patients rely on online information to manage and understand their diseases (e.g., needs for empathy, comprehensible information, and hands-on advice) (Johnson & Ambrose, 2006). Patients living with chronic illnesses (e.g. diabetes, cancer) are especially using OHCs, such as patients' forums, to help support their medical treatment and discovery processes (Fox, 2014). Studies also investigate the role of emotional support in virtual communities that help participants cope with the personal challenges of post-treatment/care (e.g., Knibb et al., 2019; Ritchie et al., 2017). Overall, giving and receiving online social support is suggested to enhance patients' well-being (Zheng et al., 2016), an essential determinant of quality of life for patients with life-threatening illnesses (Cohen et al., 1996). Some OHCs can be more closely aligned with the healthcare provider/system, and sometimes, they may be considered partner touchpoints (Lemon & Verhoef, 2016). For example, the Hospital Clinic Barcelona launched

an online networking website (forum clinic) intending to share relevant information on specific conditions, promote the active involvement of patients and, consequently, contribute to improving their experiences. Beyond OHC, many applications, portals, and mobile devices address part of the patient continuum (Luxford & Sutton, 2014). However, more research is needed to try to understand how specific external touchpoints influence the experience of patients at different stages of their journey and to determine how healthcare managers can exert more control over these types of touchpoints to enhance further PX (Ponsignon et al., 2018; Silvera et al., 2017).

— Dynamics and external influences. Considering how dynamics and external influences impact the overall experience is also essential. Past experiences can affect current experiences through expectation formation and stickiness in experience evaluations (Lervik-Olsen et al., 2015) at each stage of the experience (from pre-purchase/consumption until post-purchase/consumption) (Lemon & Verhoef, 2016). For example, in the healthcare context, it is shown that prior experience also influences the experience and perception of a healthcare service organisation's brand, which in turn positively influences the perception of quality and value, satisfaction, loyalty, willingness to recommend and word-of-mouth (WOM) (e.g., Wheelock et al., 2014).

Research has also suggested the potential impact of broader externalities on the CX (Verhoef et al., 2009). First, the dynamic external environment can significantly influence CX, such as in the case of extreme crises or economic situations (i.e., recession), which can have a strong, negative, and enduring effect on the CX (Lemon & Verhoef, 2016). Recent research has shown the impact of major external events (e.g., public health crises) on PX in healthcare. These crises have both short- and long-term effects, and more effort is required to achieve the same experience than before such crises (Gijsenberg et al., 2015). Significantly, these events can affect how specific touchpoints contribute to the overall experience (e.g., Hunneman et al., 2015) For example, the recent report of (Burrill et al., 2020) indicates that the unprecedented speed and scope of the COVID-19 pandemic is forcing all HCOs to address many unexpected and critical challenges at the same time, including not just virtual provider visits but also many complex aspects of care delivery and management.

Regarding the empirical predisposition, the research on PX adopting patient's perspective is predominantly exploratory, and insights are often gained through phenomenological and ethnographic approaches. Studies employ qualitative observation (e.g., Myburgh et al. (2016), interviews (e.g., Tsai et al., 2017) or the critical incident technique (e.g., Osei-Frimpong et al. (2015). Lamprell & Braithwaite (2016) corroborate the relevance of supporting patients to narrate their experiences across their illness journeys. The focus of many researchers has been directed to the use of the quest narrative structure as a means by which researchers and clinicians can analyze patients' stories and identify the personal transitions as people move through the events of their disease and medical trajectories (e.g., Graffigna et al., 2017). In this respect, Lamprell & Braithwaite (2016) suggest supporting patients to narrate their experiences across silos of care, using a narrative model based on the classic journey arc of fictional characters to enhance our comprehension of patients' personal experiences as they transit through the services that comprise health systems.

Another group of studies approaches the phenomenon of PX conceptually by developing systematic reviews to identify and synthesize all published qualitative research studies exploring PXs of living with certain chronic conditions (e.g., Briggs & Flemming (2007). Also, mixed methods are used to understand care journeys as multi-sources for collecting data can better understand a broad sense of patients' care journeys and capture more challenges that patients may meet when they access the service (Liu et al., 2019) An overview of PX studies taking the patient's perspective is presented in Table 2.6.

Table 2.6– Studies on PX adopting the patient's perspective

Source	Methodological Approach	Study's purpose	Main findings
Osei-Frimpong et al. (2015)	Empirical - Qualitative (semi-structured interviews incorporating the critical incident technique)	This study explores the value co-creation processes between patients and physicians within the consulting room and how their experiences influence the generated value.	By examining the experiences of these actors in the consulting room, the study identifies three critical areas essential for supporting the value co-creation process, along with corresponding elements or activities during the service encounter.The first critical area involves the social context surrounding the encounter, influencing the actors' experiences. This includes factors such as the social environment within which the interaction occurs and the actors' social skills, which facilitate effective communication and create an enabling atmosphere for service exchange. The second critical area relates to the actors' beliefs and perceptions, significantly impacting their experiences. Patients' and physicians' beliefs and perceptions drive their emotional responses and levels of trust, which are crucial factors influencing the co-creation process. Lastly, partnerships between patients and physicians require clear understanding and communication regarding their respective roles and responsibilities. The study highlights the importance of the social context, beliefs and perceptions, and partnerships between patients and physicians in influencing the value co-creation process within the consulting room. Understanding and addressing these critical areas can foster positive PXs and enhance the overall value generated during healthcare service encounters.
Osei-Frimpong & Owusu-Frimpong, (2017)	Empirical - Qualitative (in-depth interviews)	It focuses on the doctor-patient encounter process to further understand the encounter process and the consumption experience of actors. It addresses the PX in the co-creation of value in healthcare	Findings suggest that there is a need for actors to create a collaborative and relational context. The clarity of information, as well as the level of trust between the patient and doctor, will greatly affect the overall experiences and the co-creation process. The encounter process may also drive emotional, cognitive, social, and behavioural responses to both actors that, consequently, influence their experiences and willingness to co-create. These experiences are inherent in the co-creation process,

		service delivery. The doctor-patient encounter in clinical consultations generated experiences that, consequently, influenced the service outcome.	as negative experiences could impair the healing process, which could eventually negatively impact the value outcomes. A patient also shared a negative experience with a doctor, which resulted in a potential value co-destruction.
Kim (2018)	Empirical - Quantitative (survey)	It examines physician-patient interaction in the context of a healthcare sector characterized by complex, specialized services and determine how value is thereby co-created. It investigates the potential impact of patient participation through physicians' resource offerings on patient experiential value and well-being.	The results indicate that physicians provide significant affective and cognitive resources to patients; in turn, patients are actively involved in the medical encounter process. These co-creation activities lead to increases in patients' experiential value and perceived well-being. Patients play a major role in problem-solving, and service providers contribute resources such as professional expertise and effective care. Healthcare service providers can refer to the service process model proposed herein and aim to maximize patients' roles and use of their resources for patients' well-being.
Dickerson et al., (2011)	Empirical . Qualitative - (interviews)	To understand the experience of men with cancer using the Internet. The overall constitutive pattern describing the men's experience is ''cancer diagnosis as a problem to be solved.''	Five related themes included: (1) Seeking disease and treatment information from the Internet for decision-making to become comfortable with the treatment plan; (2) Organizing information to facilitate provider encounters and to monitor for reoccurrence (3) Evaluating Web information by credibility and usability with trust in the physician influencing the end decision point; (4) Symptom management by knowing possibilities by hearing patient stories; Navigating through the healthcare system politics and power. Men with cancer are incorporating Internet use into their cancer journey. They perceive changing provider-patient relationships when participating in treatment decisions and monitoring for reoccurrence.

Namukwaya et al., (2017)	Empirical - Qualitative (in-depth interviews)	The study aims to elucidate patients' experiences of their illness, their perspectives on their multidimensional needs throughout the illness journey, and their expectations regarding improvements in healthcare.	Various multidimensional needs were identified, encompassing physical, psychological, social, spiritual, and information-related aspects. These needs underscored the fundamental desire for normal functioning, control over symptoms, coping mechanisms, adaptation to life changes, and the search for meaning amidst illness. Notably, spiritual needs were perceived to be less acknowledged by healthcare practitioners (HPs) compared to other multidimensional needs. Overall, the findings highlight the diverse and nuanced needs of patients across various dimensions of their illness experience, underscoring the importance of addressing these needs comprehensively in healthcare delivery. Additionally, the study sheds light on the potential gaps in recognizing and addressing spiritual needs, suggesting an area for improvement in patient-centered care.
Holopainen et al., (2018)	Empirical - Qualitative (interviews)	This study aimed to explore and characterize the contextual nuances of patients' perceptions of lower back pain during their healthcare encounters.	Patients' conceptualizations of their healthcare journey were elucidated through several thematic dimensions, including the persuasiveness of care, lifestyle adjustments, active participation, reciprocity, and the ethicality of interactions. These themes manifested across four categories: non-encounters, seeking support, empowering collaboration and autonomic agency. The findings revealed a spectrum of clinical engagements ranging from negative and disempowering encounters to transformative and empowering experiences. Key differentiators between categories included the presence of healthcare professionals and patients' growing comprehension of their lower back pain, establishing a solid therapeutic alliance, the patient's proactive involvement, and the transition to patient autonomy and responsibility with the assurance of available support. The insights from this research can inform and enhance the care provided to patients with lower back pain. The study identified a variety of clinical encounters, predominantly with doctors and physiotherapists, but also involving other HCPs such as acupuncturists. In the initial category,

			characterized by patients seeking assistance to understand their condition, the healthcare encounters often failed to meet their expectations, lacking a meaningful connection. Transitioning from this initial stage to the subsequent category is pivotal for initiating rehabilitation efforts. Effective communication and attentiveness from healthcare professionals were highlighted as crucial elements, facilitating understanding and fostering patient-centred care despite potential language barriers.
Nakata et al., (2019)	Empirical - Qualitative (in-depth interviews and hermeneutical analysis)	The study explores medication compliance among individuals with chronic illness, specifically focusing on the sociocultural factors that influence their medication usage experiences.	Adopting a sociocultural approach, the authors examine how various micro-individual elements shape medication adherence in daily life. The research aims to provide a comprehensive understanding of the compliance journey over the long term, particularly in the case of individuals managing hypertension. The central finding underscores the profoundly liminal nature of medication compliance, characterized by fluctuations between adherence and non-adherence to prescribed instructions. Compliance is depicted as dynamic rather than static, involving continuous negotiation between adhering to and deviating from prescribed standards. This liminality is intricately influenced by the contextual factors individuals encounter, including meso-structural conditions, micro-individual factors, and interpretive acts. Micro-individual factors encompass personal attributes such as relational networks, cultural capital, and maturity-based wisdom. At the same time, interpretive acts involve individuals' practices to make sense of their illness and guide their medication usage. These interpretive acts include body reading, retrospective and prospective considerations, and negotiations within their habitus.

Source: Author's elaborations

2.5. PROPOSING A PATIENT-CENTRIC MODEL FOR PATIENT EXPERIENCE JOURNEY FOR CHRONIC DISEASES

The notion of customer-centricity as a valuable strategic approach has been proposed, implemented, and debated in the marketing literature. Sheth et al. (2000) emphasise customer-centric marketing, which revolves around understanding and delivering value to individual customers rather than mass or target markets. More broadly, there has also been a movement toward customer focus and customer centricity at the overall organisation level (Gulati & Oldroyd, 2005). Fader (2012) integrated these two approaches by emphasising customer centricity as a strategy that aligns a company's products and services with the needs of its most valuable customers to improve the long-term financial value of those customers. This shift has prepared organisations for the interdisciplinary and cross-functional coordination required to design, understand, and manage CX Lemon & Verhoef (2016).

In healthcare, HCPs are also focused on improving PXs across the patient journey and, therefore, are adopting more patient-centric approaches and creating points of contact beyond the clinical setting. To support this transition, HCOs are adopting, for instance, technologies and approaches that provide personalised experiences for patients across the patient journey (Friedman et al., 2013). Some HCOs focus on creating a solid patient-centric culture encompassing competent, high-quality care, personalised care, timely responses, care coordination, and reliability and responsiveness (Weiss & Tyink, 2009). Adopting a patient-centric approach has significant implications for designing, measuring, and improving PX (Jenkinson et al., 2002; Ponsignon et al., 2018).

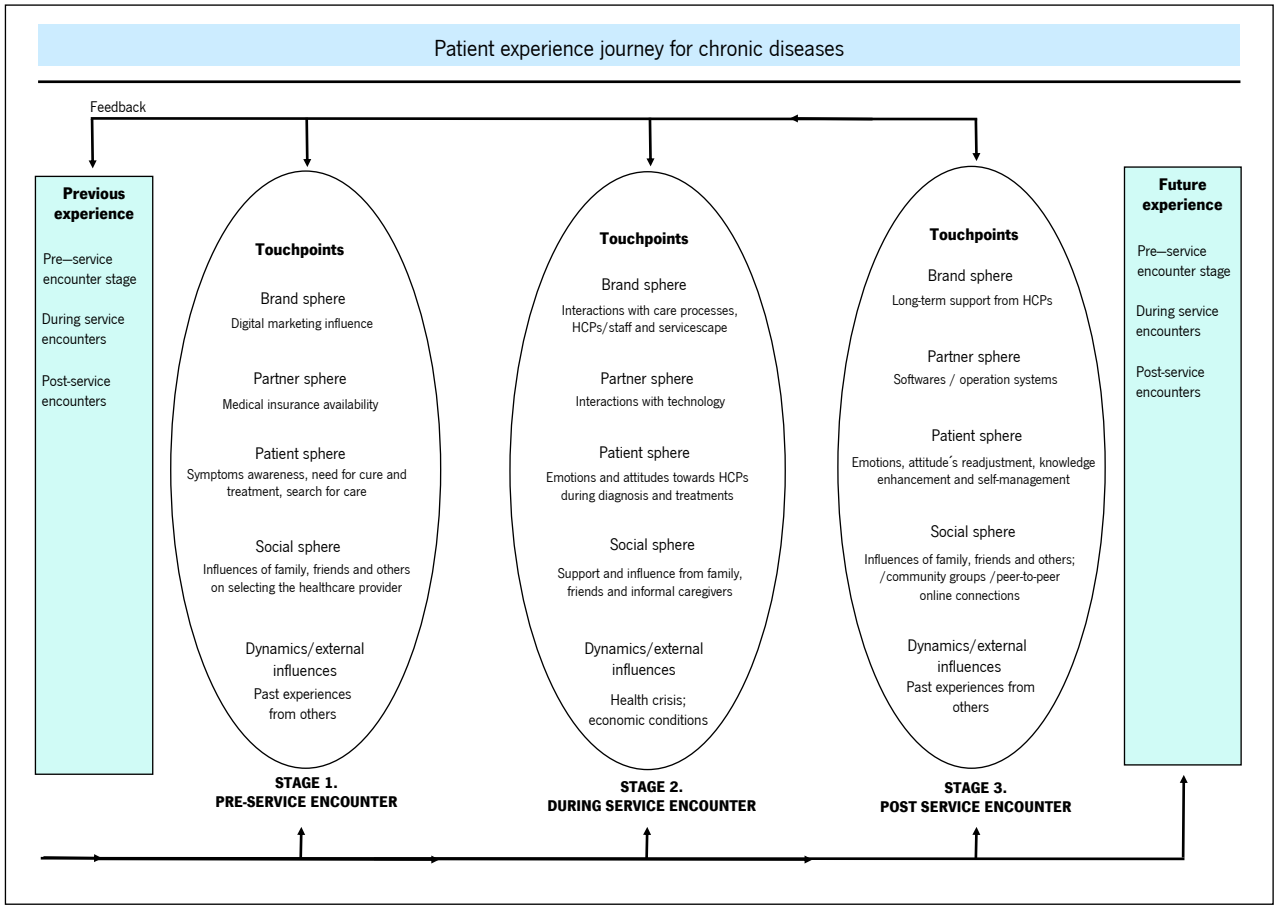
Throughout this investigation, we view PX as holistic and dynamic, consisting of the patient's journey over time and across multiple touchpoints. Thus, we propose to look at the various factors/touchpoints that build a strong PX based on the conceptual framework Process Model for Customer Journey and Experience developed by Lemon & Verhoef (2016). By applying such a model to the healthcare context, we look at the experience of patients as occurring throughout different stages and touchpoints over time. The rationale is that the experience includes many points of interaction and occurs in all facets of the healthcare system, in all encounters, in all settings, and beyond the frontiers of the hospital context (Wolf et al., 2014). The contact between the customer (patient) and the service provider (healthcare organisation - HCO/institution) is of very high intensity. It occurs through multiple touchpoints throughout the journey of the consumer (patient) (Khanna et al., 2014). The healthcare service provider and patient may coproduce service

during this journey. However, the PX of health extends well beyond the healthcare provider-patient dyad to involve the patient's own cognitive and emotional resources as well as resources from friends, family, and other patients and other organisations and the community (McColl-Kennedy et al., 2012; Sweeney et al., 2015). It implies that patients can take on a significantly more active role in their care by contributing various personal resources such as information and knowledge, and by engaging in various activities independently and with others to enhance their health and well-being (McColl-Kennedy et al., 2017a).

Our proposed model of Patient Experience Journey for Chronic Diseases (see Figure 2.1.) delineates the most relevant stages and touchpoints, spanning each phase of the patient journey. In the pre-service encounter phase, touchpoints include the influences of digital marketing (brand-owned touchpoints), patients recognizing symptoms and initiating decision-making (patient-owned touchpoints), influences from family and friends (social/external-owned touchpoints), and availability of medical insurances for selecting care providers (partner-owned touchpoints), and external influences/dynamics such past experiences from others.

During the service encounters, touchpoints encompass interactions with HCPs and care processes (brand-owned touchpoints), interactions with software systems (partner-owned), patients' development of feelings, emotions, and attitudes during diagnosis and treatments (patient-owned touchpoints), and external influences/dynamics like crises and past experience from others. In the post-service encounter phase, touchpoints include long-term support from HCPs (brand-owned), self-management practices from patients to deal with the condition (patient-owned), the influence and support from family and peers (social-owned touchpoints), and external influences/ dynamics such as past experiences. Table 2.9. specifies the model, including the description of each touchpoint type per stage.

Figure 2. 3 – Patient Centric Model for Patient Experience Journey for Chronic Diseases



Source: Author's elaborations

Table 2.7. The patient experience journey for chronic diseases with its various stages and touchpoints

Stage	Touchpoints			Main sources
	Type	Category	Sub categories / explanation/description	
Pre-service encounter	Brand-owned	Digital marketing influence	Website, search engine optimization (SEO), links, pop-ups; banner advertisements; social media; e-mails; digital television and radio and other digital media	(Purcarea, 2019) (Al-Amin et al., 2011)
	Partner-owned	Medical insurance influence	Marketing campaigns and digital ads for medical insurance. Medical insurance companies make it more affordable for patients to see a medical specialist	(Mosadeghrad, 2014)
	Patient-owned	Symptoms awareness	Noticing the first symptoms and emotional disturbances dealing with it (e.g., fear, anxiety, struggling, frustration)	(Briggs & Flemming, 2007; Goldstein et al., 2019; Leydon et al., 2003b; Manchaiah & Stephens, 2012; Ritchie et al., 2017)
		Need for cure and treatment; search for resources and information	Need for controlling symptoms and cure; seeking information from internet (i.e., websites, news) or peers for possible causes, further information/education; coping strategies; and finding the right healthcare practitioner/specialist	(Briggs & Flemming, 2007; Goldstein et al., 2019; Namukwaya et al., 2017; Ritchie et al., 2017)
	Social-owned	Influences of family, friends and others	Providing advice and guidance for selecting a healthcare provider	(Leydon et al., 2003b; Martin, 2017)
	External / dynamics	Past experiences	Prior experience influences the experience and perception of a healthcare service organisation's brand and the selection of a healthcare provider.	(Kennedy, 2017; Wheelock et al., 2014)

Stage	Touchpoints			Main sources
	Type	Category	Sub categories / explanation/description	
During service encounter	Brand-owned	Interactions with processes	Efficient and effective internal processes: I) Seamless/smooth service delivery (transition and flow between care units/departments; internal communication and coordination); II) Resource availability; III) Individual care plans; IV) Multi-professional teams, v) Timeliness (e.g., outpatient appointments; diagnosis and follow up); VI) Service variety/choice (range of services offered); iv) Capturing the voice of the patient (incorporating their feedback; understanding patients' expectations, goals, and priorities.	(Bray et al., 2015; Campbell-Crofts & Stewart, 2018; Kerin et al., 2020; Kohler et al., 2017; Ponsignon et al., 2018; Ritchie et al., 2017; Tometich et al., 2018; Travlos et al., 2016).
		Interactions with healthcare professionals (HCP)	I) Medical-technical competence (required knowledge and expertise); II) Support delivery: technical (e.g., symptom and physical activity management strategies), emotional (empathy, building trust, confidence, managing anxiety, emotions, well-being and other psychosocial challenges); and psychosocial (e.g., referrals to social services/support groups); III) Communication (e.g., understandable language; information updates frequently; information on current technologies and medications; programs/treatments; developing a solid working knowledge of their disease), IV) Availability (beyond usual job description); V) Involvement of patients and their families in treatment decision making (e.g., act as a driving force in patient's treatment decision and a strong influence on compliance with the medicine discussions about roles and responsibilities; assisting ICs in supporting the patient while maintaining their health and well-being).	(Abhyankar et al., 2019; Egan et al., 2016; Goldstein et al., 2019; Knibb et al., 2019; Kohler et al., 2017; Schildmeijer et al., 2018; Tometich et al., 2018; Ugalde et al., 2019; Walker et al., 2017; H. Zhang et al., 2018)
		Interactions with servicescape	I) Hospital environment and infrastructures (e.g., socio-cultural atmosphere - friendly, pleasant, appealing and appropriate; hospital designs and renovations; waiting rooms; environment and privacy for patient teaching and support; II) Quality of food and beverages	(Bray et al., 2015; Hamdan et al., 2016; Kaitelidou et al., 2015; Ponsignon et al., 2018; Wilde-Larsson & Larsson, 2009a)

	Partner-owned	Interactions with softwares/technology and operation systems	I) Compensation and funding systems; II) Smartphones and tablet PCs running operation systems like Apple iOS or Android designed for in-hospital management treatment of acutely ill patients; III) Electronic patient record system and central information system.	(Kaitelidou et al., 2015; Park et al., 2017; Spat et al., 2012)
	Patient-owned	Emotions during diagnosis and treatments	I) Negative emotions: (a) Initial shock of receiving the disease diagnosis, anxiety, fear, frustration; stress, uncertainty; (b) patients' negative connection to their drug/treatment (implicit wish to stop the treatment, or at least not to be obliged to follow a treatment regiment); (c) struggling with waiting times - feeling of powerlessness; II) Positive emotions: patients' positive connection to their drug/treatment (seeing the therapy as a safety anchor against the progression of the disease).	(Cheng et al., 2013; Goldstein et al., 2019; Schildmeijer et al., 2018; Tsai et al., 2017; Walker et al., 2017; H. Zhang et al., 2018)
		Attitudes during diagnosis and treatments	I) Negative attitudes: resistance; pressures on professionals; II) Positive attitudes: Acceptance and adoption of a different perspective (medication compliance).	(Egan et al., 2016; Tsai et al., 2017)
		Seeking for support and knowledge enhancement	I) Going to the medical appointments); II) Seeking information from HCPs to understand the disease, its treatment possibilities, and consequences, to gain knowledge of symptom and self-care management strategies; III) Taking a more active role in their treatment discussion by leading consultations and sharing their priorities of care, health issues, family and carer responsibilities, among others; IV) Co-producing with HCPs (showing graphical information to facilitate encounters with their providers and to monitor their health status for reoccurrence of the disease); V) Seeking contact with others (e.g., searching for other treatments/HCPs.	(Barton et al., 2019; Dickerson et al., 2011; Goldstein et al., 2019; Keeling et al., 2013; Kerin et al., 2020; Kohler et al., 2017; Manchaiah & Stephens, 2012; G. Mitchell et al., 2019b; Ritchie et al., 2017; Tometich et al., 2018)

	Social-owned	Influences of family, friends and ICs	I) Support delivery at the emotional level: supportive relationships improve patients' ability to cope with their chronic conditions; family helps patients during the participants' diagnoses and throughout their treatments, helping them reduce anxiety and depression in the hospital; II) Support delivery at the instrumental/physical level: family provides support during medical appointments; contributes to shared problem-solving.	(Cheng et al., 2013; Dickerson et al., 2011; Egan et al., 2016; Graffigna et al., 2017; Jackson et al., 2012; Kerin et al., 2020; Knibb et al., 2019; Kohler et al., 2017; Travlos et al., 2016; H. Zhang et al., 2018)
	External/ Dynamics	Externalities (e.g., health crisis)	Health crisis (e.g., COVID-19) causes negative impacts and effects on experiences of patients while accessing and interacting with HCPs.	(Bernacki et al., 2021)

Stage	**Touchpoints**			**Main sources**
	Type	Category	Sub categories / explanation/description	
Post service encounter	Brand-owned	Support delivery from healthcare professionals (HCP)	I) Giving feedback and support at discharge (discharge planning, including pictures, timelines, charts, instruction and information on how to integrate health information after discharge); II) Facilitating connections to community-based resources/social networks; III) Designing individual plans for rehabilitation; III) Providing long-term disease management support - maintaining open channels of communication and engaging in shared decision-making; encouraging patients to take their role in patient's condition (patient's empowerment); helping patients to develop a self-care routine; providing systematic follow-ups and a medication administration record for the patient to use at home; encouraging patients and ICs to maintain diaries to facilitate treatment and provide a coping method.	(Mitchell et al., 2019; Ponsignon et al., 2018; Tsai et al., 2017); Bettoli et al., 2016; O'Callaghan et al., 2011.)
	Partner-owned	Interactions with softwares / operation systems	I) Smartphones and tablet PCs running operation systems like Apple iOS or Android designed for in-hospital management treatment of acutely ill patients; II) Electronic patient record system and central information system.	(Park et al., 2017; Spat et al., 2012)

	Patient-owned	Emotions towards the disease	I) Negative: (a) anxiety and feelings of isolation at the discharge; (b) uncertainty for the future; (c) psychosocial challenges after returning home from the hospital; (d) struggling to back to normality (with health literacy affecting their ability to return to ''life''); (e) concerns about current and future emotional wellbeing, education, and employment; (f) uncertainty; frustration/annoyance, (g) problems experienced (by patients in their daily lives, outside the institutional boundaries of the hospital); feeling limitations (with activities of daily living); II) Positive emotions: (a) becoming familiar with a troublesome body; (b) emotional adjustment; (c) realizing the strength and power of body and mind; (d) cycles of hope; (e) patients' positive connection to their drug/treatment (seeing the therapy as a safety anchor against the progression of the disease); (f) grateful, hope and acceptance, remarkable resilience and a determination to maintain the identity of being a 'healthy' person, a sense of self.	(Graffigna et al., 2017; Mechen & Andrews, 2019; O'Callaghan et al., 2011; O'Gara et al., 2018; Olsson et al., 2018; Walker et al., 2017)
		Attitude´s readjustment	I) Acceptance and adoption of a different perspective (accepting the chronic nature, carrying the burden of side effects, medication compliance); II) Learning to cope with the condition; III) helping others, treating the illness experience positively and planning for the future; III) realizing the strength of, body and mind; IV) willingness to revisiting the same provider and recommend to others.	(Cheng et al., 2013; Egan et al., 2016; Schildmeijer et al., 2018; Tsai et al., 2017; Wilde-Larsson & Larsson, 2009) O'Gara et al., 2018;
		Seeking for support and information	II) Maintaining physical and mental well-being (maintain a healthy identity, to not be defined by their condition); II) Self-management (symptom management strategies at individual level; health issues); Spirituality (mantain hope, find the meaning of their ilness and for spiritual support, reestablish a sense of purpose)	(Barton et al., 2019; Dickerson et al., 2011; Kerin et al., 2020; Knibb et al., 2019; Kohler et al., 2017; Tometich et al., 2018; Travlos et al., 2016)

		Knowledge enhancement	I) Patients become experts in their illness management); II) Seeking contact with patient organisations, other therapies, and advice to get information and support. If patients are unsatisfied with the patient-provider relationship, they should seek another physician. Patients often search for information in internet forums and exercise their "voice" through debate, exchange and co-creation of knowledge; III) Organizing information (both to facilitate encounters with their providers and to monitor their health status for reoccurrence of the disease).	(Briggs & Flemming, 2007; Cheng et al., 2013; Ritchie et al., 2017; Travlos et al., 2016) Bettoli et al., 2016; O'Callaghan et al., 2011).
	Social-owned	Influences of family, friends and ICs	I) Support delivery at the emotional level: assistance by discussing and processing patients´ feelings about their illness. Being contacted by friends is beneficial for improving the symptoms of treatment and relieving negative emotional responses caused by the illness. II) Instrumental/informational support: assistance by friends and family with activities of daily living and medication management enables patients to maintain day-to-day activities that would otherwise have been difficult to sustain.	(Egan et al., 2016; Graffigna et al., 2017; Kohler et al., 2017; Y. Liu et al., 2019; Schildmeijer et al., 2018; H. Zhang et al., 2018)
		Influences of patient associations /community groups /peer-to-peer online connections	I) Practical support: (a) patients get access to referrals to medical specialists and therapy from other HCPs in the community and programs that facilitate inclusion in educational and other social settings; II) Psychosocial support: patients share information and experiences, newly diagnosed patients receive supporting adjustment by receiving an illness trajectory from others; patients share experiences, hedonic value (e.g. enjoyment from extended discussion of health); and sociability value (e.g. a sense of belongingness).	Cheng et al., 2013; Dickerson et al., 2011; Graham-Wisener & Dempster, 2017; Keeling et al., 2013; Knibb et al., 2019)
	External / dynamics	Past experiences	Prior experiences influence the perception of a healthcare service organisation's brand, which in turn positively influences the perception of quality and value, satisfaction, loyalty, willingness to recommend, and word-of-mouth (WOM).	(Kennedy, 2017; Wheelock et al., 2014)

Source: Author's elaboration

2.6. PATIENT EXPERIENCE MANAGEMENT

Within marketing literature, Homburg et al. (2015, p.8) suggest CX management as "the cultural mindsets toward CXs, strategic directions for designing CXs, and organisation capabilities for continually renewing CXs, with the goals of achieving and sustaining long-term customer loyalty". The goal of CX management (CXM) is to enhance interactions from the customer's view and, therefore, foster customer loyalty (De Keyser et al., 2015) In this view, the idea of CXM across different touchpoints in a customer journey is prominent (Lemon & Verhoef, 2016).

Practice-oriented authors in CX literature state that one of the main challenges facing organisations is managing customers who are initiating a journey, given that customers differ in their role preferences, abilities, and resources (Lemon & Verhoef, 2016). Customer`s roles can vary from synthesizing a wide range of resources and engaging with many individual stakeholders in the network to complying with a service provider's requests (McColl-Kennedy, 2015). Homburg et al., (2015) propose that organisations ought to possess the capacity to orchestrate the customer journey across various touchpoints, engage in strategic alliances, and capitalize on the organisation's capabilities. The authors also argue for an experience-oriented mindset within organisations, which seems linked to a customer-centric orientation (e.g., Shah et al., 2006).

In the next section, we transpose the insights from CX management literature to the healthcare context. In healthcare, PX is recently viewed as a holistic interactive process occurring throughout the patient´s journey, shaped by cognitive, emotional and social clues and by patient and contextual characteristics. Therefore, PX must also be considered a holistic strategic process and managed across multiple touchpoints (Danaher & Gallan, 2016; Ponsignon et al., 2018; Varnali, 2018). More specifically, we offer practical guidelines for mapping the patient journey and touchpoint design and understanding the role of alliances, network partners, and the internal HCO.

2.6.1. Key patient experience management domains

2.6.1.1. Patient journey and touchpoint design

Recent CXM research is increasingly concerned with the long-term evolution of CX journeys across multiple service cycles, namely initial, subsequent, and terminating service cycles (Siebert et al., 2020). The customer journey across multiple service cycles is diverse yet iterative in nature (Lemon & Verhoef, 2016).. Organisations are advised to enrol customers into an "ongoing cycle" of retrigger, repurchase, and re-consumption experiences (Court et al., 2009, p.101). Such an ongoing cycle is known as a "loyalty loop" (Court et al., 2009, p.102). With a focus on consistency, effortlessness, and predictability, this approach is referred to as the smooth journey model (Siebert et al., 2020). In essence, this model helps customers make an informed decision and fall into a comforting, trust-building routine (i.e., a loyalty loop).

Smooth journeys are ideal for instrumental service categories, such as healthcare, since journeys in these service categories are like "jobs to be done" (Christensen et al., 2016, p.54). Building on the smooth journey model proposed by (Siebert et al., 2020), several managerial insights can be applied to the healthcare context. First, in the initial service cycles of a smooth patient journey, patients must be motivated to make complex decisions (Leydon et al., 2003b; Martin, 2017). In this context, the service design principle offers customers decision-support at every stage of the intentional decision-making process through avenues such as brand advertising, content marketing, interactive tools, and similar methods (Radu et al., 2017).

During the subsequent service cycles, the service design principle is streamlining the patient journey by eliminating unnecessary service elements (e.g.,Brincat et al., 2020), anticipating customer preferences (e.g., Dodds et al., 2018; Trueblood & Bonk, 2019) and providing just-in-time information at each service encounter (e.g., Ponsignon et al., 2018). The journey pattern across the final also necessitates distinct termination trajectory conceptualisations (Siebert et al., 2020). Loyalty loops can end following loyalty-weakening incidents, such as when the organisation delivers poor service or when a competing organisation/service offers a better service (Fleming, 2016). One example could be patients experiencing significant difficulties navigating the transition between and within clinical services and reporting a lack of information transfer between healthcare services, which requires multiple retellings of their stories (Kerin et al., 2020). Therefore, managers must avoid such potential loyalty-weakening incidents mostly because patients choose to share their dissatisfaction with others when they have a poor experience (Brook et al., 2017).

Since experiences result from direct or indirect interactions with a organisation's touchpoints (Lemon & Verhoef, 2016), managers aiming to oversee CX from the customer perspective (McColl-Kennedy et al., 2018) must develop the ability to craft the customer journey across various stages and touchpoints (Lemon & Verhoef, 2016),. Importantly, managers need to create not only single excellent touchpoints but also a link among them so that they result from a general design and consistent framework (Rawson et al., 2013). Consumers perceive any single touchpoint in any channel as a consistent and invariable execution of the same CX concept (Addis, 2016). Yet, the (re)designing of comprehensive journeys and touchpoints presents a formidable challenge (Homburg et al., 2017; Rawson et al., 2013), given the proliferation of channels and touchpoints, rendering the customer journey increasingly intricate and difficult to navigate (Hall et al., 2017; Simon et al., 2016). The only way to achieve this goal is to map the customer journey (Addis, 2016). The final goal of designing and continually renewing touchpoint journeys is enabling the customer to connect with the service in a personal, memorable way (Pine & Gilmore, 1998) and achieving long-term customer loyalty (Homburg et al., 2017).

Similarly, the patient experience management (PXM) literature calls for the design and mapping of the patient journey across multiple touchpoints in a consistent way (Danaher & Gallan, 2016; Ponsignon et al., 2018; Varnali, 2018) to reduce the complexity of patient journeys. Mapping the patient journeys is not an easy task, as journeys are becoming more complex and extend beyond the care provider-patient dyad to capture additional value networks and resources, such as friends, family, other patients and communities (McColl-Kennedy et al., 2012).

Although the patient journey mapping concept bears similarities to "care pathways" or "service blueprinting", it is distinctive in its focus. The first - the "care pathway" - one of the concepts in health operations management, is characterized as the systematic analysis, design, planning, and management of all the steps essential for delivering a service to a patient. The care pathway has its roots in the management mentioned above theories: Critical Path Method (CPM), Lean Six Sigma, Business Process Redesign (BPR) and the Theory of Constraints (ToC) (bottlenecks) (Schrijvers et al., 2012). Some studies have been focused on redesigning the patient's care pathways to generate performance improvements and higher patient satisfaction levels (McCarthy et al., 2016). For example, McCarthy et al. (2016) propose a visual tool prototype that bridges the gap between three pillars of service quality: performance improvement, regulatory constraints, and PX.

The second - "service blueprinting" – (often called service process design) is a visual map of the service process that describes service characteristics in terms of equipment, employee responsibilities, quality, and cost factors (Varnali, 2018). Service blueprints allow employees, customers, and managers to know concretely what the service involves and understand their respective roles in its delivery (Bitner et al., 2008).

The patient journey mapping approach emerged as complementary to service blueprinting because blueprinting represents what "an organisation plans for a customer, (Zomerdijk & Voss, 2010), whereas patient journey maps represent what really happens from the customer's point of view" and places the patient at the heart of healthcare service system design. It depicts the service process from the customer's point of view, involving his or her expectations, state of mind, emotional/cognitive/behavioral responses, and barriers and motivators for action (Varnali, 2018). In CXM literature, a customer journey map can be defined as a diagram that illustrates the steps that customer(s) go through in engaging with a company, whether it be a product, an online experience, a retail experience, a service, or any combination. The goal here is to understand the myriad possibilities and paths the customer may take to complete his or her path (Lemon & Verhoef, 2016). By adopting this idea, Purcărea (2016) suggest developing "Patient Journey Maps" to compare the existing and desired experiences as a good foundation for a PX plan.

(McColl-Kennedy et al., 2017a) present a series of patient journey maps to provide insights into emotional episodes, contributing to practical recommendations for managing patient and family emotions and well-being throughout the patient journey. Thus, Grocott (2019) offers a framework for transformative process change to improve PX across the journey and value within healthcare. The study proposes the involvement of patients in service and journey design through experience-based co-design. However, despite the current interest in patient journey maps, there is still limited empirical work on this domain (LaVela & Gallan, 2014).

Researchers have attempted to identify synergies between channels based on the notion that patients should have a seamless experience. As reported by Bauer (2018), e-health disciplines are poised to serve as pivotal enablers for smoother transitions of care and improved service coordination among HCPs and specialists. The extent to which patients can collaborate effectively with their care teams will be significantly enhanced by the integration of e-health tools.

The advent of the mobile revolution and advancements in data management practices have enabled enhanced care coordination across a patient's journey. Telehealth services play a pivotal role in facilitating connected care by furnishing physicians with data that seamlessly integrate into

a patient portal. This not only enhances risk monitoring but also empowers proactive treatment approaches. Thus, clinical data scientists and informaticists partner with physicians to operationalise programs that identify new best practices and drive behaviour change, especially for those patients with costly chronic conditions and comorbidities Bauer (2018). Nevertheless, multiple touchpoints' contributions (and interactions) to a seamless PX must be addressed. In particular, examining how mobile technologies can enable the creation of new care services to enhance the PX deserves more attention (Ostrom et al., 2015).

Researchers have also prioritised the role of patient engagement at various touchpoints to create memorable care service experiences (Vogus & Mcclelland, 2016). Recent evidence shows that patient engagement is essential in achieving a high-performing healthcare system. In this regard, the objective of the study of (Kohler et al., 2017) was to develop a system-level implementation strategy to include patient and family advisors (PFAs) at decision-making points in primary healthcare (PHC). The well-established co-design methodology allowed authors to include value-based perspectives of vital stakeholders, including patient advisors. Despite the importance of patient engagement throughout the journey, there continues to be a need for more clarity on what it looks like, how it should be managed and how it improves health outcomes for patients and families (Kohler et al., 2017).

2.6.1.2. Partner and network management

Customer journey mapping has begun to include the role of partners and external influences (Chandler & Lusch, 2015). Research has broadened the perspective of the customer journey to encompass a network approach, which acknowledges the contributions of communities, experience networks, service delivery networks, collaborators, and the broader ecosystem within which the experience unfolds (e.g., Tax et al., 2013). In this respect, (Bodine & Hagen, 2013, p.7) defines a customer experience ecosystem as "the complex set of relationships among a company's employees, partners and customers that determines the quality of all customer interactions".

Such network perspective is particularly needed in healthcare services, where PX extends the care provider-patient dyad to involve value networks (Ostrom et al., 2015) and resources from friends, family, other patients or from the community (McColl-Kennedy et al., 2012; Sweeney et al., 2015). HCPs must coordinate patient care across the journey to promote wellness while remaining cost-effective (Patrício et al., 2018). In this sense, a network perspective is needed to sustain the healthcare system as a whole (Demirkan, 2013). Hence, patient well-being can only be achieved

through the joint efforts of interrelated provider networks (e.g., other organisations) and networks (Patrício et al., 2018).

In the marketing literature, Tax et al., 2013)identify specific forms such an extended service delivery network might take. The most typical is the customer-coordinated network. Here, the customer takes control of and is responsible for all external activities related to the focal experience. Applying it to healthcare could involve the patient using online health communities (OHCs) such as patients' forums (e.g., CGM in the Cloud; Diabetesmine) to support their medical treatment and discovering processes (Bauer, 2018; Fox, 2014). These online support groups enable patients to share information, stories, questions, or concerns about several conditions. It is also suggested that giving and receiving online social support enhances patients' well-being (Zheng et al., 2016), an essential determinant of quality of life for patients with life-threatening illnesses (Cohen et al., 1996). This network results in low control and higher uncertainty for the organisation (Lemon & Verhoef, 2016). Therefore, providers need insights into the functioning of OHCs in order to deliver a service that fits the patient's experience in their particular context (Heinonen et al., 2010). Keeling et al. (2013) argue that opportunities exist for healthcare service providers to learn from and collaborate with such OHCs. Managers still need to give primacy to the consumer "voice" and view of experiences within services (Baron & Harris, 2010) to drive forward healthcare service developments. Recent research highlights the importance of OHCs as valuable instruments for enhancing patient-physician relationships (Audrain-Pontevia & Menvielle, 2018) as they contribute to the engagement of patients in their care, which leads to more positive experiences (Hibard & Green, 2013). The fact that patients internally process information shared in a traditional patient–doctor encounter and share it online implies an essential role for healthcare professionals in sustaining and ensuring information quality. Furthermore, while gaining insights from what patients share in OHCs, the organisation can develop services that are more responsive to patient's concerns (Van Oerle et al., 2018).

Other forms of extended service delivery networks emerged, such as the organisation-coordinated network, where the organisation takes the lead role in connecting and coordinating all aspects of the CX. In this network, the organisation obtains greater control, lower uncertainty, and additional insights into the entire CX (Patrício et al., 2011). Considering the healthcare services context, one form of the organisation-coordinated network could be the creation and management of OHCs by HCOs. Since patients adopt an active attitude and share information with peers online, HCPs must be agile and reflect on how their service is integrated into the customer's ongoing experience and

activities beyond the traditional service process (Van Oerle et al., 2018). In this respect, managers must rely on OHCs as communication tools, co-creation platforms, or extensions to patient management systems (Blazevic & Lievens, 2008). For example, the Hospital Clinic Barcelona launched an online networking website (forum clinic) intending to share relevant information on specific conditions, promote the active involvement of patients and, consequently, contribute to improving their experiences. Beyond OHC, many applications, portals, and mobile devices address part of the patient continuum. However, only some have been adopted to encompass the patient journey (Luxford & Sutton, 2014). Nevertheless, the healthcare industry has struggled with their implementation, perhaps because healthcare customers are ill and under stress, demand high-credence services, and require considerable attention, especially if they suffer from chronic diseases (Berry & Bendapudi, 2007).

Another form of governance for such networks is the lead organisation-governed network, in which one partner or organisation takes the lead and directs the network, and network administrative organisations, a separate organisation that is set up to administer the network (Provan & Kenis, 2008). One example in healthcare could be Care Opinion (www.careopinion.org.uk), a not-for-profit online platform on which patients can provide narrative feedback about health and social care in the UK (Ramsey et al., 2019).

Partnerships have also been recognized as generating value outside the clinical boundaries (Friedman & Kovner, 2018). New tools and healthcare alternatives (e.g., telemedicine and physician reviews) are being embraced to add convenience and value for patients and promote differentiation from competitors. Also, technology like a healthcare CRM platform enables patient data to be collected, organized and analysed from multiple sources, including demographics, psychographics, social media activity, behavioural patterns, clinical history, and call centre interactions (Friedman & Kovner, 2018). This data enables organisations to construct comprehensive, 360-degree customer profiles, facilitating the delivery of tailored engagement strategies across various communication channels.. By utilizing data from various sources, HCOs can now make informed marketing decisions that coincide with the consumer's long-term health goals and the organisation's business goals (Friedman & Kovner, 2018).

2.6.1.3. Internal organisation challenges

Managing the CX also affects the organisation (Lemon & Verhoef, 2016). Homburg et al. (2015) specifically mention the need for organisations to develop a CX response orientation. PXM literature also emphasizes the need for HCPs to possess a patient orientation, placing patients at the focal point of attention within the health system (Elrod & Fortenberry, 2018). The emphasis on the patient journey guides the meaningful design and enhancement of healthcare systems, placing patients at the center of attention (Ponsignon et al., 2018). The imperative for patient orientation has generated considerable investments in tools and techniques aimed at promoting service, attention, and support (Elrod & Fortenberry, 2018).

One of the simplest and most effective approaches to encourage patient attentiveness is by posing the fundamental question, "Am I viewing things from the perspective of the patients?". It effectively reminds of priorities, builds empathy, and motivates personnel to deliver their very best continually (Elrod & Fortenberry, 2018, p.1). Vogus & Mcclelland (2016) report that patient-centred care increases patient voice on a wide array of issues previously the exclusive purview of care providers (Avgar et al., 2011). The extensive input from the patient allows doctors, nurses, and staff to have a personalized knowledge of the patient, including their health beliefs. It also allows caregivers to anticipate and attend to the patient's emotional and physical needs (Rathert et al., 2013). Patients are being increasingly integrated into medical training through initiatives where actual patients share their stories and directly engage with learners and other HCPs via formal patient-family advisory programs (Halm et al., 2006). Such interventions have an emotional impact and help make the caregiving experience (Stang & Wong, 2014). In healthcare services, a patient-centered approach represents a method of care delivery aimed at enhancing the quality of interaction between service providers and consumers. This approach prioritizes placing consumers (and their families) at the forefront of decisions that impact their well-being (Anderson et al., 2018).

PX management research has also focused on holistically redesigning service delivery (Patrício et al., 2011) to improve the overall experience and well-being (Anderson et al., 2018). Improving service delivery relates to the intentional configuration of physical and non-physical elements in a service system, including people/staff, environment/places, processes, and technology (e.g., (Klaus, 2018; Worlu et al., 2016)

2.6.1.3.1. People/staff

Vogus & Mcclelland (2016) stress the need for cultural competency. The term reflects the institutionalization of policies, practices and training staff to be culturally competent (i.e., knowledgeable of specific cultural practices and norms) and readily providing interpreters and translation services (Weech-Maldonado, 2012). It influences various dimensions for all patients, leading to more favorable ratings of communication with doctors, overall hospital rating, and willingness to recommend the hospital to others (Weech-Maldonado, 2012).

It is also recognized that improved healthcare delivery must require frontline staff with the ability to "read" patients and co-create experiences tailored to their unique circumstances (Srivastava & Thomas, 2010). Thus, fostering a doctor's interpersonal skills and establishing partnerships and empathic communication with patients leads to emotional connection, clinical outcome and PX (Kemp et al., 2014; Kennedy et al., 2014; Needham, 2012). Empathic communication attempts to understand how recommended treatment plans fit patients' lifestyles and customize them accordingly (Vogus & Mcclelland, 2016). Customizing care also includes doctors taking the time to get to know a patient as an individual by asking questions, such as the nature of the patient's work when discussing their treatment plan for their acute back pain (Shaw et al., 2005).

This customized care approach is associated with higher patient satisfaction ratings (Shaw et al., 2005). In contrast, when patients perceive low-quality communication (feeling rushed, never receiving explanations for tests, and being ignored) from a doctor, it is associated with higher levels of malpractice claims (Entman et al., 1994)

Using patient feedback to illustrate differences between expectations of the service brand and the actual service brand experience helps employees see the gap and empathize with patients (Kennedy, 2017). Indeed, healthcare services should consider enhancing the track of emotions to gather emotional demographics. It means tracking the patient's likely emotional mindset at the encounter as a function of where they come from, age, and previous encounters.

Healthcare professionals are acknowledged to have an unequivocal obligation concerning the provision of spiritual care, supported by legislation, ethical codes, and research evidence. This aligns with the transition of healthcare from a biomedical paradigm to a holistic one, which encompasses all dimensions and needs of patients and their families (Caldeira et al., 2019).

To achieve the goals previously identified, training the right people is critical as it helps to perform and deliver service that aligns with the brand promise, all contributing to the perception of service quality and minimal experience gaps (Kennedy, 2017). The underlying idea is to make the

employees satisfied, who in turn will make the customers satisfied in the best possible manner. Organisational strategies should provide all staff (e.g., nurse practitioners, physician assistants, nurses, other care team members, and the front desk and business office staff) with appropriate customer service training and support, including skill development in emotional resiliency and empathy (Klaus, 2018). Adequate motivation, empowerment, and ample rewards can generate employee satisfaction, which will be carried on to their approach to treating the customers, thereby developing a new culture of customer care (Samal et al., 2017). Some HCOs have developed and implemented compassion practices that allow caregivers to detect and respond to the unique suffering patients and their families experience (i.e., concern for patients) and encourage providers to treat them accordingly (Lown et al., 2011). Compassion practices acknowledge and incentivize compassionate actions by caregivers, while also providing compassionate support to help caregivers cope with the stresses and traumas encountered in their work (McClelland & Vogus, 2014), creating conditions where caregivers can more effectively detect and respond to suffering. For example, compassion practices like the Cleveland Clinic's "Code Lavender" team respond to employees in need of emotional and spiritual support at work (Stone, 2018) and provide a forum for processing their emotions. These practices increase psychological engagement (Kahn, 1990) and connection to the organisation making caregivers more likely to extend compassionate behaviour to patients and their families (Abendroth & Flannery, 2006).

2.6.1.3.2. Physical environment

Fottler et al. (2000) agree that the healthcare industry has recognized the physical environment as a valuable resource which can affect its customers over the last ten years. The design of hospitality healthscapes (Samal et al., 2017; Suess & Mody, 2017) based upon the concepts of servicescape (M. J. Bitner, 1992) is an example of the synergistic opportunity through the knowledge exchange between service/hospitality and healthcare research (Russell-Bennett et al., 2017). Hospitals and clinics are increasingly recognizing the crucial role of hospitality knowledge in shaping the PX (Klaus, 2018). Samal et al. (2017) also argues that the hotel sector's philosophy of guest care must be applied entirely to the hospital industry to make the experience more worthwhile. Hospitality is an industry that takes care of people outside their homes, and Mullins (1995) confers that by offering guests an effective and efficient environment, we can achieve "patient" satisfaction. HCOs need to connect people and patients in the most appropriate places—outpatient centres,

emergency departments, and the patient's home—based on patient conditions and preferences (Klaus, 2018).

2.6.1.3.3. Processes

HCOs are tasked with developing patient-centered processes that are both effective and efficient. Strategies aimed at continuous process improvement must actively involve the patient as a crucial participant and contributor to the individualized care process. By incorporating patients into these efforts, HCOs can enhance clinical outcomes and PX. Standardized processes need also to provide adequate flexibility to allow for physician autonomy, and patient-centred care focused on both clinical outcomes and quality of life (Klaus, 2018). To help managers realign the organisation's strategies, redesign processes and restructure the organisation, scholars highlight the need to establish standards and improve the quality and consistency of touchpoints (Purcărea et al. (2008) . Employees need to understand the standards to perform consistently. In the absence of standards, the quality of touchpoints is reliant solely on the discretion of individual employees. Put differently, without established standards, the customer experience quality may be influenced by the performance of the least proficient employees within the organisation Purcărea et al. (2008). Another critical aspect is to manage the role of time and temporal conditions (Vogus & Mcclelland, 2016). HCOs have implemented various innovative practices to address patient expectations regarding timing and to proactively intervene to meet patients' needs. There's a growing trend among HCOs to manage patients' expectations regarding anticipated wait times, aiming to align these expectations more closely with the actual wait times. For example, Emergency Departments (EDs) that discuss and update patients regarding expected waits have fewer dissatisfied patients than those who do not (Sun et al., 2000). EDs have also recently started displaying current wait times on their websites and billboards to attract patients (Xie & Youash, 2011). HCOs have implemented hourly rounding – intentionally and proactively checking on patients regularly to address basic needs such as bathroom, positioning, pain control, and proximity of personal items (Mitchell et al., 2014) – to meet expectations for high-quality and timely care. Specifically, hourly rounding is intended to address what is known as help uncertainty. Researchers also highlight the recurring need for cross-boundary coordination during a care episode. Then, HCOs require practices to manage smooth coordination across subunit and professional divides (e.g., among doctors, nurses, physical therapists, and social workers) because patients experience a system of care, not just a specific caregiver or even a caregiving unit (Nembhard et al., 2009). The nature of

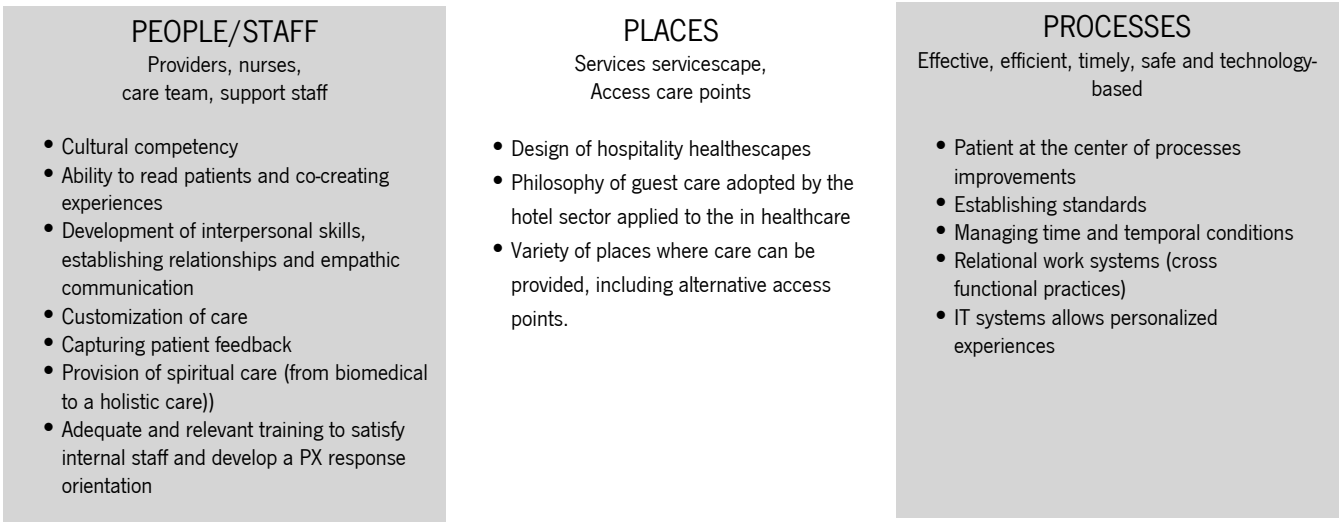
care delivery has given rise to a novel form of a high-performance work system — the relational work system ((J. Gittell et al., 2010). Relational work systems comprise an integrated bundle of cross-functional practices related to conflict resolution, performance measurement, boundary spanner roles, selection, and flexible job design (Gittell et al., 2010).

These practices prioritize care and interprofessional coordination, aiming to make the care delivery system more responsive to the individualized needs of patients and their families. The relational work system yields higher levels of patient satisfaction through relational coordination. Relational coordination combines frequent, timely, accurate, and problem-solving communication between healthcare professionals (and across professions) with relationships characterized by shared knowledge, goals, and mutual respect (Gittell, 2002). In a study of hip and knee arthroplasty, patients' higher levels of relational coordination were not only associated with significant patient outcomes such as lower post-operative pain, improved functioning, and shortened hospital stays but also higher levels of overall satisfaction with care (Gittell et al., 2000).

Lastly, specific systems, such as IT, can enhance the PX's emotional components (Ojiako et al., 2010; Trenchard et al., 2019; Wolf, 2019). For example, there are various places where care can be provided, including alternative access points available with telemedicine capabilities. The virtual environment, where patients can have fun and feel empowered, provides participants with a lived experience and generates engagement (Robson et al., 2014).

HCOs also adopt technologies and approaches that provide personalized consumer experiences across the patient journey. For example, from creating apps designed to make it easier to schedule appointments and view health information to deploying valuable and personalized marketing campaigns— providers are looking beyond simply treating health issues to differentiate from the competition and provide consumers with additional value (Friedman & Kovner, 2018). Overall, one could argue that extensive data analytics capabilities facilitate IT-enabled transformation practices and thus contribute to business value for HCOs and PX improvements. In Figure 2.2, we illustrate the discussed service delivery dimensions and in Table 2.8 we provide a summary of the main ideas related to PXM domains.

Figure 2. 4 – Internal organisation challenges - service delivery improvements to enhance PX



Source: Author's elaboration

Table 2. 8. Summary of the key PXM domains

Key patient experience management – PXM - domains
Patient Journey and Touchpoint design
— A seamless experience across touchpoints through the patient journey creates a stronger PX. — E-health tools such as apps, mobile platforms, and telehealth services are poised to play a pivotal role in facilitating smoother transitions of care and improving service coordination among HCPs and specialists. — The focus of patient engagement in interactional touchpoints aims to create memorable experiences — Managers must be concerned with the long-term evolution of PX journeys across multiple service cycles: initial, subsequent, and terminating service cycles. In the smooth journey model, a special attention must be devoted to the loyalty-weakening incidents of the terminating service cycles to enhance convenience and ultimately foster customer loyalty over time (loyalty loop).
Partner and Network Management
— When mapping and analyzing the patient journey, it is critical to consider the broader service delivery system (e.g., online communities, experience networks, service delivery networks, and collaborators) to reduce uncertainty in PX delivery. — Extended service delivery networks might take specific formats. Selecting governance models wherein the HCO assumes the lead role in connecting and coordinating all facets of the PX is crucial. The organisation obtains greater control, lower uncertainty, and additional insights into the entire PX in this network. An example could be the development of an OHC in which the HCO and its partners take the lead and manage the community. — Partnerships generate value outside the clinical boundaries. New tools and healthcare alternatives, such as telemedicine and technologies like CRM platforms, are being embraced.
Internal organisation challenges
— A patient-centric focus, in which the patient is the heart of all operations, is an essential facilitator within — HCO to create stronger PXs. HCOs require specific capabilities and an intentional configuration of physical and non-physical elements in a service system (including people/staff, environment/places, processes, and technology) to develop successful PX strategies. — Managing PX necessitates a multidisciplinary approach, involving collaboration among various functions such as IT, marketing, operations, customer service, and human resources to deliver an optimal PX.

Source: Author's elaboration

2.6.2. Driving outcomes with patient experience management

Overall, organisations able to skill-fully manage the entire experience generate valuable outcomes (Rawson et al., 2013). In contrast, unplanned and unmanaged experiences may result in a very low satisfaction and undesired outcomes (Luxford & Sutton, 2014). So, what outcomes can be driven with this expanding focus on PX management and improvement? We identify 10 central outcomes, falling under two major themes: (1) healthcare service-related outcomes and (2) Patient-related outcomes (see table XI).

2.6.2.1. Healthcare service-related outcomes

2.6.2.1.1. Generating new models of care

Porter & Teisberg (2006) argue that a focus on PX drives a move to a Value-Based healthcare (VBC) model, which is particularly emphasized in literature (Agwunobi & Osborne, 2016; Hillary et al., 2016; Porter, 2014; Porter & Lee, 2013). It means that delivering and improving value may be healthcare's fundamental purpose and the only solution for reforming healthcare versus cost shifting to patients, restricting services, or reducing provider compensation (Porter, 2014). Indeed, VBC is the best and only viable way to create better outcomes for the overall healthcare system. As the healthcare system improves, it will also draw more patients and increase the ability to help more people (Hillary et al., 2016).

2.6.2.1.2. Effectiveness of service delivery

A large body of literature has been devoted to establishing an association between PX and health-related outcomes, such as clinical effectiveness, in various disease areas, settings, and study designs. Overall, the evidence clearly shows that hospitals that perform well in patient care experience also have better service metrics (Luxford & Sutton, 2014). It is well established that higher levels of PX are associated not only with less healthcare utilization, such as hospitalization, length of stay and primary-care visits (Anhang Price et al., 2014; Black & Jenkinson, 2009) but also with technical quality-of-care delivery (Doyle et al., 2013).

2.6.2.1.3. Strong services brand differentiation

As healthcare consumers' expectations rise, PX is the central core differentiator for healthcare now and in the future (Wolf, 2018b). Moreover, consumers will share bad or good experiences with

others (Wilde-Larsson & Larsson, 2009a). Patients' decision-making is most significantly driven by the stories they are told and the recommendations they receive (Wolf, 2018b). Kennedy (2018) advances that a strong healthcare brand and a superior PX provided by skilled frontline service performers can influence consumers' healthcare choices in this highly competitive market. An illustrative case is the Mayo Clinic, which has cultivated one of the most influential service brands globally and is arguably recognized as the premier healthcare brand in the United States. The interplay between the established brand, external communications, and patients' experiences fosters brand awareness, imbuing it with significance and, ultimately, building brand equity (Berry & Seltman, 2007). Brand awareness is a customer's ability to recognize and recall a brand. It also impacts brand meaning. Brand meaning is the concept or impression immediately coming to the customer's mind about the brand. It is the organisation's reputation or image with that customer Kennedy (2018) .Brand equity, in turn, represents the degree of marketing advantage (positive equity) or disadvantage (negative equity) a given brand has compared to an unnamed or fictitiously named competitor (Keller, 1993). Kumar et al. (2018) also advocate that marketing activities create hospital brand equity (BE) through PX. The findings of their study suggest that PX is the focal mediating variable for the relationship between marketing activities and BE.

2.6.2.1.4. Patient loyalty

Substantial evidence has been found for the effect of PX on building patient loyalty (Raharjo et al., 2016; Worlu et al., 2016). Patients' loyalty in the context of healthcare is referred to as a patient's trust in and patronage of a medical organisation and a psychological tendency to purchase medical services from it repeatedly (Platonova et al., 2008). With rapid economic development and improvements in living standards, people's expectations of medical services are increasing, and patient loyalty has become increasingly important to hospitals' competitive advantage (Zhang et al., 2018). Hence, the service provided by healthcare workers is critical in determining whether patients feel that they are respected in the service delivery process (Wu & Tsai, 2007). Zhang et al. (2018) suggest that in healthcare service, the service offered by hospital staff enhances patients' perceived respect for, trust in and empathy for the hospital, eventually improving their loyalty to the hospital. First, by nature, the healthcare industry provides medical treatment and a healthcare service experience (Mandal, 2017). In addition, hospitals today must care for patients' unique needs and provide a comfortable service experience. Second, patients usually cannot accurately judge the quality or equipment of a hospital because of a lack of professional knowledge (Pusic et

al., 2012). Therefore, a hospital's service quality, especially the "soft" aspects, such as the quality of the interpersonal service provided by staff (Hutchins & Rodriguez, 2017; Ward et al., 2005), and a patient's psychological feelings, such as loyalty, become important in selecting a hospital when a patient needs hospitalization. Third, competition between hospitals has become increasingly fierce (Kooli et al., 2016). Providing good service quality and obtaining patients' loyalty has become critical to hospitals' survival. When patients need hospitalization, they will choose a hospital that they trust, and this trust comes from their loyalty to the hospital. Therefore, investigating healthcare services from the perspective of patient loyalty offers a fresh approach to explaining the nature of the service of the healthcare industry (Zhang et al., 2018).

2.6.2.1.5. Word-of-mouth (WOM)

Research indicates that better patient PXs are associated with the willingness of patients to recommend HCPs to others (Anhang Price et al., 2014). In an increasingly competitive market, HCPs continually seek new ways to achieve a competitive advantage, and WOM represents such an "opportunity because it has a powerful influence on consumers' attitudes and behaviours" (Mazzarol et al., 2007, p. 1475). Word-of-mouth (WOM) directly influences the choice of healthcare provider and treatment options and is regarded as a substantial indicator of patient satisfaction (Haase et al., 2006; Otani et al., 2009). Concerning hospitals, there are two different categories of factors influencing the WOM behaviour of patients. The first category encompasses factors that the hospital can directly influence, while the second category comprises factors that may not or are only partially influenced by the hospital (e.g., Jha et al., 2008). Factors within the hospital's sphere of influence can be divided into medical and atmospheric factors. Essential components of medical factors are interpersonal ones. Patients' word-of-mouth (WOM) is significantly influenced by various medical factors that the hospital can directly impact, such as clinical competence, hospital equipment (Cheng et al., 2003), process quality, information provision, perceived pain and discomfort (Ferguson et al., 2010), and recovery outcomes (Cheng et al., 2003; Ferguson et al., 2010).

Moreover, atmospheric factors within the hospital environment significantly shape patients' word-of-mouth (WOM). These factors encompass ambience, cleanliness, meal quality, cafeteria services, accommodation, and the availability of recreational activities (Haase et al., 2006; Klinkenberg et al., 2011). Additionally, the hospital's profit status impacts the likelihood of patients strongly

recommending it. According to Klinkenberg et al. (2011) patients' word-of-mouth (WOM) behaviour is also influenced by factors such as the academic status and size of the hospital.

2.6.2.1.6. Profitability, reimbursement and regulation of hospital services

Studies have also explored links between PX and other outcomes related to hospital performance. In this respect, the study of Richter & Muhlestein (2017) highlights that PX has had a direct financial repercussion on hospitals following the implementation of value-based purchasing by the Centers for Medicare & Medicaid Services in 2013. This initiative serves as a mechanism to incentivize or penalize hospitals based on their performance across various measures, including PX. A positive PX is associated with increased profitability, and a negative PX is even more strongly associated with decreased profitability. Management should consider improvements in training, technology, and staffing, which can be justified as a way to improve quality and Profitability. Groene et al., (2015) also report that achieving high levels of PX has become a cornerstone of hospital performance and has implications for the reimbursement and regulation of hospital services. Indeed, hospital managers seek ways to systematically improve PX across hospital departments, mainly where outcomes are used for public reporting or reimbursement.

2.6.2.2. Patient-related outcomes

2.6.2.2.1. Adherence, prevention and treatment

It is well established that higher levels of PX is positively associated with self-rated and objectively measured health outcomes: higher levels of treatment and medication adherence, as well as better utilization of preventative care services such as screenings and immunizations, can be observed as outcomes resulting from improved PXs and satisfaction with healthcare services (Black & Jenkinson, 2009; Doyle et al., 2013). For example, the study of Osei-Frimpong & Owusu-Frimpong (2017) report that consumption experiences resulted from service encounter process generated value outcomes that include receiving treatment, improved compliance, reduced visits to health facilities, and enhanced service engagement between the actors.

2.6.2.2.2. Patient satisfaction and safety (perception of quality domains)

Research indicates that better PXs are associated with quality domains and perceptions of patients regarding the elements of care. Patient-reported experience measures (PREMs) are commonly

utilized generic tools designed to assess the overall PX within healthcare settings. They are frequently employed across broader populations and in non-specific settings, such as outpatient departments. These instruments or tools have revealed positive associations between PX and patient satisfaction and safety. They are a reliable measure of how well a hospital can provide good quality service from a patient's perspective (Smith & Weldring, 2013). Some authors (e.g., Musella et al.(2017); Anhang Price et al. 2014) highlight the variable 'experience' as the most pertinent internal factor for enhancing overall patient satisfaction. Additionally, Topaloglu & Erkaya (2018) suggest that consumers facing severe medical issues exhibit an escalated requirement for empathy and enhanced experiences during interactions with healthcare services. Therefore, understanding the affective states that consumers experience and the stimuli evoking these feeling states is crucial to improving overall perceptions of service. Thus, satisfied employees create better experiences for patients, which, in turn, leads to satisfied patients (Raharjo et al., 2016).

2.6.2.2.3. Quality of life (QoL)

Research centred on consumers' experiences of health services offers valuable insights into healthcare practices. Implementation of these insights could ultimately lead to improvements in health outcomes and overall quality of life (Ponsignon et al., 2015; Sweeney et al., 2015). Researchers have examined the impact of PX improvements on health-related quality of life. For instance, Knibb et al. (2019) conducted a study investigating the experience of anaphylaxis in adult patients and its effects on health-related quality of life (HRQoL). In their study, HRQoL is described as individuals' perception of their position in life in the context of their culture and values concerning their goals, expectations, standards and concerns. HRQoL is seen as a subset of QoL, referring to an individual's perception of their health and is focused on physical, mental and social well-being Knibb et al. (2019). However, studies addressing how PX improvements lead to HRQoL still need to be made available and further examined Knibb et al. (2019).

2.6.2.2.4. Well-being

A recent literature stream suggests that focusing on PX will be essential to impacting patients' lives and promoting well-being. The previously accepted definition of well-being as a condition characterized by happiness, health, or prosperity (Gove, 2002) has been criticized for focusing on descriptions or dimensions of well-being instead of its definition. In this regard, feelings of happiness, life satisfaction, the ability to fulfill goals, and experiencing positive emotions are among

the most commonly cited aspects of well-being in the context of health (Diener et al., 1998; Pollard & Lee, 2003). Other authors have conceptualized well-being as the “people's cognitive and affective evaluations of their lives” (Diener, 2000, p.34), which “includes positive elements that transcend economic prosperity” (Diener et al., 1999, p.276). A newer approach defines well-being as a quality beyond physical and physiologic integrity that reflects the degree to which one is and becomes oneself fully and authentically, experiences connection with others and the world, and finds meaning in one's life and work. Lee et al. (2013) add that well-being reflects an individual's quality, thus encompassing what it means to be functioning as a healthy person across physical, social, psychological, and emotional domains (Pressman et al., 2013). More holistically, well-being seems to include emotional, physical, social and psychological health (Anderson et al., 2018; Ballantyne & Varey, 2006). There has been an increasing call for an increased focus on well-being, measured at many levels and in various ways (Anderson et al., 2013), providing information about how a patient or person feels (Patrick et al. 2011).

Exploring the intersection between PX management and well-being can present research opportunities to adopt the transformative potential of healthcare (Anderson et al., 2013; Berry & Bendapudi, 2007; Danaher & Gallan, 2016). This emerging area (Blocker & Barrios, 2015), referred to as transformative service research (TSR), is defined by Anderson et al. (2011, p.3) as "the integration of consumer and service research that centres on creating uplifting changes and improvements in the well-being of consumer entities: individuals' communities and the ecosystem". As positive service experiences can transform lives through service provision that enhances the well-being of individuals (Anderson et al., 2013; Anderson & Ostrom, 2015), understanding the transformational nature of experiences has important implications for service academics and providers in terms of service delivery, service interactions and service practice and policy (Dodds et al., 2018).

Studies have reported how experiences within healthcare service delivery affect patients' perceptions of well-being. In particuçar, when consumers share control of their healthcare service experiences with caregivers, this can enhance well-being outcomes for all participants in the service system Anderson et al. (2018). Other authors have investigated the potential impact of patient participation through physicians' resource offering on patient experiential value and well-being. The results indicate that physicians provide significant affective and cognitive resources to patients involved in the medical encounter process. These co-creation activities increase patients' experiential value and perceived well-being Kim (2018). Lastly, other studies also report a positive

effect of patients' experiences with peer support networks in cancer care on more positive beliefs around illness and improved psychological well-being. Such networks allow sharing of information and experience, supporting adjustment by providing an illness trajectory that cancer patients can use to prepare for their cancer journey. Graham-Wisener & Dempster., 2017). Nevertheless, studies investigating PX in the broadest sense, which means truly understanding PX all along the patient journey to improve services and impact patient's well-being, are still needed (Anderson et al., 2013; McColl-Kennedy et al., 2017b; Ryan et al., 2014).

Table 2.9 presents a summary of the discussed ideas.

Table 2. 9. Main outcomes derived by PX improvements

Healthcare service related outcomes	Relevant sources
New model of care	(Agwunobi & Osborne, 2016; Hillary et al., 2016; Porter, 2014; Porter & Lee, 2013; Porter & Teisberg, 2006)
Effectiveness of service delivery	(Black & Jenkinson, 2009; Doyle et al., 2013; Anhang Price et al., 2014)
Strong services brand differentiation	(Berry & Seltman, 2007; Kennedy, 2017; Kumar et al., 2018; Wilde-Larsson & Larsson, 2009; Wolf, 2018b)
Patient loyalty	(Worlu et al., 2016a; H. Zhang et al., 2018)
Word-of-mouth (WOM)	(Cheng et al., 2013; Jha et al., 2008; Klinkenberg et al., 2011; Anhang Price et al., 2014)
Profitability, reimbursement and regulation of hospital services	(Groene et al., 2015b; Richter & Muhlestein, 2017)
Patient-related outcomes	Main sources
Adherence, prevention and treatment	(Black & Jenkinson, 2009; Doyle et al., 2013b; Luxford & Sutton, 2014a; Osei-Frimpong & Owusu-Frimpong, 2017)

Patient satisfaction and safety	(Lee, 2011; Musella et al., 2017; Anhang Price et al., 2014; Smith & Weldring, 2013; Topaloglu & Erkaya, 2018)
Quality of life (QoL)	(Brincat et al., 2020; Knibb et al., 2019; Ponsignon et al., 2015; Sweeney et al., 2015)
Well-being	(Anderson et al., 2013; Anderson et al., 2018; Danaher & Gallan, 2016; Graham-Wisener & Dempster, 2017; Kim, 2018; Lee et al., 2013; McColl-Kennedy et al., 2017b)

Source: Author's elaboration

2.7. RESEARCH AGENDA FOR PATIENT EXPERIENCE

The first goal of this study was to provide an overview of current knowledge on PX while adopting a fresh perspective of the patient journey. Here, we provide a research agenda for PX, which will stimulate research and knowledge development in this area.

2.7.1. Understanding patient experience (PX)

2.7.1.1. PX throughout the journey: deepening stages and touchpoint understanding

There is much room for additional research to strengthen the overall understanding of PX and, significantly, the patient journey (Luxford & Sutton, 2014; Ponsignon et al., 2018). Few studies have considered the PX as a broad and holistic construct; so far, most of the research is focused on a single phase of the journey (e.g., during the consumption of care) (Franck et al., 2017), neglecting the totality of the PX. Studies neglect multiple touchpoints' contributions (and interactions) to the overall and seamless PX. Therefore, attention should be continuously devoted to the analysis of lived experiences and perspectives of patient's multidimensional needs over all the stages of their journey (Shale, 2013), such as the pre-and post-care/long-term post-consumption of care, which are the stages least understood.

A potential avenue for future research is to investigate how patients experience sequences of touchpoints throughout their journey. In this study, we have identified four types of touchpoints that influence each stage of the patient journey: brand-owned, partner-owned, customer-owned, and social/external. However, there is a substantial need for further research to comprehend the relationships among these touchpoints and their impact on each stage of the patient journey. As such, we strongly recommend that researchers investigate the contributions of multiple and different types of touchpoints to PXs in different phases of the journey (Ponsignon et al., 2018; Silvera et al., 2017). Thus, it is particularly relevant to capture the emotions and mindset of patients in which the contacts are taking place (Lotz et al., 2020). Due to the external dynamic environment, more effort is required to determine how macro developments (e.g., global health crises) affect PXs (Gijsenberg et al., 2015; Hunneman et al., 2015).

It would be particularly relevant to adopt the patient journey perspective to investigate how patients under long-term conditions (LTCs) (Gibbons et al., 2016) experience interactions with different touchpoints over time. Chronic diseases have rapidly become a significant public health and medical challenge (Schneider et al., 2009); Moreover, the study of the experiences of LTC patients

is still an overlooked research domain (Brand & Pollock, 2018; Dalsted et al., 2012; Hewitson et al., 2014).

2.7.1.2. Establishing the relationship between PX and other constructs

The emergent literature adopting the patient's perspective states that PX is a multidimensional, holistic construct focusing on a patient's cognitive, emotional, behavioural, sensorial, and social responses to a healthcare organisation's offerings during the patient's entire journey. To further understand the holistic PX construct, which is relatively broad, it is helpful to understand how PX is related to other constructs, such as the healthcare consumer decision-making process, service quality, patient expectations and satisfaction, and patient engagement. In other words, to truly understand and appreciate the renewed holistic focus on PX, we need to understand its roots—and identify and recognize the contributions of these established research areas to PX (see Appendix III). However, there is still a strong need to examine how existing constructs (e.g. service quality, patient expectations and satisfaction, patient engagement) relate to PX and interact with one another, resulting in the overall PX. In particular, identifying the critical linkages and moderators is a critical task for future research.

2.7.2. Managing patient experience (PX)

2.7.2.1. Advances in patient journey mapping – gaining PX insights that matter

Even though several approaches can be used to improve PXs and services within HCOs (e.g., service blueprinting, care pathways), the patient journey mapping—a summary of the service experiences that patients have over time – should be further considered (Boyd et al., 2012). Transposing insights from CX literature, we recommend more data-based patient journey mapping. What data do practitioners need to collect in order to manage PX? How do practitioners capture relevant details? To achieve such goals, we recommend that practitioners take advantage of multiple sources, such as qualitative visual methods, technologies, and comprehensive scales, to acquire a holistic view of PX (McColl-Kennedy et al., 2018).

Regarding the use of qualitative approaches, researchers can benefit from the power of visual methodologies to add richness and gain a deeper understanding of the experiences of clients and health practitioners (Sheridan & Chamberlain, 2011). However, potentially, visual methods, including the auto-driving photo-elicitation technique (Rose, 2016) or Zaltman Metaphor Elicitation

Technique (Zaltman & Coulter, 1995) could be worthwhile for gaining insight into PXs by uncovering unconscious thoughts and feelings about the transformational nature of services that are often difficult to obtain through standard interview and survey techniques (Rose, 2016) Although there is support for using visual methods to enhance qualitative methods and data in the social sciences, more research is required to evaluate the use of visual methods in the service research domain (Dodds et al., 2018). In addition, instead of using the patient's own words to capture discrete cognition and emotions, future research could investigate the use of wearable or mobile technology to capture how customers feel at the various touchpoints in real time (McColl-Kennedy et al., 2018).

PX is a practical and clinically significant concept to measure (LaVela & Gallan, 2014) to drive powerful managerial improvements. As such, there is an urgent need to develop scales to measure PX across the entire patient journey. The current scale scores (HCAHPS) present a limited picture of the journey (Luxford & Sutton, 2014) as they only capture the experiences with elements of care while neglecting the multiple interactions of patients before and after leaving healthcare facilities. The challenge facing researchers is determining how the richness of the PX construct can be measured succinctly and accurately across multiple touchpoints—and in different stages of the journey (Beattie et al., 2015; Salisbury et al., 2010). To foster this scale—or scales—in practice, a comprehensive, short scale should be developed, and simple and quick measures per touch point may be needed (Lemon & Verhoef, 2016).

As PX is dynamic, it would be intriguing to track it longitudinally and across different touchpoints, observing how redesigning touchpoints leads to further enhancements in PX and whether specific redesigns only yield minor improvements in perceptions of the customer experience (CX) (McColl-Kennedy et al., 2018). In this sense, we recommend using longitudinal studies to better understand long-term changes in patients' experiences.

2.7.2.2. Designing patient journey involving multiple perspectives

Overall, there is also an urgent need to promote the patient's involvement by using patient self-journey mapping or asking patients to develop ideal journeys. Touchpoints and journeys can become more adaptive— moving toward personalized journeys and engaging patients in developing their journeys on the road (Folstad et al., 2013; Lemon & Verhoef, 2016). Therefore, patient journeys must involve patients' perspectives and internal resources (Folstad et al., 2013). Only a limited number of studies in the literature focus solely on one of these groups: either internal

resources (e.g., Clatworthy, 2011; Wechsler, 2012) or "customers" (e.g., (Crosier & Handford, 2012). Nonetheless, these two participant groups may offer complementary perspectives. By comparing internal expectations of customer journeys with actual customer experiences, significant gaps in service provision may be identified (Bitner et al., 2008), thus generating suggestions for improving the service delivery process.

2.7.2.3. Managing external factors as internal resources

While most studies have concentrated on factors affecting PX that are within the control of HCOs, there is a need to understand deeper how HCOs can attempt to influence external factors that contribute to PX perceptions. This includes understanding interactions with other patients through online health communities (OHCs). Indeed, managing and thus internalizing external input constitutes a challenge that has received limited academic attention. Furthermore, with the proliferation of Internet and social media usage, traditional offline settings have virtually disappeared, and peer input has quickly become paramount in nearly all consumption decisions.(e.g. Bansal & Voyer, 2000). Consequently, research is needed on how organisations can effectively manage, direct or even incorporate valuations in designing their patient journeys. In particular, we lack an understanding of how HCOs can influence PX by HCO-initiated interaction platforms that enable patients to communicate and help each other in an environment controlled by the organisation. For example, how can healthcare practitioners rely on OHCs as communication tools, co-creation platforms, or extensions to patient management systems?

In summary, PX management should consider touchpoints that cannot be directly managed but still contribute to PX from a patient perspective. Patrício et al. (2011) introduced a network perspective on service delivery that shifts away from a solely dyadic organisation-customer perspective. Consequently, scholars have ample research opportunities to explore this concept further and empirically examine the influence of additional healthcare services and partnerships on the primary PX.

2.7.2.4. Long-term management of smooth journeys across multiple service cycles

As discussed previously, recent management research is increasingly concerned with the long-term evolution of smooth journeys across multiple service cycles, namely initial, subsequent, and terminating service cycles (Siebert et al., 2020). Therefore, this article also opens up several new avenues for future research. For example, how can HCOs accelerate the initial service cycle of the

smooth journey model in today's hypercompetitive context? How should sequences of triggers, activities, and rewards be arranged across multiple service cycles to facilitate smooth patient journeys best? Moreover, ultimately, how do we avoid loyalty-weakening incidents in termination trajectories? We also recommend that healthcare practitioners apply recent developments in CXM literature to expand on an existing loyalty loop using journey expansion pathways (Siebert et al., 2020).

2.7.2.5. Internal organisation – structure and organisational models

The complexity of journeys and the speed with which technology and consumer behaviour change may require new, flexible organisation models and cross-functional collaboration to manage PX. HCOs are adopting new ways of organizing functions to remove existing silos. For example, Cleveland Clinic restructured care around patients. Instead of the traditional hospital structure, in which a department of medicine supervises specialties (e.g. cardiology, pulmonology, gastroenterology), Cleveland Clinic created integrated practice units (IPUs) in which multidisciplinary teams treat a specific patient segment or medical condition, which is an interrelated set of patient medical circumstances addressed in an integrated way (e.g. diabetes, breast cancer, knee osteoarthritis). The Heart and Vascular Institute, a pioneering IPU, includes everything concerning the heart and circulatory systems (cardiac surgery, cardiology, vascular surgery, and vascular medicine), and cardiologists and surgeons see patients together. The perspective of this care model is to improve collaboration among care providers by making them work seamlessly together in the entire cycle of care (Porter, 2014). This transformation also indicates that HCOs are willing to make radical movements toward more flexible, patient-centric models that enable them to manage the PX effectively. In summary, researchers and practitioners should devote more attention to this domain since HCOs breaking out of the "siloed mentality" can potentially gain an unprecedented view of the patient (Lotz et al., 2018, p.2). Considering the journey, more significant efforts should be dedicated to consolidating the collective knowledge from various functions to construct a comprehensive and precise depiction of each patient's journey.

2.7.2.6. Better linkages to outcomes and focus on well-being

Our understanding of the effects of different touchpoints (e.g., brand-related and external touchpoints) on patients' health outcomes seems limited (Ugalde et al., 2019). As such, it would be helpful to investigate how patient-related outcomes are generated throughout the journey and

what touchpoints can significantly influence patient outcomes. A key research area is to explore the potential of HCOs to implement practices of PX management that could ultimately contribute to enhanced health outcomes such as well-being (Anderson et al., 2012; Osei-Frimpong & Owusu-Frimpong, 2017; Sweeney et al., 2015). For example, what strategies do HCOs employ to craft patient journeys that enhance the overall well-being of all stakeholders within the healthcare ecosystem, including patients, families, and caregivers? In doing so, we hope to contribute to the emerging fields of service design and Transformative Service Research (TSR) (Anderson et al., 2018). Table 2.10 presents a summary of the discussed ideas.

Table 2. 10 - Research agenda for patient experience (PX)

Area/domain	Topic	Research questions
Understanding PX and the journey	PX across the journey: deepening stages and touchpoint understanding	— How do patients experience sequences of touchpoints throughout their journey? And how do chronic patients experience different touchpoints across the journey and over time??
		— How does each type of touchpoint relate to the others? How do different types of touchpoints contribute to the PXs in different phases of the journey?
		— What touchpoints matter to the overall PX? Moreover, at which stage(s) might this be most effective?
		— What are the main emotions and mindsets that patients experience as contact takes place throughout the journey?
		— How do external touchpoints/dynamics (e.g. health crisis) impact the overall PX?
	Establishing the relationship between PX and other constructs	— How does an expanded conceptualization of PX relate to other vital constructs, such as patient satisfaction, service quality, and engagement?
		— What are the critical linkages among such constructs?
Managing PX and improving outcomes	Advances in patient journey mapping –	— How can we integrate new data sources and analytical techniques, such as social listening, text, photo, and video analytics, as well as location-based data, into PX analysis to gain deeper insights into PX and the patient journey?

	gaining insights that matter	— How can wearable or mobile technology capture patients' feelings at the various touchpoints in real time?
		— How can HCOs measure the holistic PX across the touchpoints throughout their journey?
		— What are the critical measures of PX at different stages of the patient journey? Is it necessary to employ distinct measures for various stages of the patient journey? Are there specific moments within the journey that are optimal for measurement? Additionally, what rapid and straightforward metrics could offer valuable insights into PX?
		— What are the main long-term changes in patient's experiences? How can longitudinal studies be used to capture such changes?
	Designing patient journey involving multiple perspectives	— How can patient journeys be designed involving both the perspective of patients and internal resources?
		— What are the enhancements observed in the service delivery process when comparing the anticipated patient journey mappings formulated by internal resources with the actual journey mappings as experienced by patients?
	Managing external factors as internal resources	— How can HCOs exert more control over non-brand-owned touchpoints (customer-, partner-, and social-owned touchpoints)?
		— How can HCOs influence PX by HCO-initiated interaction platforms that enable patients to communicate and help each other in an environment controlled by the organisation?
		— How can healthcare practitioners rely on OHCs as communication tools, co-creation platforms, or extensions to patient management systems to improve PX?
		— How do other healthcare services and partnerships impact the focal PX?
	Long-term management of smooth journeys across	— How can HCOs accelerate the initial service cycle of the smooth journey model in today's hypercompetitive context?
		— How should sequences of triggers, activities, and rewards be arranged across multiple service cycles to facilitate smooth patient journeys best?

	multiple service cycles	— How can HCOs avoid loyalty-weakening incidents in termination trajectories?
		— How can the patient journey be sustained beyond an existing loyalty loop? What journey expansion pathways should HCOs use?
	Internal organisation – structure and organisational models	— How should HCOs be structured and organized to manage PX successfully?
		— What are the key capabilities and mindsets that HCOs need to create a strong PX response orientation?
	Better linkages to outcomes and focus on well-being	— How can the collective knowledge from different functions be aggregated to assemble a detailed and accurate picture of each patient journey?
		— What is the effect of PX management on service improvements and outcomes?
		— How critical health-related outcomes are generated throughout the journey?
		— What key touchpoints have significant downstream influences on patient outcomes?
		— How can HCOs design patient journeys to increase the well-being of all participants in the healthcare system—patients, families, and caregivers?

Source: Author's elaboration

2.8. IMPLICATIONS

This work contributes to understanding and managing PX in several essential ways. We provide an extensive review of current PX opposite perspectives. Building on foundational research CX by (Lemon & Verhoef, 2016), we propose conceptualising PX as holistic, multidimensional, and dynamic. PX encompasses patients' cognitive, affective, emotional, social, and physical responses to direct or indirect interactions with the service provider across several touchpoints throughout the patient journey. In particular, we underscore the importance of viewing the PX as a compilation of multiple and often complex interactions with touchpoints over time.

Adopting a patient journey perspective represents a useful theoretical lens used to facilitate the development of a general definition of PX and delineate PX from other relational concepts.

We propose and illustrate a typical experience journey of patients suffering from chronic conditions. This is particularly valuable as chronic conditions are escalating, and the journeys of chronic patients are becoming increasingly complex, encompassing multiple interactions and touchpoints (Brand & Pollock, 2018). In particular, our proposed journey process model brings the necessary clarity to the PX domain by defining and describing the different touchpoint types chronic patients encounter throughout their journeys.

This research explores the holistic PX throughout the patient journey and investigates its outcomes. By linking PX improvements with well-being outcomes, it also contributes to transformative service research (TSR), which focuses on integrating consumer and service research to drive changes and improvements in the well-being of individuals, communities, and the ecosystem (Black & Gallan, 2015).

In summary, this essay also opens up several new avenues for future research on PX. We outline a research agenda on PX that will help stimulate further PX thought, more specifically, a better understanding of the PX occurring throughout the patient journey.

3. CHAPTER III (ESSAY II)

Online Health Communities and Chronic Illnesses: Capturing Perspectives on Experiences and Well-being

CHAPTER 3. ONLINE HEALTH COMMUNITIES AND CHRONIC ILLNESSES: CAPTURING PERSPECTIVES ON EXPERIENCES AND WELL-BEING (ESSAY II)

3.1. ABSTRACT

This study explores the expressed dimensions of the experience and well-being of chronically ill patients with type 1 diabetes (T1D) and End-Stage Renal Failure (ESRF) throughout their journey.
Data were collected using a netnographic study, particularly a qualitative approach of textual analysis of OHC threads from chronic patients with DT1 and ESRF who use such platforms to narrate and manifest their experiences and well-being across the Journey. A total of 186 discussion threads were analysed from two international OHCs. Two main themes emerged: i) expressed PX dimensions from chronically ill patients in OHCs and ii) expressed well-being dimensions from chronically ill patients in OHCs. The thematic analysis also shows that such experience and well-being dimensions emerge throughout three main stages of the patient journey: pre-service encounter stage ("What is happening to me?"), service encounter stage ("What is this disease?; What treatments do I need to do?"), and post-service encounter stage ("How do I live with this condition?").
In the initial pre-service encounter phase, individuals exhibit an awareness of symptoms (patient-owned touchpoints). Patients commonly turn to online health communities (OHCs) to gather information about and discuss their symptoms with peers, as well as to comprehend and effectively manage their symptoms. The service encounter involves the processes of diagnosis and treatment, entailing interactions with healthcare processes and professionals (brand-owned touchpoints). Patients predominantly utilize OHCs to articulate their needs and negative experiences during these encounters, such as seeking increased support from healthcare professionals at various levels (including technical, emotional, and instrumental support) and expressing the necessity for enhanced care effectiveness through multidisciplinary team collaboration. This phase underscores the significance of the patient-practitioner relationship, information exchange, and communication in shaping the PX, highlighting the importance of support delivery and multidisciplinary approaches. Finally, the post-service encounter phase involves patients engaging in self-management activities over time while seeking social support from peers, family, and ICs. Patients often express dissatisfaction with the level of social understanding and support, emphasizing the necessity for increased awareness and support from others in managing their condition.

From a theoretical perspective, this research contributes to the transformative service research (TSR) at the intersection of vulnerable healthcare service users (chronically ill patients) and OHCs, which are assumed to be online third places. From a methodological point of view, the netnographic approach improves the understanding of chronically ill patients by examining their expressions within a naturalistic setting. From the practice perspective, the study provides a basis for healthcare organisations (HCOs) dealing with people with chronic conditions, enabling them to channel their voices and improve their experiences and well-being. HCOs can utilize the results of this study to identify relevant OHCs and engage in information sharing to ensure relevant and accurate information is disseminated to patients as they seek out information concerning their health conditions. Also, with this knowledge, medical professionals can design more effective treatment modalities, improve services, and interact more meaningfully with their patients.

Keywords: online health communities, patient experience, well-being, patient journey

3.2. INTRODUCTION

Online health communities (OHCs) serve as platforms offering tailored health information on (Gallant & Coutts, 2003) and a supportive network of individuals sharing similar health conditions (Frost & Massagli, 2009). These platforms connect individuals with similar chronic conditions, sharing information and experiences, and linking patients with healthcare providers (HCPs) (Johnston et al., 2013). Virtual communities are social spaces where members gather to talk, exchange ideas, learn to form a shared vision identity, and maintain relationships, which involve trust, responsibility, commitment, and social support (Misra et al., 2008; Stellefson et al., 2013; Zhao et al., 2015).

Studies investigating patient behaviour in OHCs found that their members mainly exchange health-related information and experiences (Willis et al., 2014) while providing and receiving support (Welbourne et al., 2013). OHCs represent contexts in which members often participate in discussions whose goals include information exchange and influencing fellow members about products and brands (Muniz Jr. & O'Guinn, 2001)

From an organisational perspective, OHCs are a rich data source (Eysenbach et al., 2004) and offer excellent opportunities for exploring real-time consumer interactions about issues of importance to them. The Internet represents an appropriate alternative and valuable channel for identifying and describing patients' dis/satisfactory experiences and additional insights into patients' concerns, expectations, and needs regarding healthcare services (Keeling et al., 2013).

Literature calls for investigating the PX through the analysis of patient's participation in OHCs to identify the achievements and troubles experienced by patients (Baron & Harris, 2010). Such knowledge further constitutes a point of attention for HCPs to improve services and implement better practices. To drive forward service developments, there is a need to focus on the consumer voice and experiences within services (Baron & Harris, 2010; Nemec et al., 2018). However, healthcare professionals use social media primarily for communication with their colleagues and for marketing reasons rather than for listening to patient's voices. In addition, most HCPs reacted negatively when patients shared online health communities' content with them, resulting in feelings of disempowerment of patients (Rupert et al., 2014).

Previous studies tended to investigate the role of OHCs for patients as well as the main drivers and outcomes of participating in OHCs (Nemec et al., 2018). Recently, researchers have recognized the importance of exploring not only experiences but also the psychological states, and different facets of subjective well-being (SWB) reported or expressed by participant's narratives, (e.g.

(Batenburg & Das, 2015; Pöllänen & Weissmann-Hanski, 2020). However, although OHCs exist for chronically ill patients, little is known about the specific experience and well-being dimensions that those patients express and discuss in such environments. To the best of our knowledge, we did not find studies examining the different facets/dimensions of experience and well-being expressed in participants' narratives through OHCs. Therefore, this study aims to explore the content of participants' posts in OHCs through a netnographic approach. The study focuses on the expressed dimensions of the experience and well-being of chronically ill patients with Type-1 Diabetes (T1D) and End-Stage Renal Failure (ESRF) across various touchpoints and stages of the patient journey.

We address three core research questions:

RQ1. How do chronically ill patients express key PX dimensions in OHC?

RQ2. How do chronically ill patients express key well-being dimensions in OHC?

RQ3. How do PX and well-being relate to the journey stages?

Transposing insights from the customer experience (CX) literature, we propose that in the healthcare context, the patient journey comprises the various stages that patients undergo before, during, and after treatment(s). Throughout each stage, patients engage with multiple touchpoints, which can be categorized based on the level of control exerted by the organisation (Lemon & Verhoef, 2016).

The main contribution of this study is threefold: from a theoretical perspective, this research contributes to transformative service research (TSR) (Ostrom et al., 2010) at the intersection of chronically ill patients (vulnerable healthcare service users) and OHCs (Rosenbaum & Smallwood, 2013).

By using a netnographic approach, this study contributes to bringing a novel methodological application to the study of chronically ill patients by examining their PX and well-being expressions within a naturalistic setting (Baker et al., 2005).

From the practice perspective, this study's main contribution is to provide a basis for HCOs to deal with patients with chronic conditions, channel their voices, and improve their experiences and well-being.

3.3. THEORETICAL BACKGROUND

3.3.1. Online health communities (OHCs) and chronically ill patients

For a patient, overcoming a health issue is a challenging and emotional process. These challenges include a lack of knowledge about an illness, a specialist not conveying the seriousness of the illness in a comprehensible format, and feeling emotionally vulnerable due to a lack of control (Nambisan, 2011). The patients may turn to friends or family for information and advice on how to cope with the disease. Alternatively, they may use various Web 2.0 technologies to understand better illnesses, and treatment options, and identify potential HCPs (Chou et al., 2013; Nambisan, 2011).

Researchers have focused on patients using Web 2.0 technologies such as OHCs (Bender et al., 2013), which are a specialized subset of online communities. OHCs serve as virtual gatherings on Internet platforms, bringing together individuals with common interests and goals related to healthcare and education, aiming to engage in collaborative activities (Demiris, 2006).OHCs are usually comprised of patients with similar diagnoses (Frost & Massagli, 2009) and provide an opportunity for interested parties to access information and guidance on conditions, treatment alternatives, insights, and experiences of others suffering from similar conditions (Thackeray et al., 2008). These OHCs encompass expansive groups of individuals spread across various locations and may have varying degrees of familiarity with one another but are united by a mutual interest (Brown & Duguid, 2002; Wasko & Faraj, 2005). OHCs foster connections among their members by providing a shared communication platform, enabling the generation and exchange of knowledge, ideas, and interpretations (Brown & Duguid, 2001; Wasko & Faraj, 2005).

According to the social learning theory, people learn from observing others (Rosenstock et al., 1988) via online interactions, including OHCs. Rather than trying and failing, observing other people's behaviour allows for a more efficient way of learning behaviours (Bandura, 1977). Therefore, OHCs offer an environment for people to assist others in attempting certain behaviours (Willis & Royne, 2017).

An increase in OHC use by chronic patients is observed in numbers that are more significant than other patients concerning searching for information and sharing knowledge (Johnston, 2013). In line with previous research, patients suffering from chronic conditions can be considered vulnerable healthcare service users given their powerlessness in the healthcare service setting and circumstances that may negatively affect their sense of self (Baker et al., 2005; Parkinson et al.,

2017). Defining consumer vulnerability is complex and complicated by the fact vulnerability can be temporary or permanent (Mansfield & Pinto 2008). Vulnerability is accepted as a state of powerlessness that hinders consumption goals and may create circumstances that negatively affect perceptions of self (Baker et al., 2005). People suffering from chronic conditions often have difficulty maintaining offline connections (Yan & Tan, 2014). Even though family and friends provide support structures (Wu & Bernardi, 2021), individuals may still (1) be uncomfortable with sharing personal issues, (2) feel unable to explain their feelings to others who do not have direct experience with an illness, and (3) experience the withdrawal of friends and family as they become exhausted from long-term support (Wright, 2000).

Therefore, OHC can serve as a renewable source of support due to shared affiliation and a sense of belonging or attachment gained from fighting their medical conditions together (Molm et al., 2000; Wasko & Faraj, 2005). In other words, virtual communities and social networks satisfy a wide range of patients' informational and supportive needs (Antheunis et al., 2013; Drentea & Moren-Cross, 2005; Hogg et al., 2004) and allow patients to find the overall support that they cannot obtain in their offline lives (McLaughlin et al., 2012).

In line with this idea, OHCs are called online third places. Online third places are traditionally physical places, such as coffee shops, where consumers can meet. However, they can be non-physical places like online communities (Parkinson et al., 2017). Online third places or spaces, such as OHCs, offer several advantages for vulnerable consumer groups, such as, improving accessibility, especially for "unserved and under-served" consumers (Fisk, 2009, p.135).

An extension of access to OHCs is a crucial objective in transformative service practice (Ostrom et al., 2010) and strategies targeting vulnerable consumers (Kreps, 2008). Further, online environments characterized by two-way communication are proposed to be a pathway to consumer empowerment (Fisk, 2009).

The next subsections describe how chronically ill patients use OHCs to express their experiences and well-being states.

3.3.2. The holistic experiences of chronically ill patients in OHCs

3.3.2.1. The holistic PX across the journey and touchpoints

As previously suggested, by posting and telling their story through OHCs, chronically ill patients can share personal experiences related to the different stages of their journey. In this study, we adopt the notion of holistic PX as it unfolds throughout the patient journey, from initial

considerations about care choices to managing care at home (LaVela & Gallan, 2014). In line with this perspective, the holistic PX is construed as a multidimensional construct encompassing cognitive, emotional, behavioural, sensorial, and social responses to touchpoints encountered across the patient journey, encompassing pre-, during, and post-service encounters (Homburg et al., 2017). Touchpoints, representing interactions within the journey, can be categorized based on the entity managing and controlling them: the organisation/brand itself (in this context, the hospital/clinic), a business partner, the customer (patient), or external factors (e.g., environment). This categorization yields four main touchpoint categories such as (1) brand-owned, (2) partner-owned, (3) customer(patient)-owned, and (4) social/external-owned and also the role of dynamics and external influences (e.g., past experiences of others, the impact of broader externalities) (Lemon & Verhoef, 2016).

(1) Brand (hospital/clinic)-owned touchpoints are interactions the organisation directly controls and manages, encompassing brand-owned media (e.g., advertising, websites) and marketing mix elements (e.g., product attributes) influencing pre-, during- and post-consumption experiences.
(2) Partner-owned touchpoints refer to customer interactions during the experience that are collaboratively designed and managed by the organisation and one or more of its partners.
(3) Patient-owned touchpoints refer to customers actions and activities not controlled by the organisation of its partners.
(4) Social/external touchpoints are external actors by which customers are surrounded and that influence the experience factors (e.g., family, friends, relatives)
(5) Dynamics and external influences include past experiences of others, external environment changes such as externalities which can also impact the overall experience, shaping expectations and evaluations across each journey stage (Lervik-Olsen et al., 2015).

3.3.2.2. Expressions of the holistic PX by chronically ill patients in OHCs

In the pre-service encounters (before diagnosis), patients tend to use OHCs mainly for symptom checking and healthcare provider selection (patient-owned touchpoints). The Internet is an easy source of health information, and many patients have been found to research their discomforts online before seeking professional advice (Fox & Duggan, 2013; Tonsaker, Bartlett, & Trpkov, 2014). Data have shown that almost three-quarters of adults in the United States (US) have searched for health information on the Internet over the past 12 months, while more than one-fifth

of adults in the United Kingdom (UK) have self-diagnosed through the Internet instead of visiting a healthcare professional (Yu et al., 2019). Moreover, at this stage, recognized efforts by the hospital/clinic and its partners (e.g., medical insurance companies) to enhance accessibility and affordability, notably influencing the choice of HCPs (Mosadeghrad, 2014; Vu et al., 2016) (partner-owned touchpoints). Lastly, dynamics and external influences (e.g., past experiences of others, external environment changes) can also impact the overall experience, shaping expectations and evaluations at pre-service encounters (Lemon & Verhoef, 2016b; Lervik-Olsen et al., 2015). For example, prior experiences from peers (other patients) shared in OHCs can influence perceptions and selection of the HCOs, subsequently affecting perceived quality and word-of-mouth recommendations (Kennedy, 2017; Wheelock et al., 2014).

During service encounter stages, patients experience diagnosis and treatments. As such, they typically interact with HCPs, hospital environment and care processes (brand-owned touchpoints). Some patients share on OHCs such experiences during service encounters, in particular, the information they would not be able to obtain from HCPs, who are often perceived as not available (Rupert et al., 2014). Studies analysed what patients report about HCPs by examining popular rating sites (Kadry et al., 2011; Lagu et al., 2010; López et al., 2012). For example, the study of López et al., (2012) covered the complete process (prior contacts, direct interaction with doctor and follow-up encounters) and found specific factors included in three overarching domains: interpersonal manner, technical competence, and system issues. Similar dimensions such as communication skills, access, facilities, and staff were identified by Kadry et al., (2011) and Gheorghe & Liao (2012). Nemec et al., (2018) examined negative electronic word-of-mouth (eNWOM) in Romanian (gynaecological) OHCs and found different emotions embedded in the postings, such as irritability, anger, and rage. The study also points out essential reasons for patient dissatisfaction: malpractice, lack of information, unprofessional training, rudeness, and lack of trust. A study by Li et al (2014) done in patients' online support groups is also informative, as it reveals that the most commonly reported aspects were dissatisfaction with the physician's performance. These findings align with studies that suggest that dissatisfied patients with unmet needs for information and emotional support from HCPs more often seek alternative Internet channels, such as discussion groups and virtual patient communities (Wicks et al., 2010; Yan & Tan, 2014). This is the case when HCOs exhibit low empathy and low-quality of interaction with patients (Tustin, 2010). Lastly, Kim & Yoon (2012) analysed Korean women's online health forums

and found that members seek different types of information (advice, interpretation) concerning diverse topics before and after consulting a doctor.

Regarding the last stage of the journey - post-service encounter - literature highlights that chronically ill patients can reach out not only to their offline network of friends and family but also to their online network of peers (social-owned touchpoints). The aim is to incorporate support from friends, family, and other patients throughout the journey (McColl-Kennedy et al., 2012; Sweeney et al., 2015). These interactions allow them to actively participate in self-management (Gilbert et al, 2012). OHCs act as informal self-management programs led by peers. One strategy that individuals in this situation often pursue is connecting with others with the same medical condition. This process has been termed peer social support (Gilbert et al, 2012).

Peer social support is defined as the functional content of relationships and can be categorized into four broad forms (Coulson, 2005):

(i) Emotional support entails providing empathy, love, trust, and concern, signaling to a person that they are valued and cared for. It refers to group members posting messages to express empathy, support the emotional expressions of the recipient, or reciprocate emotion. In summary, such affective/emotional dimension of the experience is mostly related to the feelings and emotions derived from the interaction with stimuli (Preece & Ghozati, 2001; Waldner & Olson, 2007) from the environment of OHCs;

(ii) Instrumental support involves providing life-related resources that directly assist a person in need

(iii) Informational support entails offering advice, guidance, suggestions, and information that a person can utilize to address problems and consider potential solutions. Exchanging information is the main form of support provided by online groups. In summary, such a pragmatic dimension of the experience relates to the usefulness or value of being in the community (Nambisan, 2011).

(iv) Companionship, which refers to engaging in group activities, discussions, and other social interactions that enable individuals to recognize their belongingness to a larger, affirming community (Gilbert et al, 2012).

An illustrative example highlighting the significance of peer social support is the case of T1D, a chronic, incurable, and life-threatening metabolic illness. The demands of managing this condition are complex and intensive, necessitating the involvement of a specialized multidisciplinary team for clinical management (RACGP - Royal Australian College of General Practice -Diabetes Australia,

2020). Despite the assistance provided by HCPs, individuals with T1D are solely responsible for executing the daily management tasks necessary to prevent acute and chronic physical complications. This burden of responsibility can impose considerable psychological pressure (Revenson & Felton, 1989). Moreover, while health outcomes are largely manageable, fluctuations in health status are unavoidable, and complications can occur despite diligent illness management. The accompanying uncertainty and awareness of potential death or disability can exacerbate psychological tension (Egede & Zheng, 2003). Additionally, there is a tangible burden associated with the significant time, energy, and focus required to establish and maintain metabolic control in managing T1D. It places considerable pressure on patients' ability to attend to their occupational, social, familial, and personal needs and desires (Bailey, 1996). Social stigma may also accompany the responsibilities of managing diabetes (Liu et al., 2017), leading individuals with diabetes to feel isolated from their immediate social network members who may not fully comprehend their daily experiences. Therefore, information exchange and overall support through OHCs aid individuals with diabetes in making health-related decisions, empowering them to actively engage in their care and mitigate the risk of potential diabetes complications (Gilbert et al., 2012).

While offline and online social support are similar in some respects, since both provide patients with greater confidence in health self-management, OHCs are particularly suitable for emotional support thanks to the anonymity and asynchronicity of online communication (Wu & Bernardi, 2021). With anonymous communication, people often find it easier to share illness experiences online with strangers than offline contacts (Joinson, 2001). Anonymity in OHCs reduces people's fear of disclosing their experiential details and provides a safe environment where people validate one another's feelings (Wohn & Lampe, 2018). Asynchronicity of communication is another advantage of OHCs in providing informational and emotional support (Wright & Bell, 2003). Asynchronous communication in OHCs typically occurs when a user posts messages to a discussion forum, and others respond at various times. It means a significant amount of information is archived and always available to those needing support. More importantly, asynchronicity allows the message poster to carefully think about and edit his/her message before posting, which encourages a high level of self-expression and self-disclosure (Walther, 2007). By revealing more about themselves to a large audience through anonymous and asynchronous communication, members of OHCs benefit from greater empathy and solidarity than in offline support networks (Barak et al., 2008).

Also, in the post-service encounters, patients can keep engaged in self-management activities and co-creation efforts (McColl-Kennedy et al., 2012; Sweeney et al., 2015) In fact, the abundant knowledge and support shared on OHCs effectively help other OHC members cope/manage their condition over time (Loane, Webster, & D'Alessandro, 2014) and, therefore, represent a value-dense environment for value co-creation (Zhao, Wang, & Fan, 2015). Based on the SD logic, co-creation is defined as "the benefit realized from integrating resources through activities and interactions with collaborators in the customer's service network" (McColl-Kennedy et al., 2012, p.375). Prahalad & Ramaswamy (2004) highlight the critical role of the environment in promoting high-quality dialogue and interactions among the actors of the value network.

Studies reveal that patients must engage in various activities to realize patient value co-creation in the healthcare sector. Eight broad themes of activities were identified (McColl-Kennedy et al., 2012), comprising behavioral (doing) and cerebral (thinking) activities namely: (i) cooperating (by accepting information from the service provider); (ii) collating information (by sorting and assorting information, managing basic every day activities); (iii) combining complementary therapies (by using supplementary medicine (e.g., exercise, diet); (iv) co-learning (by actively seeking and sharing information from other sources); (v) connecting (by building and maintaining relationships with family and friends, doctors and other health professionals, and support groups); (vi) changing ways of doing things (in adapting to long-term changes by altering ways of managing various aspects, such as financial adjustments and engaging in activities intentionally designed to divert one's attention from the situation (e.g., taking vacations, pursuing hobbies); (vii) co-production, by for example, assisting with administering treatments, redesigning treatments, and reconfiguring the medical team); and (viii) cerebral activities, by for example, actively hoping, talking to oneself, and having a positive attitude; reframing and sense-making—accepting one's actual situation. These themes provide a basis for customer value co-creation activities in healthcare (McColl-Kennedy et al., 2012).

Constellations of value co-creation activities form different patient value co-creation practice styles or models (e.g., McColl-Kennedy et al., 2012; Nambisan & Nambisan, 2009). In each model, patients engage in diverse activities and exert more effort to contribute to their care than they traditionally would have (e.g., Ouschan, Sweeney, & Johnson, 2000). In OHCs, knowledge sharing and co-creation occur among patients with similar concerns and experiences, and their behaviours are intentional and proactive (Frost & Massagli, 2009). In this vein, the expansion of Web 2.0 and social media have revolutionized the nature of interactions from monadic/dyadic to a network of

relationships in which value is co-created among multiple actors (Storbacka et al., 2016; Tsai et al., 2017; Zadeh, Zolfagharian, & Hofacker, 2019). Given the healthcare context, OHCs are novel communication avenues established by HCPs or people who suffer from health issues (Zhao, Wang, & Fan, 2015). OHCs provide a fertile platform for resource integration by connecting patients, service providers/healthcare professionals, and government agencies (Hajli, 2014).

In summary, OHCs are widely used in healthcare research to examine how chronically ill patients interact in an online service setting, reducing self-report bias and allowing for a natural research setting. It allows a unique understanding of PX and the identification of critical touchpoints across the journey reported by participants in OHCs. Such touchpoints can be more or less prominent in different journey stages. This journey is not solely examined from a medical standpoint but is explored within the context of the care pathway experienced by patients as they navigate their disease (Cherif et al., 2020). Understanding and capturing the main dimensions of PX in OHCs could help HCOs design, deploy, and manage such OHCs more effectively and improve services towards chronically ill patients.

3.3.3. The Well-being dimensions of chronically ill patients in OHCs

Different terms are used in the psychology literature to describe well-being. Well-being is not only multidimensional but also spans across multiple levels. Rather than targeting well-being at a specific level, community psychologists recognized that individuals cannot be understood in isolation from their broader environment (Ng & Fisher, 2013). Likewise, well-being should also be understood on multiple levels simultaneously. Cowen (2000) proposes that well-being should go beyond the personal and intra-psychic and require divergent solutions across different levels. The author explicates that wellness exists but along a continuum and can be nurtured or inhibited by external circumstances.

In addition, well-being depends on many aspects of life, so any simplistic solution cannot solve it, but only comprehensive strategies targeting various levels. Cowen (2000) specifically highlighted several sources of influence that had a tremendous impact on people's wellness: (a) the family context in which a child can naturally develop through infancy; (b) educational experience; (c) significant social setting or mediating structure in which people interact with one another; and (d) larger society. Researchers further argued that well-being is deeply embedded in the social environment, including family, community, and society (Nelson & Prilleltensky, 2005; Prilleltensky & Prilleltensky, 2006). In their words, "well-being is not personal, organisational, or collective, but

their integration. For any of these spheres – personal, organisational, or collective – to experience well-being, the other two must be in equally good shape" Prilleltensky & Prilleltensky (2006, p.11) Thus, to understand well-being through a holistic perspective, Nelson & Prilleltensky (2005) suggested the personal (such as self-esteem independence), interpersonal (having a supportive relationship and freely engaging in society), and collective levels of well-being (being able to acquire community resources). Prilleltensky & Prilleltensky (2006) explained that social groups cannot function properly without the contribution of optimism, self-efficacy, and an equal sense of purpose. Similarly, people cannot flourish without an immediate environment that is stimulating, respectful, affirmative, and reflective and a broader society that is resourceful, fair, and free of corruption. In other words, to enable people to be optimistic, have self-efficacy, determination, and personal growth, at the personal level, an enabling organisational structure and a community with justice is necessary, if not a must (Diener et al., 2017).

3.3.3.1. Subjective Well-being (SWB) dimensions

The term SWB (Diener, 1984) pertains to subjective well-being, encompassing individuals' sentiments toward life and their assessment of affective states. It includes their overall happiness, life satisfaction, and experiences of positive and negative emotions (Ng & Fisher, 2013). The literature emphasizes five dimensions of SWB, which are essential to consider: cognitive, affective, physical, eudaimonic, and social.

The first type, cognitive well-being, is related to people's evaluations in terms of cognitive reflections. It represents reflective evaluations of life and its various domains, including work, and pertains to how individuals assess their overall satisfaction with life (Ryan & Deci, 2008). Additionally, it can encompass a broad evaluation of life in general or life during a specific period (Evers et al., 2012).

The second type, affective well-being, pertains to an individual's emotional state, encompassing positive and negative affect. Positive affect comprises the range of emotions experienced when circumstances are favorable, including momentary feelings (e.g., enjoyment) and sustained moods (e.g., contentment). Conversely, negative affect encompasses momentary emotions such as anger, sadness, stress, and worry, as well as longer-lasting moods like depression that persist over time (Diener et al 2017; Ng & Fisher, 2013). Therefore, according to the hedonic perspective, well-being entails the overall subjective experience of happiness, positive affect, and minimal negative affect

(Bradburn, 1969; Diener, 1984) emphasizing the pursuit of pleasure and happiness as life's ultimate goal (Ng & Fisher, 2013).

The third type, physical well-being, refers to health and healthy behaviours. This dimension is assessed by an individual's perceptions and understanding of their health, including but not limited to overall health, chronic condition diagnoses, health problems that get in the way of daily functioning, experience of pain, and feeling rested (Evers et al., 2012).

The fourth type, eudaimonic well-being, includes meaning and purpose in life, supportive social relationships, and feelings of mastery (Diener et al., 2017). It posits that genuine happiness transcends the mere fulfillment of immediate desires. The eudemonic highlights positive psychological functioning and human development, functioning optimally in individual and social life (Ryff & Keyes, 1995).

Lastly, the fifth dimension, social well-being relates to how people function effectively regarding social challenges and tasks. Keyes (1998) suggested five dimensions of social well-being, namely (i) social integration, the individual's ability to participate fully in society), (ii) social contribution, the extent to which a person can provide valuable contributions to the world); (iii) social coherence understanding, and making sense of societal events and circumstances), (iv) social actualization, the envisioning of the future potential of society) and (v) social acceptance, the trusting and accepting of both the positive and negative aspects of human nature. The social acceptance means that achieving well-being extends beyond individual experiences to resonate effectively and coherently in the public sphere (Ng & Fisher, 2013).

3.3.3.2. Expressions of SWB dimensions in OHCs

Previous studies investigating the link between OHCs and well-being have mostly considered what patient well-being outcomes result from using and interacting with other patients in OHCs (e.g., (Pham et al., 2019; Zheng et al., 2016). For example, the research of Zheng, Yao, & Fan (2016) suggests that the dynamics of OHCs and the two-way online social support (receiving and giving online social support) enhances the psychological well-being of the members. However, these studies do not cover what the chronically ill patients share in OHCs about their well-being across their journey, examining the different facets/dimensions of well-being expressed in participants' narratives through OHCs.

3.4. METHOD

3.4.1. Research strategy and design

This study aims to explore the content of participants' posts in OHCs. In particular, it focuses on the expressed dimensions of the experience and well-being of chronically ill patients with T1D and ESRF throughout their patient journey.

Data were collected using a netnographic study. Netnography entails a qualitative research approach that transposes and adapts the traditional, in-person ethnographic research techniques to the study of online cultures and communities formed through computer-mediated communications (Kozinets, 2002, p.2). Netnography is also considered an emerging methodology in which researchers embed themselves in the online environment to take an observational "deep dive" into online conversations (Tenderich et al., 2019, p.1). It is used here to provide insights into the PX and well-being dimensions throughout the patient journey.

Netnography and related methods have been used to research health topics as activities are facilitated digitally, and platforms gather communities of members interacting online (Perren & Kozinets, 2017). This study used a qualitative research design based on netnography, which facilitates a better understanding of the lived experience of the informants (Van Maanen, 2011) and the obtention of in-depth information on their experiences and well-being dimensions across the patient journey.

We conduct a textual analysis of OHC threads from chronically ill patients (T1D and ESRF) who use such platforms to narrate and manifest their experiences and well-being across the Journey (before, during, and after diagnosis).

Diagnosed with a chronic disease such as T1D or ESRF accentuates human vulnerabilities (Timko & Janoff-Bulman, 1985). Indeed, individuals grappling with chronic diseases often encounter feelings of vulnerability, a sense of loss of control, and uncertainty regarding their future (Arora et al., 2007). T1D and ESRF patients carry physical risks (e.g., comorbidities, hospitalizations, mortality/fatality), social stigma (e.g., exclusion/rejection), and long-term healthcare concerns (e.g., self-management of a long-term condition) (Campos et al., 2015; Lyng et al., 2021). Moreover, T1D and ESRF are a compelling context to explore the expressions of experiences and well-being, given the prevalence of web-based narratives of chronically ill patients. Patient narratives are illustrative, individual accounts of patients' experiences with certain health conditions. Recently, the role of web-based patient narratives as a source of information, insight, and support for

healthcare users and providers has been increasingly emphasized (Drewniak et al., 2020). Therefore, our study seeks to better understand vulnerable consumers (suffering from T1D and ESRF) and investigate their experiences and well-being expressions as they engage in active discussions in OHCs.

We conduct a retrospective study of Internet-based discussion threads in which participants in the online discussion group are "conscripted" to the research (Keeling et al., 2013, p.69). The central aim was to contribute to developing improved health service provision and enhancing the voice of consumers within such complex services. This is especially true since "contributory patients" access information online and interact with others to narrate their experiences through OHCs. Therefore, most of those participating in the OHCs we studied would accommodate more improved care services and support (Keeling et al., 2013).

Moreover, our research is a covert study. Covert research is research that is not declared to the research participants or subjects (Spicker, 2011). The non-manifestation of the researcher in the community allows: i) avoiding bias (Tenderich et al., 2019) ii) observing the natural context and behaviour of the participants, iii) weakening the content posted, and iv) dealing with sensitive/risky patients (Costello et al., 2017). A researcher's active participation in an online community is challenging and appropriate, particularly when researching online communities dealing with extremely sensitive or risky matters (Costello et al., 2017). In summary, the researchers did not participate or engage in any OHC related to the study, and the activity was limited to viewing content and gathering data.

The fieldwork followed the steps described by (Kozinets, 2002): (a) preparation for entry into the field, (b) data collection, and (c) data analysis.

3.4.1.1. Preparation for entry into the field

We selected two international OHCs using the following steps. Firstly, international community mapping was carried out using search engines. Several English language communities using the most extensive search engine (Google) were identified. The search was performed between January and December 2021 by using the following keywords: “Online Health Communities”; “Chronic illnesses”; “Type-1 Diabetes”; and “Chronic Kidney Disease”. This search initially resulted in communities based worldwide; predominantly, and as expected, these communities were based in the US. Secondly, we focused on detailed discussion forums around two diseases of interest: T1D and ESRF. Additional inclusion criteria were considered (Hammersley et al., 2007; Kozinets,

2002, 2010) such as i) OHCs with publicly accessible information or accessible information after request; ii) high post traffic and impact in terms of interactions/contributions (e.g., comments)/ with ongoing, recent, and regular communications; and iii) heterogeneity: several different participants; data-rich, with detailed and descriptive data. Notably, to avoid obvious bias, we excluded from our search those forums managed by medical organisations (Keeling et al., 2013). For this study, we followed two OHCs. The first (OHC for T1D) is an online community of over 600,000 people with about 2900 medical conditions, including T1D, amyotrophic lateral sclerosis, mood disorders, HIV, and rare diseases. The second (OHC for chronic kidney disease - CKD) offers a safe and supportive place where patients and caregivers can share experiences, ask questions, and get answers related to kidney health, kidney disease, transplantation, and living organ donation. In both communities, participation is free and anonymous.

In each community, we specifically selected the discussion threads in the forums dedicated to the T1D and ESRF. After a brief registration process[3], participants type a message on their computer that is immediately published on the website. Others can similarly log in and post responses to the message, creating discussion threads (Pham et al., 2019). Both communities are peer-to-peer only and do not include healthcare professionals or medical interventions. However, these online platforms provide moderators for contact and support. Moderators are responsible for removing inappropriate messages such as advertising or providing medical advice, contacting members by e-mail to explain the website's rules, and banning inappropriate participants. However, the most frequent activity of the moderators is to make proactive contributions to the community and model and reinforce appropriate behavior and discussion, such as welcoming new members, contributing their own experiences, and providing links to high-quality information resources (Pham et al., 2019). The current study examined each OHC individually but also looked at the differences among the two communities.

In line with previous online research exploring vulnerable healthcare service users' narratives, our study uses a naturalistic qualitative research approach to analyzing forums' existing threads (Keim-Malpass et al., 2014; Keim-Malpass & Steeves, 2012). Naturalistic inquiry is a qualitative research method used to examine people's life experiences in context-bound settings (Armstrong, 2010; Lincoln & Guba, 1985) – In this case, chronic patients' experiences and well-being are narrated through OHCs. Hence, in this study, the unit of analysis consists of each unique post by individual

[3] - Registration process requires a username and an e-mail address. In the specific case of OHC for T1D, the user must specify whether he/she is joining for his/her health and wellness or as a caregiver for someone else. The user can also specify his/her medical condition/illness (optional).

community members. The post is any narrative message from anyone within the online community (Stempel, 1952, p.333).

Following this approach, the researcher began by immersing themselves in the natural setting to become familiar with the context to "question their assumptions and act like strangers to the setting as "naive" observers" (Flick, 2009, p.21). Immersion began before formal data collection by actively observing discussion posts /threads or exploring user interactions for two months (December 2020 – January 2021). Each OHC was checked weekly, noting new threads, and returning to previous threads to explore comments and discussions. This immersion period was critical to understanding the real-time sharing of experiences and well-being of participants with T1D and ESRF(e.g., diagnosis, discovery, and daily self-management) and how users communicate with one another. Given the everyday appeal of OHCs, it was possible to investigate patients' experiences longitudinally. This form of naturalistic inquiry allowed a better understanding of the evolution of patients' stories and provided evidence of their experiences throughout the Journey– before, during, and after diagnosis.

3.4.1.2. Data collection

Following immersion, a more systematic analysis progressed by manually downloading relevant threads from each discussion page. Discussion threads examined in the study followed specific inclusion criteria. First, the thread in the data directly addressed experiences related to the individual's T1D and ESRF journey through textual data. Single introduction threads from moderators or patients were excluded from the data. The analysis of small samples of OHCs allows deep insights into understanding a specific phenomenon among a subset of the online population (Kitchin & Lauriault, 2015) such as patients' experiences with T1D and ESRF. Data collection was conducted between January and July 2021 in four rounds. The initial two rounds aimed to identify prominent themes qualitatively. Rounds 3 to 4 focused on adding depth to the initial findings in each area. The data included 186 forum threads published and accessible online between December 2011 and June 2021 (see Table 3.1). Each patient's thread functions as a narrative of part of her/his life dealing with the disease in real-time as he/she progresses through his/her journey of coping with DT1/ESRF.

Table 3.1- Details of the OHCs analysed

Online Health Community	Time of the community	The time of analysis (discussion threads included in the data)	Total of active members diagnosed (at the moment of the study)	Total of discussion threads in the forum	Total of discussion threads included in the data
Focused on several illnesses, including T1D condition	2005-2024 (19y)	2011-2021 (10y)	4,239 active members	84	84
Focused on chronic Kidney Disease CKD, in particular, ESRF	2017-2024 (7y)	2017-2021 (4y)	6,714 active members	2,719	102 (includes the threads filtered by "stage4-5 of CKD - ESRF)

Source: Authors' elaboration

In line with previous studies examining user-generated content and public health issues, the sample size in our study was determined to be an appropriate volume of data for analysis while still being small enough to engage in the critical but labour-intensive qualitative approach that considers each discussion thread as a holistic unit of analysis (Laestadius & Wahl, 2017).

3.4.1.3. Data analysis

Inductive thematic analysis was used to identify recurring patterns within the dataset. Participants' messages were examined in the context of the discussion threads posted to identify what they shared with peers, as evidenced by the content of their postings. Initial active reading of each thread involved searching for meanings and patterns rather than casually reading the data (Braun & Clarke, 2006). This approach allowed interpretations to emerge from the data, to derive categories from threads (inductive approach), and to produce a final list of themes summarizing the data. Then, the number of messages within each theme was counted. A theme is deemed prominent when several participants present a topic (Tenderich et al., 2018). It was also verified whether more than one theme was represented in each message (Smedley & Coulson, 2017).

Categories and subcategories were developed progressively from the data, and as such, the data analysis represents a "second-level scheme" (Miles & Huberman, 1994, pp. 61). This structure facilitated analysis and formed the basis of our interpretation. Thus, the contents' threads were analysed to identify patterns related to existing literature to develop theoretical insights. This deductive process was applied to determine whether coded data could be categorized into the core dimensions that underpin the holistic and multidimensional construct of experience and well-being (Dodds et al., 2018; Knibb et al., 2019; Ng & Fisher, 2013).

Once a workable set of themes and concepts was established, we distilled the emergent 2nd-order themes into a highest-level category Corley & Gioia (2004) which consisted, in this case, of experience and well-being expressions throughout the patient journey.

For rigor and trustworthiness, the content of the threads was examined by the principal researcher and then reviewed and discussed by the research team (Smedley & Coulson, 2017). The research team met after each round of data collection to discuss emerging themes, build consensus on any discrepancies, and avoid bias and subjectivity (Tenderich et al., 2019). Based on this, a common and uniform category system forms the coding guideline (Mayring, 2014).

Our data structure is illustrated in Table 3.2. demonstrating the development of our first-order concepts into second and third-order themes, following the approach of Corley & Gioia (2004) and Gioia, Corley, & Hamilton (2013).

The themes are discussed by reporting the range of views on each and evidencing these with paraphrased and verbatim quotes.

3.4.1.4.Ethical considerations

Regarding the ethical aspects of the study, we adopted the argument of Langer & Beckman (2005). Since the content of the analysed posts in the two OHCs was publicly available, there was no need to request authorization for the data collection or disclose the researcher's presence and intentions while conducting the study.

Table 3.2 – Categorization process leading to identifying the experience and well-being dimensions of chronically ill patients with T1D in OHC

First order concepts	Second order categories	Highest theme
— Identifying the T1D/ESRF symptoms and seeking help within the community	— Symptoms awareness and search for care (pre-service encounters) *(patient-owned touchpoints)*	Expressed experience dimensions in OHCs
— Need for medical, technical skills/competence: patients reporting HCPs struggling with the diagnosis (T1D). — Need for informational support from HCPs i.e., using glucose devices, managing insulin administration and sugar levels) (T1D); receiving information and effective/clear communication about test results, meals/foods, having a supportive and knowledgeable team care (ESRF) — Need for emotional support from HCPs (ESRF) — Need for effectiveness of care processes accessing a multidisciplinary team care (T1D/ESRF) and effective internal procedures of treatment (e.g., insulin injections, glucose tolerance test) (T1D)	— Interactions with HCPs and care processes: need for support from HCPs and effectiveness of care processes (during service encounters) *(brand-owned touchpoints)*	
— Need for more psychological support from family and friends: higher levels of disinformation about the disease (T1D/ESRF) — Need for informational support from peers: (a) General information about T1D/ESRF through media content such as videos, events, podcasts, blog posts and research, books (b) Advice for lifestyle management - nutrition & sports (T1D/ESRF) (c) Advice for complications and common comorbidities management (T1D/ESRF) (d) Advice for drugs and symptoms management (ESRF) (e) Advice for technologies management (e.g., continuous glucose monitoring devices	— Interactions with social actors: need for support (post-service encounters) *(social-owned touchpoints)*	

(CGMs), test strips and technologies, insulin pumps, pod therapy) (T1D) (f) Advice for finding health insurances (T1D/ESRF) (d) Advice for ICs: how to deal with patients and support them (T1D/ESRF)		
— Co-production: patients take an active role in organizing clinical appointments and information both to facilitate encounters with their providers and to monitor their health status (T1D/ESRF) — Connection: Patients taking an active role in actively sharing and integrating information from others (illness trajectories and experiences) (T1D/ESRF) — Co-learning: patients taking an active role in seeking and sharing information from other sources (e.g., Internet, other doctors/other health professionals), becoming experts, and developing coping strategies) (T1D/ESRF) — Combination of complementary therapies: Patients taking an active role in engaging in different activities and therapies such as praying, animals, music, alternative therapies (T1D/ESRF) — Cerebral activities: Patients taking an active role in adopting positive thinking and attitude	— Value co-creation activities (post-service encounters) *(patient-owned touchpoints)*	
— Cognitive well-being: life satisfaction/evaluation (T1D) — Affective well-being: affective reactions /moods (positive and negative) (T1D/ESRF) — Physical well-being: physical health and healthy behaviours (T1D/ESRF) — Expressing eudaimonic well-being: acceptance, adoption of a positive perspective, being goal-directed and proactive (T1D/ESRF)	— Well-being at the individual level: cognitive (T1D), affective (T1D/ESRF), physical (T1D/ESRF) and eudaimonic (T1D/ESRF).	Expressed well-being dimensions in OHCs
— Social well-being: social integration and contribution	— Well-being at the collective level: social	

Source: Authors' elaboration

3.5. FINDINGS

The data generated valuable insights into what chronically ill patients (suffering from T1D and ESRF share in OHCs regarding their overall experiences and well-being across their journey. Two main themes emerged: i) expressed PX dimensions from chronically ill patients in OHCs and ii) expressed well-being dimensions from chronically ill patients in OHCs.

3.5.1. Themes and subthemes

3.5.1.1. Theme I: Experience dimensions expressed by chronically ill patients in OHCs

An overarching theme captures the most relevant PX dimensions expressed by chronically ill patients with T1D and ESRF in both communities. This theme entails four main subcategories: (i) symptom awareness and search for care, (ii) Interactions with HCPs and care processes: need for support from HCPs and effectiveness of care processes, (iii) Interactions with social actors: need for support and (iv) value co-creation activities.

3.5.1.1.1. Subtheme I - Interactions with social actors

This subtheme relates to the interactions with social actors and the need for social support (psychological and informational). The call for social support becomes particularly pronounced as patients transition to managing their condition at home (self-management stage) (see Table 3.3).
The psychological support relates to the need for a better understanding of the disease from various sources such as family, friends, ICs, and peers. For instance, individuals with T1D report frustration with unsolicited health advice from individuals unfamiliar with the distinctions between Type-1 and Type-2 diabetes. Similarly, participants with ESRF express frustration in educating others on managing the disease.
The informational support is related to the sharing of disease-related information through various media content such as videos, events, podcasts, blogs, research, and books. For example, those with T1D emphasize the significance of such content for individuals managing the condition or newly diagnosed. Similarly, ESRF participants highlight the importance of comprehensive information on renal replacement techniques (RRTs) for patients in the pre-dialysis stages. Additionally, participants utilize OHCs to offer and seek advice across several domains related to their condition. Notable topics include lifestyle management encompassing nutrition, sports, and leisure activities. For instance, T1D participants seek advice on meal preparation, insulin adjustments, carbs counting, weight loss, healthy recipes, and supplements, while those with ESRF

focus on renal diet tips. Questions also arise regarding approved workouts for T1D patients and concerns about exercise recommendations from cardiologists and nephrologists for ESRF patients. Furthermore, participants guide managing complications or comorbidities, emphasizing the importance of adopting coping strategies to mitigate stress and its impact on mental health. Topics related to symptom management, drug management, and medical device usage are also discussed. Participants express a keen interest in understanding prescription medication purposes, adherence, and dealing with side effects. Additionally, there is a strong focus on learning and optimizing health devices and technologies for monitoring and treating conditions over time, particularly among T1D participants. For example, T1D participants show particular interest in managing hypoglycemia, a common condition among T1D patients whose blood sugar (glucose) level is lower than usual.

Regarding medical devices or technologies for treatment, participants demonstrate a strong interest in learning and better using health devices and technologies for monitoring/treating their conditions over time. However, this topic is much more emphasized by T1D participants. T1D patients ask for information and tips to manage their continuous glucose monitoring devices (CGMs), insulin pumps, pod therapies or test strips. In the case of ESRF, participants express interest in using apps to monitor/track their mineral intakes.

Moreover, the necessity of securing health insurance is highlighted in both communities, with T1D participants particularly emphasizing the need for third-party entities to cover diabetes supplies. Adequate and affordable health insurance is crucial for accessing necessary supplies, medications, education, and healthcare services.

Lastly, ICs also engage in the communities, expressing interest in accessing information on effectively caring for chronically ill patients.

Table 3.3 – Subtheme I - Interactions with social actors

First order concepts	N	Illustrations
Need for psychological support: a better understanding of the disease	6 (OHC_T1D 3 (OHC_CKD)	(T1D) I would love to talk to other Type 1's. It would be great to talk to another person with Diabetes about life. (T1D) It sounds frustrating to be misunderstood by people who need to learn about your condition. I know receiving unsolicited health advice is always frustrating, especially from people who just do not get it. I look forward to reading more informative posts in the future. (CKD) So, I have "arrived" stage 5? Nobody gets it. I feel like a deer in the headlights and hear the car's engine getting louder. But all my "dear" friends and family go on grazing in the field while I stand quietly panicking. Does anybody relate? Could you write to me? It sure would be nice to have a comrade to chat with. (CKD) I have given up explaining how I feel or what kidney disease means to friends and family. I have made good friends here and thank God for this little community; otherwise, I would feel very alone.
Need for informational support - sharing general information about the disease	16 (OHC_T1D) 34 (OHC_CKD)	(T1D) I know someone who has made peer support and advocacy her focus. She has founded a psychosocial peer support conference for adults with Diabetes and co-founded an advocacy organisation for easy and effective diabetes policy advocacy. She also writes a popular patient blog, ThePerfectD.com, which publicly discusses her experiences. In a recent interview, she talks about societal stigmas surrounding Diabetes and how important it is to connect with others who share it. (CKD) There is a great book called "Help, I Need Dialysis! It is not expensive, and I ordered it from the Medical Education Institute, but it is also available from Amazon. It offers information on all modalities and explains everything in detail. It could offer you additional insight to alleviate some of your concerns. CKD) Not Sure What All the Lab Results Mean? (...)I was classified as CKD stage G5/A3, GFR <15 and albumin creatinine ratio >300 mg/g but then was classified as Stage 4 chronic kidney disease. What do the numbers mean? I see a different doctor every time I go; only two

		have talked to me. They want my PCP to handle stuff other than kidneys, but my PCP is afraid of screwing up my kidneys.
Need for informational support – advice for lifestyle management (nutrition & sports)	47 (OHC_T1D) 39 (OHC_CKD)	(T1D) I need to lose about 20 kilos. It is not very comfortable. I am tired of hearing from doctors that being overweight results from combining insulin and various medications. The reboot series has inspired me, and I have started juicing vegetables and a lot of green ones. I have noticed that my need for insulin has decreased significantly, and my levels are more stable. Has anyone else tried anything else for type 1? (CKD) My main problem right now is trying to figure out what to eat. I do not usually cook and try to remember what foods have potassium and phosphorus. (CKD) One question on exercise: I have been working out in the Gym for the past 25 years, and I do moderate exercise, not very strenuous. Now, I am doing only aerobics and stopped weight training completely. Is this OK? What are your thoughts on exercise?
Need for informational support – advice for managing specific conditions, complications/comorbidities	40 (OHC_T1D) 13 (OHC_CKD)	(T1D) Me and my partner decided to start trying for a baby; I was wondering if anyone else had trouble conceiving or if it takes longer to conceive if you have Diabetes. (CKD) About five weeks ago, I had a terrible time with excruciating gout in my kneecap. The time before that was about nine months ago, which started in my big toe on my left foot. On my last visit to the nephrologist, I was told that my GFR (Glomerular Filtration Rate) was now at 14. Twelve months ago, it was 26. I hope now that the decline has something to do with the gout. However, I am now being assessed for a transplant, but I hope my GFR will increase now that my uric acid levels are normal, and the gout has cleared out. Does anyone else have problems with gout?
Need for informational support - advice for managing symptoms and drugs	16 (OHC_T1D) 17 (OHC_CKD)	(T1D) I'm just curious to hear from other Diabetics about your most effective way to treat low blood sugar. (CKD) I am very close to needing dialysis. I was always exhausted and had nausea, indigestion, and no appetite. I find that some food goes down better than others. If this has happened to you, what do you find to eat?

Need for informational support - advice for health devices and technologies	46 (OHC_T1D) 2 (OHC_CKD)	(T1D) If you have a continuous glucose monitor (CGM), try to look at it after a given meal and get an idea of what the trends and overall impressions you are seeing. (CKD) I used MyFitnessPal before, but the information in their library needs to be more accurate and have potassium and phosphorous information.
Need for informational support - advice for finding health insurances	11 (OHC_T1D) 3 (OHC_CKD)	(T1D) Does anyone know how I would find a physician who would order my diabetic supplies on my behalf so that I can have them covered under my insurance policy? If so, could you help me take advantage of this benefit? (CKD) It would be a great time to visit a "registered" dietitian. These professionals will draw and analyze blood and create an individualized path forward, specializing in various medical issues. Medicare and other insurance will pay for visits to a "registered" dietitian.
Need for informational support - advice for ICs	3 (OHC_T1D) 1 (OHC_CKD)	(T1D) I am not diabetic, but I live with a person with type I Diabetes who is very labile. I am used to coping with insulin shock episodes, but he occasionally goes hyperglycemic, vomiting, and dehydrated. His diet is poor. The last time he went hyperglycemic, I got him some vitamin drinks and a couple of oranges. I phoned my pharmacist. They had rehydration/mineral supplements, but he seemed OK with just the soda fruit. Any other suggestions for simple home first aid? (CKD) My mother-in-law has stage 4/5 kidney disease and Crohn's and Raynaud's. I was researching Humira and Crohn's when I came across this site. I am looking for the best way to help her with Crohn's without affecting her kidney disease.

Source: Authors' elaboration

Legend:

N – Number of discussion threads posted about the subcategory

OHC_T1D – Online Health Community focused on T1D condition

OHC_CKD – Online Health Community focused on CKD condition

3.5.1.1.2. Subtheme II - Patients as Co-creators of Value

The findings reveal that chronically ill patients report on OHCs their value co-creation activities mainly post-service encounters (see Table 3.4). The data highlight five primary co-creation activities: co-production, connecting, co-learning, combining complementary therapies, and cerebral activities. Co-production involves patients actively organising clinical appointments and information management, facilitating interactions with HCPs, and monitoring their health status. Connecting signifies patients' active engagement in sharing and integrating information from others, including their illness trajectories and personal experiences. Co-learning pertains to patients assuming an active role in managing their diseases, acquiring expertise, and developing coping strategies through seeking and sharing information from sources such as the Internet and healthcare professionals. Participants commonly combine complementary therapies, incorporating activities and therapies such as prayer, animal-assisted therapy, music therapy, and alternative treatments into their self-care routines. Lastly, patients engage in cognitive activities by fostering positive thinking and attitudes toward their diseases, contributing to their overall well-being and disease management efforts.

Table 3.4 – Subtheme II - Patients as Co-creators of Value

First order concepts	N	Illustrations
Co-production	4 (OHC_T1D) 2 (OHC_CKD)	(T1D) Here is a tip that might help to bring to your doctor's attention: Take your insulin, take a picture of what you eat (if you have a smartphone, there are a few apps out there that can help: My Sugar and Meal Memory spring immediately to mind), then set a timer to check your blood glucose levels 1 1/2 to 2 hours after eating. You can show your pre-blood glucose, what you ate, and your post-meal blood glucose level. (CKD) Despite being at stage 5, the essential keys are working with your nephrologist and putting together an action plan that suits your needs; it will include treatments, medication, and diet, which is the big key. If you have not already, list what you eat and bring it to a scheduled nephrologist appointment for discussion. Your doctor should shed some light for you and refer you to a renal dietician in your area who will put together a list of healthy, nutritious, and appetizing foods based on your labs if they have not done so already.

		Print out your labs from your patient site, check off any flags, and note questions for your doctor so that you never leave the office wondering.
Connecting	8 (OHC_T1D) 13 (OHC_CKD)	(T1D) I am a Type 1 who was diagnosed 25 years ago. I am still adjusting daily and learning more, so I am here. I hope to gain some direct knowledge from the experiences of others because knowledge is the key to success. I hope to offer some experience that may also help someone else. (CKD) I am currently in stage 5 of CKD. I am trying to find others in a similar situation to understand what I should be feeling/experiencing. I realize not everyone will be the same, but there should still be some similarities. This will help me relate and potentially relieve frustration or depression.
Co-learning	8 (OHC_T1D) 12 (OHC_CKD)	(T1D) I am a T1D runner and a clinician. I suffer from post-exercise hypoglycemia. I have been developing an app to integrate the exercise data from my Fitbit with glucose measurements to identify trends, prevent lows, and optimize my workout safely. Does anyone else suffer from similar problems? Would anyone be interested in an app like this? (CKD) I have since researched independently and paid to have my blood tests run (including cystatin-c, which the nephrologist never mentioned) by an independent lab. I am in the process of finding a different nephrologist as I cannot trust the previous one.
Combining complementary therapies	3 (OHC_T1D) 4 (OHC_CKD)	(T1D) There are dietary things I do, and I also see a Chinese acupuncturist who is no-nonsense with those needles. (T1D) I love animals and classical music and pray a lot. (CKD) My motto is: I can get busy living or get busy dying. It is that simple. I am so glad you found this site, and it does help to talk to others who are walking the same steps. God is Good.
Cerebral activities	6 (OHC_T1D) 12 (OHC_CKD)	(T1D) I have been living with T1D since 1966. I have minimal complications even after all this time, and I contribute that to thirst things: A have a positive attitude - a "can-do" approach. (CKD) It is about staying positive, lifestyle changes and finding something significant about each day! It is a process/ journey; we are all walking together here.

Source: Authors' elaboration

3.5.1.1.3. Subtheme III - IInteractions with healthcare providers (HCPs) and care processes

The interaction with HCPs and care processes entails the reported experiences during service encounters and interactions with HCPs and the need for overall support from HCPs (see Table 3.5). Participants within the OHCs request (1) Technical medical skills/competence. This specific topic is discussed among T1D patients in the community who report several difficulties from HCPs with the diagnosis of their condition); (2) Informational support. T1D patients in the community highlight the importance of essential support from HCPs, namely, in using invasive glucose devices (i.e., insulin pumps) to manage insulin administration and sugar levels. Regarding ESRF, patients stress the relevance of receiving information and effective/clear communication about test results, meals/foods, and having a supportive and knowledgeable team care; (3) Emotional support. This topic is mainly discussed among ESRF patients within their community. Participants show the need for genuine encouragement, compassion, and active listening from HCPs; and (4) Effectiveness of care procedures. The relevance of being followed by a multidisciplinary team care is particularly emphasized in both communities. For patients with T1D and ESRF, it is critical to have a team of professionals from various disciplines working together to deliver comprehensive care that addresses as many of the patient's needs as possible. T1D patients also stress the relevance of more effective procedures by HCPs (i.e., insulin injections and glucose tolerance tests.

Table 3.5 – Subtheme III - Interactions with healthcare providers (HCPs) and care processes

First order concepts	N	Illustrations
Interactions with HCPs: need for - medical technical skills/competence HCPs	7 (OHC_T1D) 0 (OHC_CKD)	(T1D) I have had poorly informed doctors tell me that since it started at such a late age, it cannot be type 1. (T1D) I do not know where to classify myself (...) He has reclassified me as "abnormal glucose tolerance – other". So, officially, I have been an early Type 1 diabetic. And now, my endocrinologist does not know what I am. He is guessing I will return to being an official Type 1, Type 2, or Type something someday.
Interactions with HCPs: need for informational support from HCPs	13 (OHC_T1D) 8 (OHC_CKD)	(T1D) I have been having constant nocturnal hypos for 22 days. I have been happy with the results since I had been diagnosed. I have been getting high glucose levels. I do not want to change my dosage because I am finally happy about the results, and it is the first time I have felt in

		control and not have Diabetes control me (...). I have tried to contact my local doctors, surgery, hospital, and diabetes nurse, but none have bothered to contact me or help me, so I am lost now (...) So, is there any advice I can get from you guys? (CKD) There is no cure for kidney issues, but as some of these great folks have stated to you, the goal is to keep healthy and stop the progression of the disease. Life has no guarantees, but with a communicative medical team, proper medication, and a diet designed to your individual needs, hopefully, the disease will be contained.
Interactions with HCPs: need for emotional support from HCPs	0 (OHC_T1D) 4 (OHC_CKD)	(CKD) The problem is that some doctors are on another planet when it comes to 'bedside manner'. (CKD) (...) Any physician not listening to and working with a patient (...) should be discharged from the case.
Interactions with care processes: need for a multidisciplinary team care (effectiveness of care processes)	3 (OHC_T1D) 12 (OHC_CKD)	(T1D) I have been living with T1D (...) I have minimal complications even after all this time, and I contribute that to thirst things: An above-average DCT (Diabetes Care Team). The team should include an endocrinologist, a CDE (Certified Diabetes Educator), a nutritionist, a podiatrist, and an ophthalmologist. I also have on my team a cardiologist (heart specialist) and a nephrologist (kidney specialist) to keep my heart and kidney functions checked regularly. (CKD) Getting a good doctor, including his/her office team and pharmacist, is essential, and there are no easy ways to find out, notwithstanding ratings, rankings and listing in awards.

Source: Authors' elaboration

3.5.1.1.4. Subtheme IV - Symptoms awareness and search for care

This symptoms awareness subategory covers the need for symptom checking, which marks the journey's beginning (see Table 3.6). Some participants revealed in both OHCs the need to identify the disease (T1D/ESRF) based on the symptoms reported by peers within the community. The data highlights the relevance of this category for patients with ESRF.

Table 3.6 – Subtheme IV - Symptoms awareness and search for care

First order concepts	N	Illustrations
Symptoms awareness	6 (OHC_T1D) 15 (OHC_CKD)	(T1D) My daughter, age 12, has been tested for celiac, thyroid, and regular bloodwork, all normal. The paediatrician says it is Diabetes, and the Endo says these are symptoms the paediatrician should handle. Has anyone had similar problems or have suggestions for what to do next? (ESRF) (...) Could the ladies share some experiences about their symptoms at stage 5 CKD? My GRF is now down to 10. My phosphates are higher, and potassium is raised too. I have noticed that my monthly period has stopped for the first time (...). Is this a common symptom when your function declines?

Source: Authors' elaboration

3.5.1.2. Theme II: Well-being dimensions reported by chronically ill patients in OHCs

Several dimensions of well-being reported by chronically ill patients were identified at two levels: (i) individual and (ii) collective. They are explained in the following sub-sections.

3.5.1.2.1. Subtheme I - Well-being at the individual level

Four well-being dimensions were found at the individual level: cognitive, affective, physical, and eudaimonic (see table 3.7). The first dimension - cognitive - relates to life satisfaction/ evaluation and represents how participants evaluate their lives as a whole or a specific lifetime. T1D participants positively evaluated their lives when using insulin pumps. In some cases, the difficulties with weight management lead participants to the "heaviest" period of their lives. No reports of cognitive well-being dimensions were found within ESRF participants.

The second dimension – affective - relates to emotional health and is represented, in this case, by the participant's negative emotions. Both participants with T1D and ESRF reported negative emotions (i.e., fear, anxiety) while trying to recognize the symptoms. During the service encounter stage, some participants reported feelings of sadness, despair, and confusion while receiving the diagnosis. At the post-service, most of the participants finally manifested frustration, depression, exhaustion, and sadness, mainly because of the global misunderstanding of their diseases (lack of support).

The Physical dimension relates to the physical health of participants. Both participants reported their first symptoms (i.e., T1D participants mentioned losing weight and feeling sleepy, while participants with ESRF described nausea and feeling sleepy). Moreover, they also report additional health problems while living with their conditions. For example, T1D participants specifically report problems related to weight management and glucose control (i.e., weight maintenance and control of A1c.[4] However, most T1D participants report improvement in some areas, such as weight maintenance and better control of A1c parameters due to the use of insulin pumps.

Lastly, the eudaimonic dimension is related to the acceptance, ability to fulfil goals, adoption of a positive perspective, and being goal-directed and proactive. Participants from both communities mainly report this dimension of well-being during the self-management stages.

[4] - Glycated hemoglobin (A1C) test. A fasting blood sugar level of 126 mg/dL (7.0 mmol/L) or higher suggests type 1 diabetes.

Table 3.7 – Subteme I - Well-being at the individual level

First order concepts	N	Illustrations
Cognitive well-being	3 (OHC_T1D) 0 (OHC_CKD)	(T1D) I have had Diabetes for 28 years. I have been on the pump for the last six years, and my A1c has remained at or around seven since going on the pump - probably the best decision I ever made to go on the pump. (T1D) I am 43 years old and the heaviest I have ever been. I need to lose about 20 kilos. It is not very comfortable. I am tired of hearing from doctors that it combines insulin and various medications.
Affective well-being	37 (OHC_T1D) 7 (OHC_CKD)	(T1D) Being diagnosed with a lifestyle-changing chronic Illness can cause sadness and depression. Please consider talking with your healthcare team about these feelings (which are just as important as discussing your diabetes treatment plan). (CKD) I am currently in stage 5 of CKD. I am trying to find others in a similar situation to understand what I should be feeling/experiencing. I realize not everyone will be the same, but there should still be some similarities. This will help me relate and potentially relieve frustration and depression.
Physical well-being	40 (OHC_T1D) 15 (OHC_CKD)	(T1D) I knew something was wrong with my body as my butt muscles got loose, and I was sleeping all the time. (PLM3) Even with a pump, I have times when Bg is crazy! Does anyone else have that trouble? What helps you? Stress seems to be a factor as hormones. (CKD) I developed an upset stomach two days ago, and yesterday, I had a metallic taste in my mouth. At first, I thought I had a touch of food poisoning as I did not care for some veggie cakes I had for lunch. However, now I'm wondering if this is kidney related. Any information would be appreciated. (CKD) I am new (...). I had severe pain, nausea, sweats, and lethargy during the attack, feeling like passing out (especially standing) to start. Itching, loss of appetite, restless leg syndrome, memory/blank. It is not good. I had a couple of attacks where I could not get out of bed for days. Possible Stage 4 or 5?

Eudaimonic well-being	9 (OHC_T1D) 17 (OHC_CKD)	(T1D) If "I" could give one piece of advice to someone with a chronic condition, it would be grief. Falling apart and mourning the life before your diagnosis is perfectly acceptable. There will be plenty of time to be brave, courageous, and inquisitive. Get the grief out of the way first. Please do not put it off or deny it as I did years after my diagnosis because grief is inevitable. (CKD) Focus on how thankful you are for your wife and kids, and focus on doing things for and with them. Showing them how to deal with life's troubles will make them extraordinary people and help them worry less. Here is a good mantra for you, "I am strong, I am capable, I am thankful for my improving health, my family and each day that I am granted on this Earth." (NKF2) I am age 80. My mother lived until age 96. I aim to die as healthy as possible rather than win the "years until death contest." Whether you believe in God (as I do), when we pass to the other side, it is out of our hands.

Source: Authors' elaboration

3.5.1.2.2. Subtheme II - Well-being at the collective level

At the collective level, participants identified two dimensions of social well-being during the self-management stage: social integration and contribution (see table 3.8). Social integration relates to the relationship with the community/society. It is represented by participants expressing their capability to be a part of or close to the community. Social contribution represents the degree to which participants can offer something valuable to the world (their social value and contribution).

Table 3.8 – Subtheme II - Well-being at the collective level

First order concepts	N	Illustrations
Social integration	2 (OHC_T1D) 2 (OHC_CKD)	(T1D) After my diagnosis, I did not know another person with T1D and wished to talk to someone about the daily challenges and fears. The Internet opened my world and gave me confidence, compatriots, and support worldwide. Without the ability to get help online and share my thoughts and experiences, I would not be living well with Diabetes today. (CKD) The sharing you all did about your situations was inspiring and thought-provoking. What a generous community. I thought

		I knew what I wanted, but now I see that much more research and study needs to be done by myself.
Social contribution	3 (OHC_T1D) 2 (OHC_CKD)	(T1D) There was a time, probably as I was going through high school and college when I did not even want anyone to know I had Diabetes. However, it was not until after I got out of college that I realized I had an opportunity to educate others if they were asking about Diabetes. So now I am more than happy to tell people about it and its residual effects, such as kidney disease, heart disease, blindness, and nerve damage. (CKD) You will find a great group of people here to offer support. I was my husband's caregiver and living kidney donor, so I can offer that side if needed. I wish you the best, and you made a positive step forward by joining this group.

Source: Authors' elaboration

3.5.2. Mapping the expressed experience and well-being dimensions across the journey in OHCs

3.5.2.1. PX across the journey expressed in OHCs

The research aims to explore the expressed experience dimensions in OHCs by chronically ill patients (T1D and ESRF). Such experience dimensions are analysed through the lens of the patient journey, which encompasses multiple stages traversed over time by individuals before, during, and after service encounters.

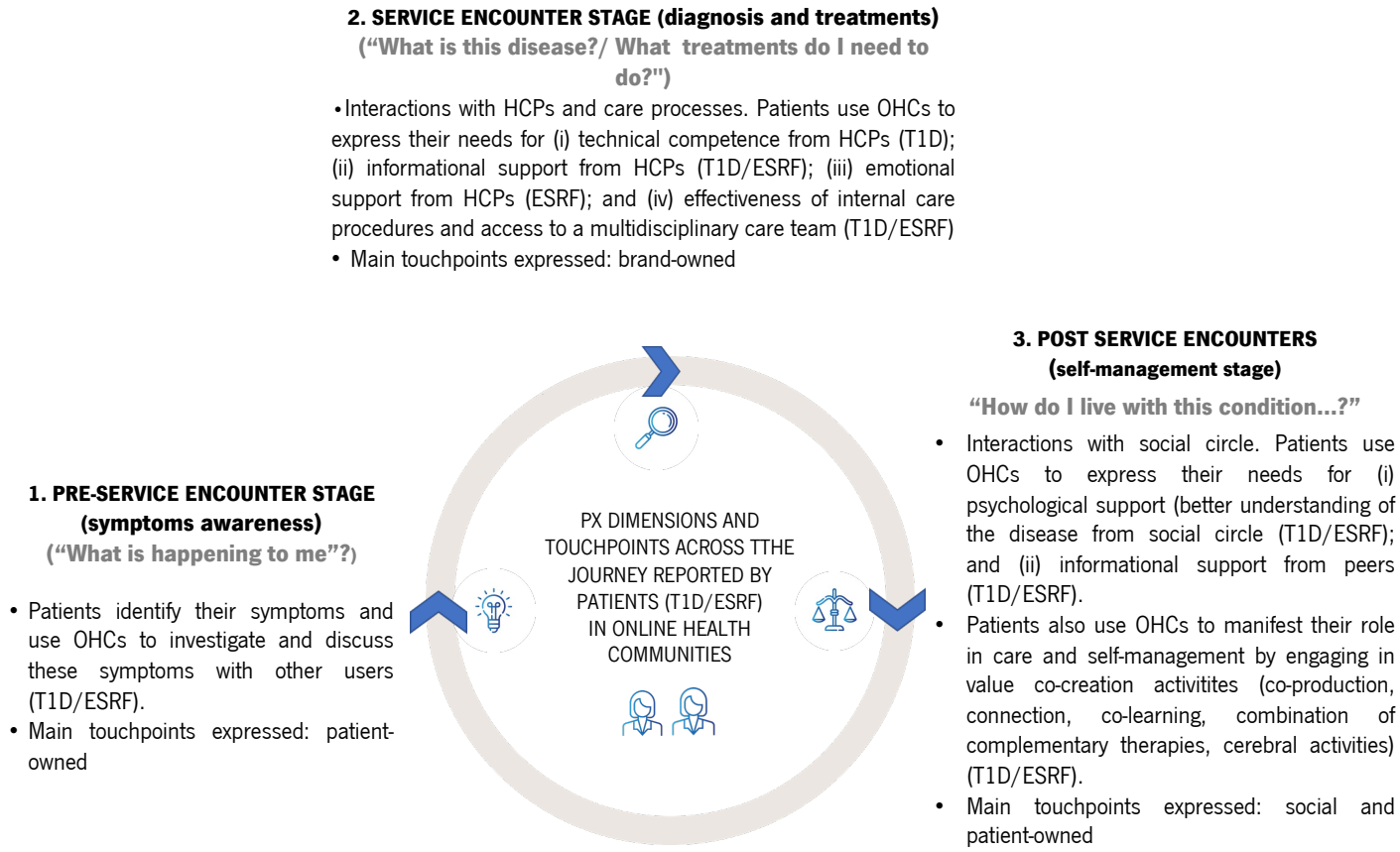
In the first stage, pre-service encounters ("What is happening to me?"), patients identify the symptoms, seek to explore them and find treatment options within OHC (patient-owned touchpoints).

The second stage entails the diagnosis and treatment stage ("What is this disease? What treatments do I need to do?"), including multiple outpatient consultations and patients interacting with HCOs and HCPs to receive the diagnosis and follow the prescribed treatments (brand-owned touchpoints). However, while interacting with HCPs and the care processes, patients experience issues and challenges in OHCs. In particular, groups of patients (T1D/ESRF) express the need for support from HCPs (informational and emotional) and also more adequate /effective care procedures (e.g., multidisciplinary team care). While the informational support (e.g., information about relevant topics such as drugs, symptoms, and nutritional plans) is emphasised by both groups, the emotional support is particularly enhanced by ESRF patients.

Lastly, the post-service encounter stage entails the self-management of the disease ("How do I live with this disease?"). This stage encompasses interactions with social actors and patients' activities/practices in dealing with and coping with the disease. Regarding the interactions with the social sphere, patients (both T1D and ESRF) express the need for more psychological support (better understanding and comprehension of the disease) from external actors (e.g., family, ICs, and friends) in OHCs. In particular, participants expressed a need for more knowledge and understanding about T1D and ESRF diseases. Moreover, participants report the need for informational support from the community, as they value receiving general information about the disease, advice for lifestyle management, and managing symptoms, medication, and technologies. At this stage, participants can engage in value-cocreation activities, including co-production, connecting, co-learning, combining complementary therapies, and cerebral activities.

Based on these findings, we developed a framework (see Figure 3.1) delineating the relationship between each stage of the journey and the most critical experience dimensions and touchpoints expressed by individuals living with chronic illnesses (T1D and ESRF).

Figure 3.1– PX experience dimensions/touchpoints across the journey reported by chronically ill patients (T1D/ESRF) in OHCs

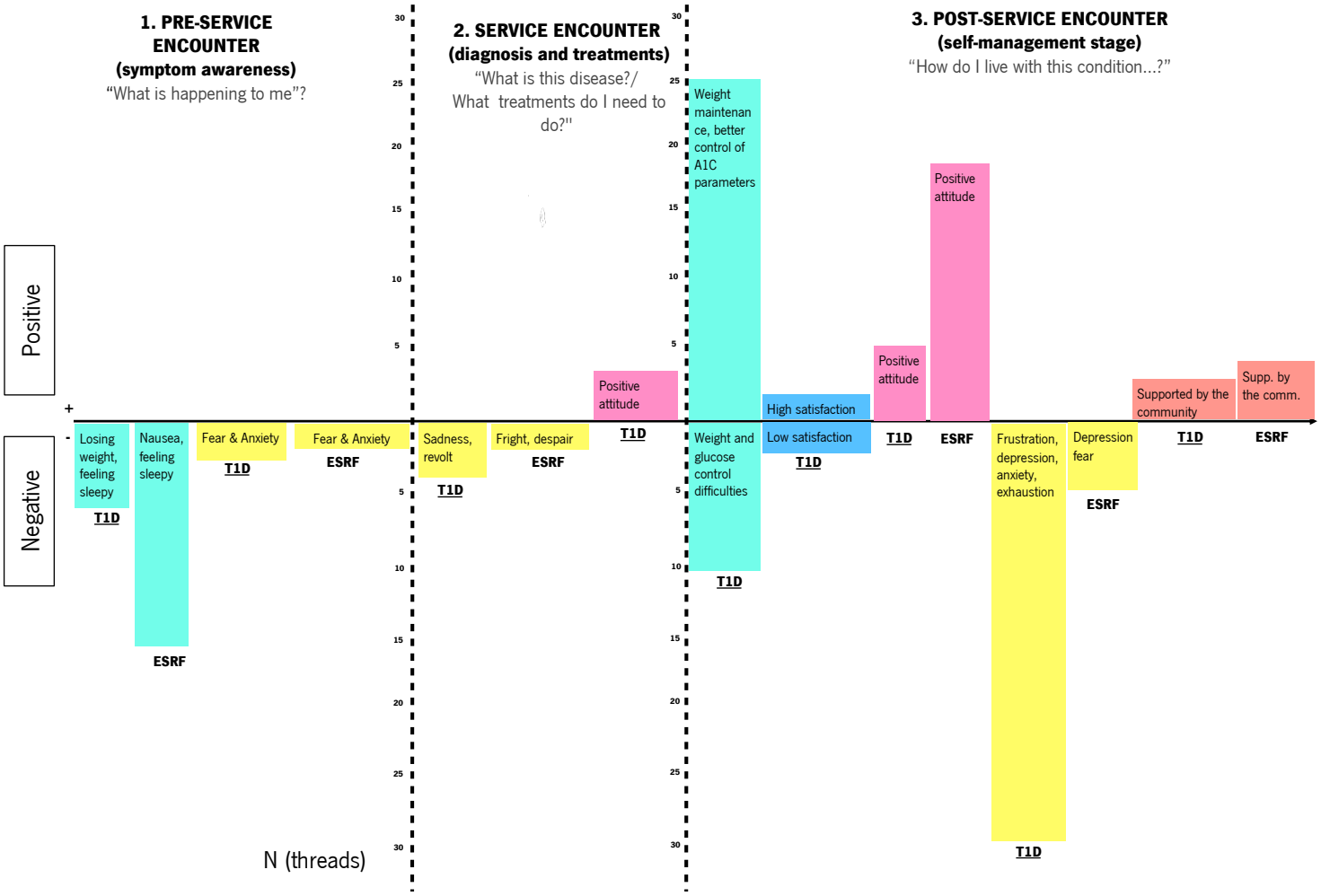


Source: Authors' elaboration

3.5.2.2. Well-being dimensions across the journey expressed in OHC

The findings demonstrate the link between each stage of the journey and the dimensions of well-being captured among chronically ill participants, specifically those with T1D and ESRF, within OHCs (see Figure 3.2). For individuals with T1D, five dimensions of subjective well-being emerge across their journey, encompassing cognitive, physical, affective, eudaimonic, and social. Notably, improvements in physical well-being, particularly in weight management and A1c parameters control facilitated by insulin pumps, are commonly reported. However, affective well-being is often characterized by negative emotions such as frustration, depression, anxiety, and exhaustion, predominantly stemming from societal misunderstandings of the disease among the general public, family, and friends. Conversely, individuals with ESRF exhibit expressions across four dimensions of subjective well-being: physical, affective, eudaimonic, and social. Physical well-being is marked by symptoms such as nausea and excessive fatigue. Eudaimonic well-being is notable for a positive outlook towards the future, encompassing goal-oriented behaviours and increased proactivity in managing their condition over time.

Figure 3.2 – Well-being dimensions across the journey expressed by T1D/ESRF patients in OHCs



Source: Authors' elaboration

Legend:

Physical well-being	Eudaimonic well-being
Affective well-being	Social well-being
Cognitive well-being	

3.6. DISCUSSION

This paper investigates the expressed experiences and well-being dimensions of chronically ill patients (T1D and ESRF) across touchpoints and stages of the journey within OHCs.

Reagrding the expressions of experience dimensions in OHCs, this study highlights three main subthemes. First, this study shows the pervasive need of chronically ill patients (T1D/ESRF) for more social support, including a better understanding and comprehension of the disease from others (e.g., family, ICs, and friends), and more literacy about their condition. These patients also seek for more informational support from others, such as receiving practical advice on medication and symptom management, sports and nutrition, and general information about the disease. These findings extend Coulson´s (2005) definition of tangible assistance to tangible online social support, which refers to the specific online activities that individuals may undertake for the benefit of others. In addition, these results both support and offer further insight into extant studies that highlight the power of OHCs to enable individuals to call for peer social support to share their illness stories in direct and explicit ways to provide learning for others and coping strategies throughout the illness experience (Gonzalez-Dolginko, 2016; Keim-Malpass & Steeves, 2012; McCosker & Darcy, 2013, Barlow et al., 2002)). Nevertheless, this study reveals three new topics: participants seeking informational support for managing health devices and technologies such as CGMs and insulin pumps (T1D), how to find and select health insurance, and how to succeed as ICs.

Overall, this study also identifies two main dimensions of the experience in OHCs: the pragmatic and empathic. The pragmatic dimension of the experience relates to functional goals such as seeking information and support. The empathic dimension of the experience entails the emotional fulfilment derived from interactions within the OHCs (Nambisan, 2011).

The study shows that chronically ill patients (T1D and ESRF) express their pivotal role in self-management by engaging in value co-creation activities (patient-owned touchpoints), including co-production, connecting, co-learning, combining complementary therapies, and cerebral activities, what goes in line with previous literature (McColl-Kennedy et al., 2012).

Second, chronically ill patients (T1D/ESRF) use OHCs to express their experiences not only outside, but also inside the boundaries of the HCOs. In particular, they report negative aspects of their service encounters and the need for more technical competence, emotional and informational support, and adequate /effective care procedures (e.g., multidisciplinary care teams). These findings highlight the significance of the patient-practitioner relationship, information exchange,

and communication in shaping the PX (Coyle & Williams, 1999; Crow et al., 2002), while underscoring the importance of support delivery and multidisciplinary approaches.

Lastly, the findings of this study show that chronically ill patients (T1D/ESRF) discuss their doubts and symptoms with others, aligning with the desire of chronically ill patients to understand and manage their symptoms effectively (Yu et al., 2019).

Regarding the expression of well-being states in OHCs, this study highlights two main subthemes: well-being at the individual level (the most expressive) and well-being at the collective level. Indeed, chronically ill patients (T1D/ESRF) mostly expressed in OHCs four dimensions of well-being at the individual level: (i) cognitive, (ii) physical, (iii) affective, and (iv) eudaimonic. At the collective level (social well-being), two main types were identified, such as (i) social integration (e.g., a sense of belonging to a group of social media acquaintances) and (ii) social contribution (e.g., opportunity for nurturance, assisting others). Indeed, this study corroborates that well-being is a multidimensional, multilevel concept (Farin & Nagl, 2013).

Results show that T1D patients use OHCs to manifest mainly physical well-being (positive parameters related to the disease) and affective well-being (negative feelings regarding the lack of social support/understanding about the disease). On the other hand, ESRF mainly uses OHCs to manifest eudaimonic well-being (positive attitudes toward the future) and physical well-being (negative physical moods due to the severity of symptoms).

This research shows how the PX and well-being relate to the journey stages. The initial stage, the pre-service encounter, involves the awareness of symptoms (patient-owned touchpoints). The subsequent stage, the service encounter, encompasses diagnosis and treatment, involving interactions with healthcare processes and professionals (brand-owned touchpoints) to receive the diagnosis and follow the prescribed treatments. Lastly, the post-service encounter is characterized by patients enrolling in self-management activities over time; that is, they manage the disease and develop coping mechanisms (patient-owned touchpoints), while seeking active social support from others, such as peers, family, and ICs (social-owned touchpoints)

This study brings several contributions. The research is focused on chronically ill patients, who are seen as vulnerable healthcare service users, therefore contributing to the emerging domain of TSR at the intersection of vulnerable healthcare service users and online third places (Rosenbaum & Smallwood, 2013). Our findings also contribute to recent theoretical discussions in the services

marketing literature around the need to move beyond service-dominant logic to understand services with little to no service-provider interaction (Strandvik & Heinonen, 2015).

This study extends previous research and provides some novelty potential by extending current studies focused on drivers and outcomes for participation in OHC. Indeed, this research illuminates what chronically ill patients (T1D and ESRF) express about their specific experiences and well-being dimensions across various touchpoints and journey stages, therefore contributing to advancing PX and healthcare service management literature.

Moreover, we conduct this research by using a netnography, which allows us to gather and explore the narratives of patients in an unobtrusive way within a naturalistic setting (Baker et al., 2005). It offers a valuable means of understanding PXs and well-being dimensions that may be challenging to capture through traditional face-to-face interviews (Rhoades et al., 2001; Sanders et al., 2011). This approach also enables us to gather insights into experiences in the present moment and reflections stemming from interactions with multiple peers, rather than from interactions with a single researcher. In other words, it offers a more authentic portrayal of how individuals and their ICs navigate and cope with chronic illness (Kirk & Milnes, 2016).

This research also has important implications for both patients and HCPs/HCOs. First, for patients and families/ICs, this research empowers them to search for additional knowledge and take a more active role in their healthcare management through the utility of obtained information in OHCs (Eysenbach & Diepgen, 1999; Hogg et al., 2004). Such enhanced knowledge may impact offline roles, enabling international comparison of treatments (Laing et al., 2005) and promoting more informed decisions by healthcare service users (Hall et al., 2015; Willis et al., 2016).

This study also suggests that OHCs supplement professional support, enabling patients and ICs to share experiences, feelings, and strategies for living with long-term conditions with peers and develop the expertise to empower them in interactions with healthcare professionals (Kirk & Milnes, 2016).

The narratives shared by patients within OHCs present numerous opportunities for HCPs to gain deeper insights into the needs and challenges encountered by patients (Gurrieri & Drenten, 2019). Professionals can utilize the results of this study to collect insights from what patients share in OHCs that help to design more effective treatment modalities, improve services, and interact more meaningfully with their patients (Nambisan & Sawhney, 2009; Winkelman & Choo, 2003). Patient narratives can also extract important information regarding improving or innovating HCO's services (Nambisan & Nambisan, 2009; Winkelman & Choo, 2003). By actively engaging with these

supportive communities, HCPs can acquire valuable insights into improving the management of brand-owned touchpoints, particularly regarding support delivery, both during and after care service encounters (Gurrieri & Drenten, 2019) and conducting a more egalitarian communication characterized by equality, respect, and openness among participants (Fox, Ward, & O'Rourke, 2005) and harmonious relationship (Smailhodzic et al., 2016). Furthermore, this research opens new perspectives of HCOs creating their OHCs for patients to discuss helpful information, experiences, complementary and alternative therapies, and new technologies. Also, healthcare service users can collaborate with HCOs to develop informational content that can be shared with wider audiences, in turn facilitating understanding about specific procedures and working to allay concerns and fears that may arise because of this information remaining hidden (Gurrieri & Drenten, 2019).

3.7. LIMITATIONS AND FUTURE RESEARCH AVENUES

While this research has revealed several noteworthy findings and contributions, certain limitations that pose challenges for future research must be acknowledged.

3.7.1. Broadening the domains of data collection

First, the study sample included only OHCs that have origins in the USA and are highly reputed, and this might limit the generalizability of the study findings to other OHCs. Therefore, future research could examine experiences and well-being dimensions in OHCs from other geographical contexts, especially those outside the USA. Also, as this study focuses on two specific chronic conditions, future research could be focused on other illnesses beyond T1D and CKD.

Second, most netnographic marketing studies are conducted on traditional online discussion forums. As the uses of the Internet have evolved, different domains of data collection for netnography have emerged. For example, different review sites now constitute an essential source of information for service customers and have become valuable domains for data collection in netnographic studies (Björk & Kauppinen-Räisänen, 2012; Hamilton et al., 2011). Moreover, as the social media trend grows, many social networking sites have developed into exciting platforms for netnographic research. Instagram has been used in some netnographic studies (e.g., Gurrieri & Drenten, 2019). However, service researchers would benefit from closely examining other social networking sites like Twitter, YouTube, and Pinterest. In addition, mobile apps, such as WhatsApp, Facebook Messenger, or Telegram, offer new domains for netnographic data collection. The mobile context becomes increasingly relevant for netnographic research as mobile internet use proliferates worldwide (Heinonen & Medberg, 2018).

3.7.2. New methodological combinations

With the increasing dynamism and online social interaction, combining traditional offline methods with ethnography often makes sense. As mixed-methods approaches have proven helpful in marketing (Bahl & Milne, 2006; Harrison & Reilly, 2011), more such research is encouraged. Combinations can generate insights beyond what the original methods themselves could produce. Therefore, future research using netnography can be combined with, for example, surveys (Chan & Li, 2010) (e.g., chronically ill patients participating in surveys in OHCs) and in-depth interviews

to facilitate direct questions to chronically ill patients about their experiences and well-being throughout their journey).

3.7.3. Longitudinal approaches

The findings relate to two OHCs for two long-term conditions during a month. Therefore, longitudinal design could be used to monitor experiences and well-being over time. Longitudinal research offers the possibility of capturing and understanding changes in customers' processes, but it is seldom used because of the time and cost involved (Bryman & Bell, 2011).

3.7.4. Broadening unit of analysis - from text to non-text content

Future netnographic studies should explore content from forum discussion threads and non-text content, such as pictures and videos. This gives researchers a larger and more complete picture of the phenomenon under study, which is related to the experiences and well-being expressions across the journey of chronically ill patients. This is because pictures and videos have gained popularity as a means of online communication. For example, (Kedzior, 2014) gathered all these data types in his study on customers' experiences of the digital world. Moreover, customers' photos and videos produced and shared online provide excellent opportunities for service researchers to understand different service offerings from the customer's perspective. When reporting such research findings, including the visual data, and finding a suitable balance between images and text (Ball & Smith, 1992). Audio material is also worth considering. In addition to text, videos, and photos, Healy & Beverland (2013) collected digital audio recordings from relevant websites in their study on the furry subculture. Using textual, visual, and audio data sources gave the authors a holistic view of this subculture's online behaviour.

4. CHAPTER IV (ESSAY III)

Understanding and Managing the Experience of Chronically ill Patients throughout the patient Journey: what really matters? Insights from participants

CHAPTER 4. UNDERSTANDING AND MANAGING THE EXPERIENCE OF CHRONICALLY ILL PATIENTS THROUGHOUT THE JOURNEY: WHAT REALLY MATTERS? INSIGHTS FROM PARTICIPANTS (ESSAY III)

4.1. ABSTRACT

The patient experience (PX) unfolds within complex journeys involving multiple stakeholders engaged in service provision. Given its holistic and dynamic nature, PX encompasses myriad interactions across all facets of the healthcare system, spanning various encounters and settings and extending beyond the confines of hospital contexts. PX transcends the traditional care provider-patient dyad to encompass additional value networks and resources, including the involvement of friends, family, fellow patients, and communities. However, more empirical work is needed on this topic. Most studies focus on the healthcare service perspective, mainly contributing to improving processes and service quality dimensions. Indeed, as patients' experiences in their healthcare journeys are not always well understood, it is essential to document patients' journeys across program and organisational boundaries. Lastly, the study of the holistic experiences of chronically ill patients, known as vulnerable healthcare consumers, is also an overlooked research domain- Even though some studies have adopted the patient's perspective and investigated the experiences of chronically ill patients from the lens of the journey, the majority of the research focuses on a single stage of the process, especially during service encounters, therefore neglecting the totality of the PX, that is, all the interactions across all the stages.

Therefore, this study undertakes an Interpretive Phenomenological Analysis (IPA) for a comprehensive examination of the holistic experience of individuals with chronic illnesses, precisely Type 1 Diabetes (T1D) and End-Stage Renal Failure (ESRF), throughout their journey. The research collects and integrates the perspectives of patients, informal caregivers (ICs), and healthcare providers (HCPs) from a Public Hospital in Portugal (Hospital of Braga) (n=38), employing a mixed qualitative methodology and triangulating data from various sources. The study's empirical findings unveil critical insights into PX across multiple spheres – brand, patient, social, partner, and external – traversing the three stages of the journey. At pre-service encounters, patients identify symptoms and search for care (patient-owned touchpoints). During the service encounters, the study highlights the pivotal role of interactions with processes and staff (brand-owned touchpoints). Enhancing the effectiveness of care delivery, encompassing aspects such as timeliness, access to

and communication with the hospital, and strong response capacity, proved imperative to foster a positive PX. Furthermore, HCPs establish meaningful relationships with patients by offering emotional, technical, and psychosocial support and demonstrating availability, which also positively influences the experiences of chronically ill patients.

The hospital information systems/technologies (partner-owned touchpoints) are also critical in enhancing the effectiveness of service encounters with HCPs. The COVID-19 pandemic (external influence), acting as an external influence, facilitated the adoption of telehealth, enabling HCPs to enhance interactions with patients unable to attend medical consultations. Lastly, the post-service encounters stage relates to the role of patients in care and self-management (patient-owned touchpoints). Patients face the challenges of managing daily disease-related issues, including technological devices, dietary habits, physical activity, and medication adherence. Moreover, patients must adapt their lifestyles to accommodate chronic illness, engage in activities promoting physical and mental well-being, augment knowledge, and develop coping strategies. This stage also encompasses the influences of the social circle (social-owned touchpoints). Patients typically feel a lack of support from others due to the higher level of disinformation and stigma towards these diseases.

Overall, the most overarching theme was the interactions between HCPs and care processes (brand-owned touchpoints) during the service encounter stage, followed by the role of patients in care and self-management (patient-owned touchpoints) and the influences of the social circle (social-owned touchpoints), both in post service encounters.

This research significantly contributes to the literature on healthcare service research and PX by elucidating how touchpoints shape the experiences of chronically ill patients throughout their journey. The study proposes patient journey models tailored to the two chronic conditions under investigation and a set of practical recommendations and guidelines for the hospital under study to improve the management of PX, thereby enhancing service delivery and well-being outcomes and inspiring other similar healthcare institutions. Lastly, future research directions in this domain are delineated.

Keywords: Patient experience, patient journey, chronic disease, healthcare services

If 'patient experience' is a topic whose time has come, 'patient journey' is a topic whose time is overdue.

(Lamprell & Braithwaite, 2016, p.1)

4.2. INTRODUCTION

Patient experience (PX) is emerging as an essential focus area for researchers and healthcare practitioners (Trenchard et al., 2019). The rapid expansion of the PX concept has been encoraged by the rise of a new consumer mindset (Wolf et al., 2014), in which experience is a crucial driver for healthcare consumer making. Indeed, the decision-making process of healthcare consumers is fundamentally rooted in their need to feel their experiences recognized and valued (Wolf, 2018b).

Patients today engage with the healthcare system across various touchpoints through numerous settings and channels. Indeed, PX goes beyond the care provider-patient dyad to capture additional value networks and resources, such as friends, family, other patients, and communities. The underlined concept here is the patient journey, which defines the set of stages through which the patient goes from the moment he/she perceives symptoms and decides to schedule a medical appointment until the end of the service, also including the moments after medical appointments and when they are managing their condition daily day (Wolf et al., 2014). Understanding and managing the holistic PX is essential to improve healthcare services delivery and generate critical well-being outcomes for patients and families (Anderson et al., 2012; Ponsignon et al., 2015, 2018; Rosenbaum, 2015).

Overall, research on PX is still dominated by the organisational perspective which focuses on capturing the feedback of patients regarding their interactions with the elements of care (e.g., respect, information and communication, physical comfort, emotional support, and access to care) through questionnaires and surveys (Ahmed et al., 2014). Also, it focuses on how to design PXs and underlying internal processes to improve the efficiency and effectiveness of care (Anhang Price et al., 2014). Yet, this viewpoint fails to consider the holistic and multidimensional nature of PX, which encompasses interactions between patients and HCPs across various touchpoints and channels extending beyond the boundaries of the healthcare organisation's context (Ponsignon et al., 2018). In addition, PX encompasses more than just interactions between patients and HCPs to include the involvement of additional value networks and resources such as friends, family, other patients, and communities.

Despite the increasing attention devoted to holistic PX as incorporating the patient journey as a whole, there are still few empirical studies on this domain (LaVela & Gallan, 2014). Therefore, the literature calls for studies focusing on PX throughout the patient journey, and, therefore, on understanding patient behaviour, explaining underlying psychological processes (Kranzbuhler et al., 2018) and comprehending patients' subjective experiences as they transit through the services that comprise health systems (Ponsignon et al., 2018). Moreover, the use of qualitative approaches to discover and explore the PX as a whole can provide valuable information for practitioners and researchers (Cognetta-Rieke & Guney, 2016). Unlike PX data gathered in questionnaires and surveys, which often cannot encompass that breadth and depth (Karassavidou et al., 2009; Rashid & Jusoff, 2009), qualitative data express the deeply personal, narrative nature of the journeys that patients take, creating opportunities for qualitative healthcare research.

Furthermore, patient journeys must incorporate the perspectives of patients themselves and the internal resources of HCPs (Folstad et al., 2013). Existing literature focuses on either one of these groups exclusively: either on internal professionals (e.g., Clatworthy, 2011; Wechsler, 2012) or patients (e.g., Crosier & Handford, 2012). Nevertheless, these two participant groups can provide complementary insights. By juxtaposing healthcare professionals' internal expectations with patients' actual experiences, significant discrepancies (Bitner et al., 2010) in service delivery may emerge, thus facilitating the identification of areas for improvement in the service delivery process. Researchers, clinicians, and policymakers have much to gain from addressing the holistic PX across the journey, especially when health conditions take patients into chronic states (Lamprell & Braithwaite, 2016). In fact, the concept of the patient journey in healthcare has gained attention with the rising prevalence of chronic illnesses. This is primarily due to the prolonged nature of these illnesses and the frequent presence of multiple co-existing conditions, which exacerbate the complexity of the journeys (Brand, 2018). For instance, conditions like chronic kidney diseases or diabetes often require ongoing management and involve the coordination of care among various HCPs. Also, the literature suggests that patients with chronic conditions are disappointed by the lack of availability of HCPs and, often feel neglected and not treated with compassion (Berglund et al., 2010; Wessel et al., 2012).

Exploratory studies add that most participants report experiencing a total lack of post-discharge care coordination, which leads to feelings of anxiety and uncertainty (Benham-Hutchins et al., 2017). However, to our knowledge, only a few qualitative studies have empirically explored patients' experiences with chronic illnesses along the journey.

Among the empirical studies that explore the experiences of chronically ill patients using the patient journey as a theoretical lens, some focus specifically on certain phases of the journey, such as cancer diagnosis (e.g., Leydon et al., 2003), and on analysing the evolution and influence of specific touchpoints throughout the phases of the journey, such as the communication dynamics and processes effectiveness (e.g., Berglund & Westerlund, 2016; Boyd et al., 2012). In the medical and PX literature, it is possible to find some studies that take a more holistic approach and seek to map the experience of patients with chronic conditions throughout their journey (e.g., (Manchaiah & Stephens, 2012). However, these studies do not allow us to differentiate between types of touchpoints or organise them into categories based on the degree of control of the organisation, and such distinction is relevant, in the sense that it allows for a better understanding and management of PX.

Based on the identified knowledge gaps in the literature and building on CX definitions and conceptualizations (e.g., Lemon & Verhoef, 2016), we draw on the notion of PX as having a holistic nature, involving complex, social and dynamic interfaces and natures and occurring throughout the patient journey. Indeed, this qualitative study aims to analyze PX throughout the patient journey, by exploring chronically ill patients' cognitive, affective, emotional, social and physical responses to any direct or indirect contact with the service provider across multiple touchpoints during the journey, inside and outside the healthcare context (Danaher & Gallan, 2016; Wolf et al., 2014). In this study, we investigate the holistic PX by integrating the perspectives of multiple participants. Our research questions are as follows:

RQ1. How do the experiences of chronically ill patients unfold throughout their journey?

RQ2. How do different touchpoints influence the experience of chronically ill patients throughout the journey?

RQ3. How can the experience of chronically ill patients be managed to generate service delivery improvements and well-being outcomes?

Through these research questions, we aim to explore how the experience of chronically ill patients occurs throughout the different stages of the journey while considering its rich, holistic and multidimensional nature. We explore how different touchpoints influence the PX throughout the journey and propose two journey maps adapted to the chronic conditions under study. We establish routes for HCPs and HCOs to develop a PX response orientation. Our research presents important implications by proposing guidance for future care service research and managerial implications for healthcare institutions.

4.3. CONCEPTUAL BACKGROUND

4.3.1. Patient experience: a fertile field of research

Healthcare services are a part of everyone's life, directly affecting their daily routines and long-term well-being. These characteristics make them a crucial aspect of consumer experiences (Berry & Bendapudi, 2007; Danaher & Gallan, 2016). Indeed, the healthcare sector provides a fruitful context for exploring new theories and concepts in marketing and consumer research, particularly in understanding the consumer (patient) experience (Dodds et al., 2018). PX is increasingly recognized as a vital focus area for researchers and an important management goal across healthcare practitioners (Beattie et al., 2015; Danaher & Gallan, 2016; Ostrom et al., 2015).

The widespread adoption of the PX as a research field has been derived from three primary factors, namely (1) the challenging roles and complex condition of patients (Padma et al., 2009); (2) technology advancements in healthcare (Anderson et al., 2018) and (3) the resource constraints and pressures encountered by HCPs (Dobele & Lindgreen, 2011).

Although there is growing interest in the subject, there is still a lack ok consensus and a of a globally accepted definition of PX in healthcare. Research into the PX concept has progressed through two contrasting theoretical viewpoints, resulting in different research streams focusing on either healthcare service providers or the perspective of patients (LaVela & Gallan, 2014; Wolf et al., 2014). The first – the healthcare service provider perspective - assumes that experiences are designed and that patients will perceive the elements of care. Within this perspective, focal constructs include the healthcare environment, patient-care services interactions, organisational culture and context. Also, according to this view, the PX can be conceptualized as a patient's experiences of care and as the feedback from the patient, about these experiences with elements of care (Ahmed et al., 2014). Research methods used by studies that adopt the organisational view of PX are predominantly quantitative (surveys) and focus on measuring the impact of healthcare dimensions /features on PX.

In contrast to the healthcare service provider perspective, the patient perspective focuses on understanding patient behaviour and explaining underlying psychological processes (Kranzbuhler et al., 2018). The critical assumption of this view is that value is idiosyncratic, experiential and contextual (Vargo et al., 2017). The healthcare service provider and patient may coproduce service during this journey, but the PX of health extends well beyond the healthcare provider-patient dyad

to involve the patient´s own cognitive and emotional resources as well as resources from friends, family, and other patients and from other organisations and the community (McColl-Kennedy, 2015; McColl-Kennedy et al., 2012; Sweeney et al., 2015). It means that the patients can have a much more active role in their care by contributing with a range of personal resources such as information and knowledge, and by engaging in a range of activities by themselves and with others to improve their health and well-being (McColl-Kennedy et al., 2017b). The focal constructs within the patient's view include environmental and personal factors, cognition, affect, senses and patient journey. Building on the CX literature, scholars have come to agree that in a healthcare context, PX occurs throughout the patient journey, which begins from the first-time patients consider where they are going to get their care and ends when they leave the clinic/hospital context to manage their care at home (Luxford & Sutton, 2014). Indeed, this viewpoint contrasts with the previous one (service provider perspective) by considering the holistic and multidimensional nature of PX, including many points of interaction and occuring in all facets of the healthcare system, in all encounters, in all settings, and beyond the frontiers of hospital context (Ponsignon et al., 2018; Wolf et al., 2014).

However, despite the increasing interest in the patients' view, the service provider's view still dominates most PX empirical research. Therefore, as there are still gaps in our understanding of patients´ experiences as they engage with and transit through the healthcare environments implicated in their trajectories, investigating PXs across silos of care based on the journey may be a valuable approach (Lamprell & Braithwaite, 2016).

4.3.2. Establishing the realm of PX as holistic and occurring across the journey

Drawing on the patient view and incorporating insights from CX literature, PX can be characterized as being holistic and dynamic in nature, consisting of the patient's journey over time and across multiple touchpoints. The journey occurs in multiple service cycles (Siebert et al., 2020) and can be conceptualized in three generic high-level stages: pre-service encounters, during service encounters and post- service encounters.

In each stage of the journey, patients experience and interact with different types of touchpoints, only some of which are under the clinic/hospital control (Lemon & Verhoef, 2016). Thus, the patient journey aims to identify the key interactions and their meanings from the patient's perspective, not restricting the analysis only to what happens inside the boundaries of the healthcare context. In the first stage, pre-service encounter, patients notice a symptom and become

familiar with a troublesome body ((Schildmeijer et al., 2018) and consider where to get care (alternatives of service providers) (Luxford & Sutton, 2014). The second stage – during service encounters – involve all the interactions with the healthcare service providers, including undergoing procedures, interacting with the physical environment, and health staff (e.g., Berglund & Westerlund, 2016) and the customer value co-created in healthcare service delivery process (e.g., Kim, 2018). The last stage – post-service encounters – involves activities such as patients providing feedback, following up on the service received, seeking additional support or information, scheduling future appointments or services, and engaging in value co-creation activities (McColl-Kennedy et al., 2012). It extends from the service encounters to the end of the patients' life, therefore constituting the largest portion of the journey (Lemon & Verhoef, 2016). In each journey stage, patients might interact with several touchpoints. In CX literature, touchpoints can be broadly understood as episodes of direct or indirect contact with the brand" (Baxendale et al., 2015, P.236) groups of experiential aspects (Berry et al., 2006); or as verbal or nonverbal interactions that an individual consciously associates with a specific company or brand (Duncan & Moriarty, 2006). Touchpoints can also be classified based on the subject that manages and controls them (the company itself, a business partner of the company, the customer, or external factors). Adapting this view to the healthcare context, we can identify four categories of experience touchpoints: brand (hospital)-owned touchpoints, partner-owned touchpoints, customer (patient)-owned touchpoints, and social/external touchpoints. In this case, hospital/brand-owned and partner-owned touchpoints would be more internal-initiated, whereas the patient-owned and social/external touchpoints would be more external-initiated (Lemon & Verhoef, 2016).

Regarding the brand (hospital)-owned touchpoints, HCOs can use and take advantage of digital marketing, internet tools, search engines and social media to influence healthcare consumers in seeking care and selecting the healthcare provider (Purcarea, 2019). Moreover, during service encounters, several service dimensions exert influence on PXs, including the physical environment (physical evidence), interpersonal care activity (people/staff), technical processes and administrative procedures (processes), service communication (promotion), service charge (price), access convenience (place) and social responsibility (ethical dimension).

Partner-owned touchpoints are considered interactions during the experience that are jointly designed, managed, or controlled by the organisation and one or more of its partners, such as agencies, multichannel distribution partners, technology and communication channel partners (Lemon & Verhoef, 2016). For example, hospitals can establish partnerships with medical

insurance companies, which make it more affordable for patients to see a medical specialist (Mosadeghrad, 2014; Vu et al., 2016).

Patient-owned touchpoints are patient actions/activities that are part of the overall PX but that the organisation, its partners, or others do not influence or control (Lemon & Verhoef, 2016). Patient-owned touchpoints can occur before service encounters, including patients first noticing a symptom, thinking about their health needs, and seeking to see a healthcare provider. However, they become more critical and prevalent during and after the consumption of care, when patients engage in value co-creation activities, such as cooperating with HCP, showing compliance with medical instructions, managing the practicalities of life, emotion regulation, and relationships with family and friends (e.g., McColl-Kennedy et al., 2012; Sweeney et al., 2015).

Social-owned touchpoints recognize the critical roles of others in shaping PX. Throughout the experience, patients are surrounded by external touchpoints (e.g., other patients, family, friends, and environments) that may influence their decision process, feelings and experiences (Lemon & Verhoef, 2016). Third-party information sources influence patients, such as online health communities (OHCs) and social media (Keeling et al., 2013).

Lastly, it is also essential to consider how dynamics and external influences impact the overall PX. Past experiences can affect current experiences through expectation formation and stickiness in experience evaluations (Lervik-Olsen et al., 2016) at each stage of the experience. For example, the literature suggests that prior experiences of others also influence the experience and perception of a healthcare service organisation's brand, which in turn positively influences the perception of quality and value, satisfaction, loyalty, willingness to recommend and positive word-of-mouth (WOM) (e.g., (McColl-Kennedy et al., 2018; Wheelock et al., 2014) The dynamic external environment can also have a significant influence on PX, such as in the case of extreme crises (e.g., COVID-19 pandemic) or economic situations (i.e., recession) that can have a strong, negative, and enduring effect on the PX (Hunneman et al., 2015; Ou et al., 2013).

4.3.3. PX across the journey applied to the context of chronic illnesses

Researchers, clinicians and policymakers have much to gain from exploring patients' experiences throughout their journey, especially when health conditions take patients into chronic states. Chronic illnesses are defined as conditions that last a year or more, require ongoing medical attention, and limit activities of daily living (Goodman et al., 2013) and include a broad range of physical illnesses (e.g., arthritis, asthma, chronic respiratory conditions, diabetes, heart disease,

chronic kidney disease and hypertension). These chronic conditions significantly impact individuals, their families, and the health service (Golics et al., 2013). There is also evidence that strategies to engage, support and empower people with chronic conditions are essential in improving health outcomes (e.g., Epping-Jordan et al., 2004).

Overall, studies that conduct a qualitative research on experiences of chronically ill patients throughout the journey (see Table 4.1) focus on exploring (1) the experience at specific stages of the journey such as pre-service encounters (e.g., Leydon et al., 2003); (2) how specific needs for touchpoints evolve throughout the journey, such as the communication process and dynamics and digitalisation (e.g., Maas et al., 2023; Mitchell et al., 2018); and (3) the PX as a whole, throughout the all the stages of the journey (e.g., Broughton et al., 2017; Walker et al., 2017) also involving healthcare professionals to identify areas of convergence and divergence of perspectives (e.g., (Berglund & Westerlund, 2016a; Manchaiah & Stephens, 2012). For example, Broughton et al. (2017) investigated how patients undergoing chronic fatigue syndrome (CFS/ME) perceived their journey through interviews with 16 adults receiving treatment at one of three outpatient NHS specialist CFS/ME services. The findings revealed various factors shaping participants' experiences, such as personal traits like determination and hopefulness and service-related aspects like adaptability and positive and supportive relationships with clinicians and medical professionals. Participants expressed how these specialised services played a crucial role, given the contested nature of the condition. Many participants also mentioned a need for acknowledgement, medical assistance, and social support before accessing such specialised care. Ultimately, the study highlighted the significant role of NHS specialist CFS/ME services in enhancing patients' quality of life through validating their experiences, embracing change, offering practical guidance and assistance, and fostering therapeutic outcomes.

In addition, Walker et al. (2017) conducted a study aimed at investigating the experiences of patients living with chronic obstructive pulmonary disease (COPD) and their perceptions of community healthcare services for COPD in order to elicit emotional reactions and generate potential items for a patient-reported experience measure specific to COPD. The research involved qualitative face-to-face interviews with 64 COPD patients in the United Kingdom. Analysis of the interview data revealed five overarching themes: 'Journey to diagnosis', 'Smoking', 'Usual care', 'My everyday life', and 'Exacerbations'. Within these themes, twenty-one affective responses were identified and categorised as either 'negative', 'positive', or 'bivalent'. Notably, 'Frustration' emerged as a prevalent negative affective response across four themes. Conversely, 'Gratitude', 'hope', and

'happiness/enjoyment' were identified as more prevalent positive responses, spanning multiple themes in the interview data.

Lastly, the study of Manchaiah & Stephens (2012) examined the journey of adults with gradual onset acquired hearing impairment. Data were collected from 16 audiologists and from 4 adults with sudden onset acquired hearing impairment through semi-structured interviews. A patient journey template for sudden onset acquired hearing impairment was developed based on crossing the professionals' and patients' perspectives. The study identified six key phases that patients with sudden-onset acquired hearing impairment will likely to go through: awareness, movement, diagnostics, rehabilitation, self-evaluation and resolution. The main difference between these two groups' perspectives was seen in the self-evaluation phase: some stages within this phase were recognised by the patients rather than the professionals.

Even though these studies focus on the patient journey, they present pitfalls, as they do not categorise or classify the different types of interactions into touchpoint categories. The main advantage of identifying and classifying touchpoints is to help organisations (in this case, hospitals) better understand their nature and how they can be better managed and influenced. Therefore, this study aims to transpose insights from the CX literature to explore the experiences of chronically ill individuals across their journey and identify how the different categories of touchpoints (brand/hospital-, patient-, partner, social and external-owned) influence and shape PXs.

Table 4. 1 - Representative qualitative studies on experiences of chronically ill patients across the journey

Conceptual studies			
Author(s), title and journal	Purpose	Method	Main conclusions /contributions
Lamprell & Braithwaite (2016). Patients as storytellers of healthcare journeys. *Medical humanities*	Provides investigation of a story-telling model that could facilitate patients to narrate their experiences of healthcare systems	Conceptual	Explores the role of patients as storytellers in healthcare journeys and highlights how patients' stories provide valuable insights into their emotions, perspectives, and interactions within the healthcare system. They propose a journey model derived from the literary arts. The authors present a new idea for applying this model as a narrative structure by which patients may construct their stories about being in and moving through the healthcare system.
Luxford & Sutton, (2014). How does patient experience fit into the overall healthcare picture? *Patient Experience Journal*	Addresses the integration of PX within the broader healthcare context (moved from 'nice' to 'necessary').	Conceptual	Examines the evolving landscape of healthcare delivery and discusses the multifaceted nature of PX, which encompasses clinical interactions and factors such as communication, accessibility, and emotional support. The authors also highlight the importance of systematically capturing and analyzing patient feedback to drive continuous improvement in healthcare services. They advocate for a holistic approach that integrates PX data with clinical outcomes and operational metrics, facilitating informed decision-making and enhancing overall healthcare quality. The article underscores the transformative potential of prioritizing and designing PX into the expanding care continuum, ultimately leading to improved patient outcomes, greater satisfaction, and enhanced organisational performance.

Wolf et al. (2014) Defining patient experience. *Patient Experience Journal*	Explores the multifaceted nature of PX, emphasizing its subjective and dynamic dimensions and determine the extent to which clear and formal definitions of PX exist.	Conceptual	Defines PX as the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care. They highlight key elements of PX, including clinical interactions, communication, physical environment, emotional support, and care coordination. The authors also underscore the importance of understanding PX from the patient's perspective, emphasizing the role of empathy, respect, and dignity in shaping perceptions of care quality. Furthermore, the article delineates the distinction between PX and patient satisfaction, emphasizing that while patient satisfaction reflects perceptions of care received, PX encompasses the entire journey of care delivery. The authors stress the need for HCOs to prioritize PX as a strategic imperative, integrating patient feedback into quality improvement initiatives and fostering a culture of patient-centered care.

Empirical qualitative studies			
Focus on specific stages of the journey			
Author(s), title and journal	Purpose	Method	Main conclusions and contributions
Leydon et al., (2003).The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of cancer care*	Provides an insight into the time between first noticing a symptom, attending a healthcare provider and obtaining a cancer diagnosis.	Focus groups (n=16) and interviews (n=17) with cancer patients, UK.	Investigates the emotional and practical experiences of individuals diagnosed with cancer, as well as the experiences of their family members and ICs, throughout the journey towards diagnosis. The article explores the multifaceted challenges and coping mechanisms encountered by those affected by cancer from the initial suspicion of symptoms to the confirmation of diagnosis. Participants recount their emotional responses, interactions with healthcare professionals, communication within their support networks, and coping strategies amidst the uncertainty and distress associated with the diagnostic process. Overall, the article highlights the profound impact of the diagnostic journey on individuals with cancer, their family members, and caregivers. The study elucidates the challenges of navigating the healthcare system, managing emotional distress, and adjusting to the implications of a cancer diagnosis on various aspects of life. Furthermore, the article underscores the importance of effective communication, support networks, and patient-centered care in facilitating coping and adjustment throughout the diagnostic journey.

Focus on specific touchpoints dynamics across the journey			
Author(s), title and journal	Purpose	Method	Main conclusions and contributions
Mitchell et al. (2019) From telling to sharing to silence: A longitudinal ethnography of professional-patient communication about oral chemotherapy for colorectal cancer. *Psycho-Oncology*	Examines the changing dynamics of communication through the patient's journey from diagnosis of colorectal cancer to posttreatment of chemotherapy	Observation (60 hours of observational data from interactions between 15 HCPs, 8 patients and 11 family members over a 6-month period; Semi-structured interviews with patients (n=16); Focus groups with HCPs (n=3); UK	Examines the evolution of communication patterns over time, focusing on transitions from initial information provision to ongoing dialogue and potential periods of silence within the professional-patient relationship. Authors observe and document interactions between HCPs and patients throughout the trajectory of oral chemotherapy treatment for colorectal cancer. They analyze the nuances of communication exchanges, including the manner in which information about treatment options, side effects, and supportive care measures is conveyed and received by patients. Authors found shifts in communication dynamics, from the initial stages of information sharing to subsequent phases characterized by increased patient autonomy, shared decision-making, and potential lapses in communication leading to periods of silence.

Maas et al. (2023) The never-ending patient journey of chronically ill patients: A qualitative case study on touchpoints in relation to patient-centered care. *PLos ONE*	Investigates the chronically ill patients' needs for digital alternatives for touchpoints. Specifically, the study explores which digital alternatives patients would like to see implemented into their patient journey to help healthcare professionals providing patient-centered care (PCC).	Case study - semi-structured interviews (n=8) and documental analysis. Netherlands	Investigates the ongoing journey of individuals living with chronic illnesses, with a particular focus on digital touchpoints within the context of patient-centered care. The research aims to understand the experiences of chronically ill patients and the role of digital touchpoints in their healthcare journey. The research explores how digital touchpoints influence PXs, engagement with healthcare services, and overall satisfaction with care delivery. It examines factors such as usability, accessibility, effectiveness, and perceived value of digital touchpoints in facilitating patient-centered care. Additionally, the study investigates the integration of digital touchpoints into existing healthcare systems and their impact on care coordination, communication between patients and providers, and self-management of chronic conditions.

Focus on the journey as a whole			
Author(s), title and journal	Purpose	Method	Main conclusions and contributions
Broughton et al., (2017) Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): a qualitative study in England. *BMC Health Services Research*	Captures the experiences of patients who have been treated by NHS specialist CFS/ME services in England.	Semi-structured interviews (n=16); UK	Provides insights into the lived experiences, perceptions, and challenges faced by patients with CFS/ME when accessing and receiving care from NHS specialist services. Participants share their perspectives on various aspects of their healthcare experiences, including interactions with healthcare professionals, access to specialist services, treatment approaches, communication, support, and overall satisfaction with care received. The study findings illuminate the multifaceted experiences of adult patients with CFS/ME within the NHS specialist services landscape. Participants revealed both positive aspects, such as supportive HCPs as well as challenges and areas for improvement, including the perceived lack of validation and medical and social support before attending a specialist service. The study underscores the relevance of enhancing access to specialist services, improving communication between patients and healthcare professionals, and fostering a supportive and understanding healthcare environment for individuals living with chronic conditions like CFS/ME.

Rush et al. (2017) Seeing the rural healthcare journeys of older adults with atrial fibrillation (AT) through a photographic lens. *Chronic illnesses*	Explores the healthcare journeys of older adults living in rural areas who have atrial fibrillation (AF), a common heart rhythm disorder.	As part of a larger mixed methods study 10 older adults with AF living in rural communities were recruited and followed over six months through a combination of face-to-face and telephone interviews. Photographs (n= 483) were submitted along with personal journey logs to report healthcare interactions; Canada.	Explores the healthcare journeys of older adults living in rural areas who have atrial fibrillation (AF). The study uses a methodology involving photography to gain insights into the experiences of these individuals as they navigate healthcare systems and manage their condition within the rural context. Photovoice is a visual research method that empowers participants to capture their lived experiences through photography and share their perspectives through facilitated discussions. In this study, older adults with AF residing in rural areas were provided with cameras and asked to take photographs that represent their healthcare journeys, including challenges, barriers, and facilitators they encounter.
Berglund & Westerlund (2016). Patient organisations and primary care development: reactions by patients with chronic diseases. *Patient Experience Journal*	Explores how patients with chronic diseases, as well as members of patient organisations, perceive primary care and how they think about how to participate in primary care development.	Focus groups (n=6) with patients (n=28); Sweden	Explores how patients with chronic conditions perceive and respond to initiatives aimed at improving primary care services in collaboration with patient organisations. Key themes were identified: (1) Availability of care, (2) How to be met by professionals, (3) Information needs and (4) Continuity and prevention in care. The most important aspect for participants was to meet the same doctor at every visit and to be met with empathy and knowledge about the disease. Suggestions about better use of technical information services, introduction of a coordinator in the waiting room and longer and varied open hours also came up. The information needs for newly diagnosed and those with a long disease trajectory differed and care treatment plans were asked for by many participants.

Manchaiah & Stephens (2012). The 'patient journey' of adults with sudden-onset acquired hearing impairment: a pilot study. *The Journal of Laryngology & Otology*	Examines the 'patient journey' of adults with sudden-onset acquired hearing impairment.	Semi-structured interviews (n=20) with audiologists and adults with sudden-onset acquired hearing impairment; UK	Explores the experiences, challenges, and coping mechanisms of individuals who have recently acquired hearing loss, with a focus on understanding the trajectory of their journey from the onset of symptoms to seeking and receiving appropriate healthcare interventions. Participants share their personal experiences, emotions, and the impact of hearing loss on various aspects of their lives, including communication, social interactions, and daily activities. Additionally, the research highlights various stages in the patient journey, including the pre-service encounters (recognition of symptoms, seeking medical help); service encounters (undergoing diagnostic evaluations, receiving treatment or interventions) and post-care encounters (resolution, adjusting to life with hearing impairment).

Source: Authors' elaboration

4.4. RESEARCH DESIGN AND CONTEXT

4.4.1. Research strategy and design

This study is exploratory and qualitative. In qualitative studies, the researcher seeks to produce results by describing, explaining and interpreting the data. Qualitative research is commonly associated with an inductive process, which means that theories are born from the observations made by the researcher. This process involves an interactive and non-sequential perspective defending the fact that each investigation component has direct implications for the others (Thomas, 2006; Zhang & Wildemuth, 2009). By adopting a qualitative approach, this study aims to explore a phenomenon - patient experience (PX) - from a holistic perspective involving the vision of several informants: patients, informal caregivers (ICs) and health care providers (HCPs). The study's exploratory nature is justified by the nature of the research questions, initiated by "how" and the still scarce level of development theory of the research problem (Wolf et al., 2014).

In terms of research design, this study adopts the Interpretative Phenomenological Analysis (IPA), which is used to explore in-depth the lived experiences of individuals. It aims to understand how people make sense of their own experiences and the meanings they attribute to those experiences at a time. IPA emphasizes an idiographic approach, meaning that researchers focus on understanding each participant's unique, individual experiences rather than seeking generalizable findings across a larger population (Smith & Osborn, 2004). Fundamental IPA principles are a commitment to understanding the participant's lived, conscious experience and adopting a psychological focus on personal meaning-making in specific contexts– the researcher aims to make sense of the participant who is trying to make sense of his/her own experiences using memory and language) (Smith & Osborn, 2004; Tax et al., 2011). As the unit of analysis in this study is people's (patients) interactions within multiple touchpoints throughout their journey, and the study seeks to understand different perspectives on the PX, through participants' eyes, IPA was considered to be a good fit between the research aims and objectives and a recognised data analysis methodology.

4.4.2. Procedures of primary data collection

Regarding main primary data collection, we conducted 40 interviews (individual and collective) with multiple informants (patients, ICs and HCPs, n=38), and collected six patient diaries. All informants were recruited through purposive sampling, a non-probabilistic technique widely used in qualitative research to use limited resources effectively (Patton, 2002). Also, purposive sampling means the researcher intentionally selects individuals knowledgeable about or experienced with a specific phenomenon (Creswell & Clark, 2011). In addition to knowledge and experience, Bernard (2002) reinforce the relevance of participant-related factors, such as availability and willingness to participate and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner.

4.4.2.1. Individual in-depth interviews with patients

We conducted 19 in-depth, in-depth, face-to-face interviews with adult chronically ill patients attending scheduled outpatient visits at one public Hospital in Portugal (Hospital of Braga). The in-depth interview format was explicitly chosen to allow the gathering of insights into the experiences, perceptions, mental models, affective reactions, and explanations of behaviours associated with their disease and interactions with healthcare services. In this study, chronically ill patients were selected as there has been an increase in the incidence of chronic diseases which are essentially (1) permanent, (2) produce disabilities/deficiencies, and (3) driven by irreversible pathological changes, therefore requiring intense training of the patient for rehabilitation, and also extended periods of supervision, observation, or care (Van Oostrom et al., 2016). Thus, the inherent vulnerability of chronically ill patients makes it increasingly critical to investigate all the variables that influence PXs over time. It is therefore hoped that this research will shed light on the relationship of certain variables and the experience of chronically ill patients throughout their journey and the importance of optimising services for these patients.

We selected two groups of chronic conditions: (1) Type-1 Diabetes (TD1) and (2) End Stage Renal Failure (ESRF). The first (T1D) is a severe and chronic disease that occurs either when the pancreas does not produce enough insulin (a hormone that regulates blood glucose) or when the body cannot effectively use the insulin it produces (World Health Organization (WHO), 2023). Raised blood glucose, a common effect of uncontrolled diabetes, may, over time, lead to severe damage to the heart, blood vessels, eyes, kidneys and nerves (World Health Organization (WHO), 2023). People with T1D require daily insulin administration to regulate the amount of glucose in their blood. If

they do not have access to insulin, they cannot survive. Symptoms include excessive urination and thirst, constant hunger, weight loss, vision changes and fatigue (World Health Organization (WHO), 2023). Although less prevalent than Type 2 Diabetes (T2D), T1D implies a particular and demanding approach due to its implications. Therapeutic education, multidisciplinary support, self-control and self-management are fundamental tools for those with the disease. T1D requires support in different areas, such as prevention, treatment, rehabilitation and quality of care. Furthermore, T1D is also a strategic priority for the National Association for the Protection of Diabetics in Portugal (APDP2, date).

The second disease (ESRF) is the last stage of chronic kidney disease (CKD), where the kidneys have lost almost all their function. The kidneys can no longer effectively remove waste and excess bodily fluids or perform their other essential functions. During ESRF, patients may experience a wide variety of symptoms as kidney failure progresses. These include fatigue, drowsiness, decreased urination or inability to urinate, dry skin, itchy skin, headache, weight loss, nausea, bone pain, skin and nail changes and easy bruising (American Kidney Fund, 2024). Therefore, dialysis or kidney transplantation are necessary treatments for the patient to survive because their kidneys are no longer able to sustain life on their own (American Kidney Fund, 2024). In Portugal, the prevalence of patients undergoing renal replacement techniques (RRTs) has been increasing every year, and the incidence of patients on dialysis is one of the highest in Europe. The phase of selecting the RRT is strongly susceptible for patients, as they may become dependent on treatment from ICs and HCPs, with repercussions for their physical and psychological state (Muehrer et al., 2011). There is, therefore, an increasing need to study the experience of these types of patients to improve their well-being and the care provided to them.

Patients with T1D and ESRF were selected from a public Hospital in Portugal – Hospital of Braga. The choice of this Hospital was based on two main criteria: (a) geographical proximity, which translates into greater convenience in collecting and accessing data and (b) the Hospital's strategic priorities, including improving the PX and services. The Hospital's institutional review board approved the research protocol.

Regarding the eligibility of patients, we defined as inclusion criteria patients (males and females, with 18+ years) attending (1) first consultations at the service and (b) follow-up consultations at the service. The service directors and physicians from endocrinology and nephrology services helped to select potential informants to participate in the study. The leading researcher then collected the individual's informed consent and conducted the interviews.

The interviews aimed to uncover the experiences of chronically ill patients (T1D and ESRF) throughout their journey. Using an interview protocol (see Appendices IV and V), an effort was made to solicit participants' narratives, perspectives and perceptions. The interview script was tested with a sample of 5 participants, including one nephrologist, one endocrinologist and three patients with T1D and ESRF from other public hospitals in Portugal. The interview guide was then modified and adapted to the type and condition of the patients. The questions were aimed at (1) understanding how their experiences varied and were impacted by multiple factors, such as actors (e.g., HCPs, other patients, family, ICs), resources, and the overall service system(s) throughout their journey, and (2) exploring key PX improvement domains.

A flexible approach was adopted so that interviews flowed in a conversational style, where informants could ask questions and concerns, allowing new insights and trajectories to emerge (Denzin et al., 2017). Throughout the interviews, informants' reflection was facilitated through timely probing, active listening, and the use of silence (Robinson, 2023). Following each interview, the interviewer promptly noted participants' reflections and her own emergent sensemaking in field notes, and conducted a methodical debriefing with the research team. The debriefing aimed to gather immediate insights and enhance the data's quality and trustworthiness in real-time. (McMahon & Winch, 2018). The debriefings also acted as informal support within the research team to enable professional detachment and complete attention to the deeply personal experiences that the participants were sharing (Dickson-Swift et al., 2009). The interviewing continued until saturation (Saunders et al., 2018). On average, interviews lasted 50 minutes and were conducted between January and June 2022 at the Clinic Academic Center (2CA-Braga, Hospital of Braga).

Patients were also invited to participate in a follow-up, in-depth interview – six months after their first interview. The follow-up interview served to access their reflections, stories and critical incidents and identify the main changes in their experiences over the last six months (e.g., changes in perceptions, motivations, and attitudes). The dates for the follow-up interviews were prearranged with the patients at the end of the first round of interviews. Of the 19 patients invited, six accepted to participate (3 T1D and 3 ESRF patients). The follow-up interviews lasted 60 minutes and were conducted between October and December 2022 at the Clinic Academic Center (2CA-Braga, Hospital of Braga) on the day of their medical appointment.

4.4.2.2. Patient diaries

In our study, we invited T1D/ESRF patients to log specific information about their reflections, observations and feelings throughout their journey in an unstructured diary (Hyers, 2018). Six patients accepted to participate (3 T1D patients and 3 ESRF patients) and immediately received an hand-written A5 pad and pencil to report their data. Patient diaries were developed longitudinally, that is, over an extended period of 6 months. The primary purpose of diaries was to (1) capture patients´ relatively immediate and spontaneous assessments of their daily experiences (Poppleton et al., 2008) and (2) identify potential main changes in attitudes, motivations, behaviours, and perceptions of patients over the six months. We then conducted post-diary interviews to follow up on events discussed in the diary by patients (Gill & Liamputtong, 2009), thereby extending our understanding of the diary text and clarifying uncertainties (Poppleton et al., 2008).

4.4.2.3. Individual in-depth interviews with healthcare providers (HCPs)

Ten in-depth face-to-face interviews were conducted with a multidisciplinary team of HCPs from the Hospital of Braga (n=15) upon presentation of an informed consent form. The HCPs selected were doctors and service directors of the endocrinology and nephrology services, as well as nutritionists and nurses responsible for supervising and providing care to patients with T1D ESRF. The questions were essentially aimed at (1) understanding the experience of these professionals while interacting with DT1/ESRF patients, (2) exploring their perceptions regarding the experience of DT1/ESRF patients throughout the different stages of their journey and (3) identifying critical domains for improving PX. The process of conducting interviews with HCPs also included a flexible approach and debriefings with the research team. On average, interviews with HCPs lasted 80 minutes and were conducted between January and April 2022 at the endocrinology and nephrology services of the Hospital of Braga.

4.4.2.4. Focus group with healthcare providers (HCPs)

One focus group was held with a group of nutritionists (n=5) responsible for supporting endocrinology services and T1D patients (with and without insulin pumps). The topics were essentially aimed at (1) understanding the experience of nutritionists while interacting with DT1 patients, (2) exploring their perceptions regarding the experience of DT1 patients throughout the

different stages of their journey and (3) identifying critical domains for improving PX. The group promoted synergy and spontaneity by encouraging the participants to collectively comment, explain, disagree, and share their views. Thus, experiences were shared, and opinions that had not come out during individual interviews were voiced (Stewart et al., 2007). The duration of the focus group discussions was 190 minutes and was conducted in April 2022, at the nutrition service unit of the Hospital of Braga.

4.4.2.5. Individual in-depth interviews with informal caregivers (ICs)

Lastly, four in-depth, face-to-face interviews were conducted with the ICs of the patients with ESRF who were interviewed. The ICS was invited during the interviews with ESRF patients. These interviews aimed to (1) explore their own experiences as being caregivers of chronically ill patients; (2) explore their perceptions about the experiences of ESRF patients throughout the different stages of their journey, and (3) propose key domains and actions to improve PXs. The interviews took place between January and April 2022, with the average interview time being 30 minutes. Similarly to the previous interviews, we followed a flexible approach and conducted debriefings with the research team. A coding list (patient/informal caregiver) was then created using a list of pseudo-randomised numbers to avoid a direct association between the patient's code and their caregiver.

Overall, all interviews (individual and collective) with patients, HCPs, and ICs were audio-recorded (with a physical voice recorder) after consent was obtained, assurances were given that pseudonyms would be used, and responses were anonymised. Collectively, all the interview transcripts counted 211 single-spaced pages.

The tables 4.2. and 4.3 provide an overview of the main stages of data collection, along with the total number of participants and techniques employed (table 4.3).

Table 4.2 – Overview of the main stages of data collection

Phases	Phase I	Phase II	Phase III
When	Jan-Apr 2022	May-Oct	Oct-Dec 2022
How (data collection techniques)	▪ Interviews with patients (T1D/ESRF) ▪ Interviews and focus group with HCPs ▪ Interviews with ICs	▪ Patient diaries (patients reporting on diaries their reflections, perceptions and stories)	▪ Post-diaries follow up interviews with patients (T1D/ESRF) to analyze the content of the diaries

Source: Authors' elaboration

Table 4.3 – Overview of the number of participants and techniques employed

Primary data collection	Interviews			Participants
	N (first interviews)	N (follow up interviews)	N (total interviews)	N (participants)
Patients T1D	10	3	13	10
Patients CKD	9	3	12	9
Sub total	19	-	25	19
Healthcare providers endocrinology (T1D)	6	-	6	10
Healthcare providers nephrology (CKD)	5	-	5	5
Sub total	11	-	11	15
Informal caregivers (T1D)	0	-	0	-
Informal caregivers (CKD)	4	-	4	4
Sub total	4	-	4	4
Total	34	6	40	38

Source: Authors' elaboration

4.4.3. Informants profile

Eleven (58%) male and 8 (42%) female informants (patients) were interviewed, ranging from 19 to 84 years of age (see Table 4.4). Of the 19 informants, 10 (53%) were diagnosed with T1D and 9 (47%) with ESRF. Again, of the 19 informants, 14 (74%) are non-active workers (most of them reformed or unemployed), while only 5 (26%) participants worked full-time. Thirteen (68%) held ADSE card[5] and private health insurance, while the remaining 6 (32%) reported having no health insurance. Most of the informants, 15 (79%), were from the Braga district, while only 4 (21%) were from other North locations of Portugal. Our sample mainly consisted of low-literate patients, 14 (63%) with primary education (six to 15 years old) and upper secondary education (15 to 18 years old). Only 7 (37%) pursue a higher education course. Regarding lifestyle characterisation, most informants are non-smokers and have residual drinking habits (13, 68%) but show little or nonphysical activity habits (12, 63%).

Fifteen HCPs were also interviewed, of whom 13 were female (87%) and two male (13%). Of the 15 interviewees, 10 (67%) belonged to the endocrinology unit and 5 (33%) to the nephrology unit. Of all the participants, 3 (20%) are nurses, 4 (27%) are doctors, 2 (13%) are service directors, and 6 (40%) are nutritionists. Of the 15 interviewees, the majority (n=9, 60%) were between 29 and 39 years old. Most of the participants have between 6- and 10-years of experience.

Finally, four female ICs were interviewed. The majority of the group were aged 50 or over, retired, and had a high school education. In total, 38 participants were recruited, and 40 interviews were conducted. A more detailed description of the informants is presented in the Appendix VI.

[5] The ADSE Network allows Portuguese beneficiaries to access healthcare based on a network of providers who have signed an agreement with ADSE, IP. There are several advantages for the beneficiary when obtaining healthcare in the ADSE Network: More economical - the beneficiary only pays the co-payment. The following can be beneficiaries: All workers with a permanent or fixed-term public employment relationship (CTFP).

Table 4. 4 - Summary profile of the informants

Patients' profile

	N	%
Gender		
Male	11	58%
Female	8	42%
Total	19	100%
Age		
18-28 years	6	32%
29-39 years	2	10%
40-49 years	2	11%
50+ years	9	47%
Total	19	100%
Location		
Braga district	15	79%
Other north locations	4	21%
Total	19	100%
Level of education		
Higher education	7	37%
Basic Primary school	7	37%
High school	5	26%
Total	19	100%
Employment status		
Non-active	14	74%
Active	5	26%
Total	19	100%
Disease /chronic condition		
T1D	10	53%
CRF	9	47%
Total	19	100%
Health insurance		
Have Health insurance	13	68%
No health insurance	6	32%
Total	19	100%
Smoker habits		
Regular smoker	6	32%
Non-smoker	13	68%
Drinking habits		
Regular driking	6	32%
Residual drinking	4	21%
No alcohol	9	47%
Total	19	100%
Physical activity habits		
No physical activity	8	42%
Residual physical activity	4	21%
Regular physical activity	7	37%
Total	19	100%

Healthcare providers (HCPs) profile

	N	%
Gender		
Female	13	87%
Male	2	13%
Total	15	100%
Age		
18-28 years	0	0%
29-39 years	9	60%
40-49 years	3	20%
50+ years	3	20%
Total	15	100%
Service Units		
Endocrinology	10	33%
Nephrology	5	67%
Total	15	100%
Role/ function		
Nurse	3	20%
Service director	2	13%
Nutritionist	6	40%
Doctor	4	27%
Total	15	100%
Experience		
1-5 years	0	0%
6-10 years	6	40%
11-20 years	4	27%
20+ years	5	33%
Total	15	100%

Informal caregivers (ICs) profile

	N	%
Gender		
Male	0	0%
Female	4	100%
Total	19	100%
Age		
18-28 years	1	25%
29-39 years	0	0%
40-49 years	1	25%
50+ years	2	50%
Total	4	100%
Level of education		
Bachelor	1	25%
Basic Primary school	1	25%
High school	2	50%
Total	4	100%
Employment status		
Reforemed	2	50%
Unemployed	1	25%
Active worker	1	25%
Total	4	100%

Source: Authors' elaboration

4.4.4. Additional sources of data for triangulation

Additional data from non-participant observation and text-based documents were collected for data triangulation. By combining multiple sources of evidence, we aimed to cross-validate; that is, to seek convergence and corroboration of findings (Stavros & Westberg, 2009). In other words, by triangulating data, we attempted to provide a "confluence of evidence that breeds credibility" (Eisner, 1992, p.110) and thus reduce the impact of potential biases that can exist in a single study.

4.4.4.1. Non-participant observation

We conducted a non-participant observation of the informative session about RTTs at the Hospital of Braga nephrology service (see Table 4.5). These mandatory informative sessions about RRTs occur weekly at the hospital and promote the interaction between nurses and a group of ESRF patients who need to decide about the type of their future RRT. By conducting non-participant observation, we aimed to (1) analyse the interactions between ESRF patients and HCPs during the informative session about RTTs, (2) identify the main convergences and divergences between what patients and nephrologists said in the interviews about informative sessions on RRTs and their actual behaviours and attitudes during such sessions; and (3) gain a an in-depth appreciation of situations that could not be easily captured through interviews (Liu & Maitilis, 2010).

Non-participant observation was overt, meaning that research subjects knew that the principal researcher was present but did not interact with the researcher. We recognise that overt non-participant observation can be biased through the observer effect when people change or seek to improve an aspect of their behaviour just because they are aware of being observed (Lugosi, 2006). However, the overt approach was selected based on recommendations from the Hospital's Data Protection Unit and Research Ethics Committee. Three hours (n=3) were observed with written field notes. Indeed, field notes were written in a reflective style as informed by ethnographic principles (Eriksson et al., 2012) and captured five main categories: (1) the flow of the process (from the moment patients arrive at the session until they leave), (2) physical room layout, materials and resources, (3) duration of the session, (4) number of people, (5) roles of attendees, (6) the nurse communication and overall performance (e.g., communication style and empathy); (7) topic being discussed, and (8) the structure and content of the session (how it was organised, what type of activities were performed, what contents were shared and how); and (9) the feedback, attitudes and emotions showed by patients during all the session. Also, observations of mood, tone and

points of perceived tension were also noted and registered. Finally, the researcher wrote up individual critical learnings from the filed notes and impressions right afterwar, reviewed all our data, highlighted essential passages, and tried to find patterns within the data. The observation yielded a total of 2 single-spaced pages of field notes.

Table 4. 5 – Non-participant observation

Non-participant observation	Detailed information
Date and hour	29/11/2022; 9.30-12.30 A.M.
Unit of observation	Interaction between ESRF patients and HCPs during the informative session about RRTs
Place	Nephrology service, Hospital of Braga
Observation hours	3
N (patients)	3
N (informal caregivers)	4
N (nurses)	1

Source: Authors' elaboration

4.4.4.2. Text-based document analysis

A text-based document analysis was conducted to systematically review or evaluate documents from the institutional website of the Hospital of Braga and other online media channels (see table 4.6) The main goal was to corroborate findings from primary data (Bowen, 2009) by exploring emerging themes in the data that would capture the experiences of chronically ill patients throughout their journey and within the services of the Hospital of Braga. Hence, the text-based document analysis involved examining the overall content scope of each text to appreciate their coverage of PX-related topics. The criteria used for document analysis were (1) to have a clear contribution to the issues being explored (in this case, documents that explicitly mentioned the PX domain or PX-related topics); (2) to be comprehensive (covering the topic altogether or broadly) or selective (covering only some aspects of the topic); (3) to contain information about the author of the document and the sources of information; (4) to be publicly available; and (5) to be related to the T1D and ESRF conditions and the nephrology/endocrinology services of the Hospital of Braga.

We employed the READ approach (Dalglish et al., 2020) to conduct the text-based document analysis, a systematic procedure for collecting documents and gaining information from them in the context of health. The initial step consisted of getting the materials ready. It included (a) defining the topic (PX-related information from the Hospital of Braga), (b) selecting the publication dates (from the time the Hospital passed from PPP[6]to a PBE – Public Business Entity: 2019-2022), (c) finding channels (institutional website, online media channels); and (d) defining the types of documents (formal/official documents from the institutional website such as strategic reports, newsletters and working documents such as PPT presentations; news from online journals and magazines). The following steps were to extract data, analyse data and distil findings. At this last stage, the analysis stopped when we felt we had obtained all the documents that met our criteria, and saturation occurred (when we fully or sufficiently understood the phenomenon we were studying). Overall, of the 94 documents collected between June – December 2022, we analysed 20

[6] - A Public-Private Partnership (PPP) is a partnership between the public and private sectors to deliver a project or service traditionally provided by the public sector.

Table 4.6 - Text-based document analysis

Types of documents (2019-2022)	N
Information / news from the institutional website	6
Newsletters from the institutional website	3
Strategic and financial reports from the institutional website	4
Information /news in online journals	7
Total	20

Source: Authors' elaboration

4.4.5. Additional sources of data for generating managerial implications

In this research, we focus on exploring the experiences of patients suffering from chronic conditions (T1D and ESRF) throughout their journey. The overarching objective is to use these insights to formulate recommendations to enhance the care delivery by the endocrinology and nephrology services within the Hospital of Braga, thereby fostering health outcomes, such as patient well-being. To refine managerial implications and furnish pertinent recommendations for improving the experiences of chronically ill patients and healthcare services delivery at the Hospital of Braga, we collected two additional data sources, namely:

(1) Examining the best practices in PXM within the national healthcare landscape. The goal was to analyse the best practices in PXM at a national scale within the realm of chronic illnesses, encompassing an analysis of thirteen public hospitals within the National Health Service, Northern Regional Health Authority (ARS Norte Administração Regional de Saúde do Norte, IP). The study was carried out by analysing the institutional websites of each hospital, institutional publications, and internal presentations from the hospitals (e.g. IPO-Porto).

(2) An analysis of posts/threads from publicly accessible social networks (official Facebook of the Hospital of Braga and public complaint portal "Portal da Queixa"[7]). The use of a netnograpgy approach allowed us to embed in the online environments and to take make an in-depth observation of online conversations (Tenderich et al., 2019, p.1) between patients. The ultimate goal was to identify the main improvement areas suggested by patients suffering from chronic conditions on such social networks. The choice of the start date for the analysis (2019) considered the transition from PPP to a PBE. A total of 428 posts published in social networks between 2019 and 2022 were collected and analszed (see table 4.7).

[7] - The complaint portal ("Portal da Queixa") is a Portuguese, online consumer social network that connects consumers and brands. It allows consumers to voice their complaints, resolve them and share positive and negative opinions.

Table 4.7 – Additional sources of data for generating managerial implications

Best practices collection	N
Public Hospitals (National Health Service, Northern Regional Health Authority	13
Netnography (2019-2022)	N
Posts from Facebook page	162
Posts from complaint portal ("Portal da Queixa")	266
Total	428

Source: Authors' elaboration

4.4.6. Data analysis

4.4.6.1. Qualitative data analysis (QDA)

All the interview recordings were transcribed using verbatim and reviewed for errors by the researcher and a sample of informants. Such review ensured trustworthiness and congruence between the research team's explanations and participants' sensemaking of their experiences and situations. In addition, the interviews were translated into English. The researcher searched for thematic expressions and quotes from participants.

We employed a three-stage coding process (Gioia et al., 2013). We first employed open coding to label the raw data shared by participants. Then, we conducted axial coding with thematic analysis, which resulted in second-order constructs. Finally, we continued to condense and abstract the themes (see Table 4.8), focusing more on theoretical development, until we derived the following aggregate six dimensions: (i) "Interactions with the hospital processes, staff and servicescape"; (ii) "the role of patients in care and self-management"; (iii) "the influences of the social circle"; (iv); "other external influences and dynamics" and (v) interactions with technology". These themes fit into the brand-, patient-, social-, external/dynamics and partner-spheres, respectively.

In this study, we used a combination of deductive and inductive coding approaches (Proudfoot, 2022). Firstly, a top-down approach (deductive coding) was employed, where the researcher developed a codebook with an initial set of codes. The codes were based on the research questions and on the existing research framework/theory. Then, a ground-up approach (inductive coding) was used, where the researcher derived codes from the data. The prevalence of themes was counted in terms of the number of different informants who articulate the theme across the entire data set. We revisited individual interviews and (re)coded passages as we moved iteratively through the interpretation process. The thematic approach was also used to analyse all data sources. For

supporting the entire data analysis process, we used NVivo, a qualitative data analysis (QDA) tool. During this process, several rounds of coding were performed, using various data exploration types, such as crosstabulations, charts, and other tools to build, revise and systematise findings. Due to the iterative nature of the interpretive approach employed in this research, the researcher discussed the findings at multiple points with the research team and revisited the transcripts to move the analysis forward. Overall, the research team meetings were critical for supporting the development of themes, refinement of concepts and verification of interpretations (Crepeau, 2000).

Table 4.8. Themes and subthemes generated from primary data

Themes and subthemes	Sphere	N
Theme 1. Interactions with the processes, staff and servicescape	Brand (hospital) Sphere	38 (100%)
Subtheme 1. Drivers of ineffectiveness of care and internal processes		
Subtheme 2. Positive interactions (HCPs towards patients)		
Subtheme 3. Drivers of effectiveness of care and internal processes		
Subtheme 4. Negative interactions between patients and HCPs		
Subtheme 5. Negative interactions with servicescape		
Subtheme 6. Positive interactions with servicescape		
Theme 2. The role of patients in care and self-management	Patient sphere	33 (86,8%)
Subtheme 1. Daily challenges associated with the disease		
Subtheme 2. Adjusting life to the chronic illness		
Subtheme 3. Symptoms awareness and seeking care		
Subtheme 4. Negative emotions and attitudes towards the condition		
Subtheme 5. Positive emotions and attitudes towards the condition		
Theme 3. The influences of the social circle	Social sphere	32 (84,2%)
Subtheme 1. Lack of support from social circle		
Subtheme 2. Support delivery from social circle		
Subtheme 3. The role of OHCs and patient groups		
Subtheme 4. The challenging role of ICs		
Theme 4. Other external influences and dynamics	External influences	15 (39,5%)
Subtheme 1. Positive and negative consequences of COVID-19		
Subtheme 2. Negative influence of past experiences from others		
Theme 5. Interactions with technology	Partner sphere	5 (13,1%)
Subtheme 1. Disadvantages of the hospital information technologies		

Source: Authors' elaboration

4.4.6.2. Multiple Correspondence Analysis (MCA)

In this study we aimed to obtain a holistic picture of the salient relationships among qualitative variables based on the Multiple Correspondence Analysis (MCA) technique. MCA is an exploratory data technique for analysing relationships between categorical or categorised variables encompassing more than two categorical variables (Johnson & Wichern, 2007). Indeed, MCA aims to address the need to quantify qualitative information obtained through nominal variables. It allows simplifying complex data (Doey & Kurta, 2011), yielding a simple and exhaustive analysis. It is an ideal technique to analyse this form of data because of its ability to extract the most critical dimensions, allowing simplification of the data matrix (Palmer, 1993). The use of MCA is, thus, particularly relevant in this study and other similar studies where a large amount of qualitative data is collected and where qualitative variables can become sub-optimised in the data analysis (Costa et al., 2013). Moreover, MCA becomes valuable due to its flexible data requirements (Hoffman & Franke, 1986) as the only strict data requirement is a rectangular data matrix with non-negative entries (Doey & Kurta, 2011).

Regarding the analysis and interpretation, MCA analyses produces a multidimensional graphical map called a biplot. This is a great advantage as makes data analyses more accessible than statistical techniques not providing dual displays (Hoffman & Franke, 1986).

MCA uses the chi-square to measure the distance between points on the biplot. It is important to note that the chi-square distance can be used to examine the associations between categories of the same variable but not between variables of different categories. The Pearson chi-square test tests the significance of association. Hence, MCA shows how the variables are related or associated by the approximate distance of points to one another on the biplot, not just that they are associated (Johnson & Wichern, 2007). Hence, the outcomes of MCA are understood by examining how points are positioned relative to each other and distributed across dimensions. When categories have similar distributions, they are represented closer together in space (Tabachnick & Fidell, 1996). The ultimate goal of MCA is to explain the maximum amount of variance (or inertia) in the model using the fewest dimensions possible. Typically, this involves representing the data in a biplot with two or three dimensions. Researchers usually select a sufficient number of dimensions, often two, which facilitates data visualization and interpretation (Giffi, 1996).

The object of MCA in this study was to identify salient relationships among qualitative variables (sociodemographic, clinical, lifestyle and experience variables) transformed into cross tables and to demonstrate the results in a graphical manner (biplot). In particular, the analysis was based on assessing the sample of patients (T1D and ESRD) who received medical services at the Hospital of Braga. A total of n = 19 individuals with no missing values were included in the analysis. We performed the analysis with two MCA dimensions. Discrimination measures and a joint plot of category points were obtained. The coordinates of each category on each dimension are displayed to determine which categories are similar for each variable. The lines' length and steepness indicate each variable's discrimination measures for the two considered dimensions in the discrimination measures plot. The IBM SPSS Statistics (Version 29) was used for the statistical analysis.

In this MCA procedure, all the assumptions of this technique were verified (Garson, 2008), namely (1) the homogeneity of variance across row and column variables was met. MCA assumes that the statistical properties are similar across rows and columns. For example, there must not be any empty variables (i.e., variables for which all entries consist of zeros); (2) discrete data was the type of data being analysed; (3) the data was made up of several categories (in this case, twelve); (4) all values in the frequency table were non-negative so that the distances between the points on the biplot are always positive.

Regarding the MCA limitations, it should be emphasised that the results obtained are based on geometric considerations and are limited to the cohort studied; therefore, the conclusions drawn should not be extrapolated or generalized.

The Table 4.9 provides an overview of the main research steps and decisions conducted within this study.

Table 4.9 - Research overview

Research overview	
Research gaps	Research gaps: (1) Overall research on PX is still dominated by the organisational perspective (captures the feedback of patients regarding their interactions with the elements of care through surveys). Therefore, literature calls for studies focusing on the holistic PX throughout the journey, exploring the patient behaviour, explaining underlying psychological processes and depicting the interactions between patients and HCPs to include the involvement of additional value networks and resources such as friends, family, other patients, and communities. (2) The study of the holistic experiences of chronically ill patients is still an overlooked research domain. Few studies have empirically explored patients' experiences with chronic illnesses along the journey, and most of them do not allow us to differentiate between types of touchpoints or organise them into categories based on the degree of control of the organisation (hospital). Such distinction is powerful because it allows for a better understanding and management of PX.
Purpose and research questions	Purpose: This study aims to explore the realm of experiences of chronically ill patients throughout the patient journey. It specifically aims to address the holistic phenomenon of PX by investigating the interactions of chronically ill patients across multiple touchpoints throughout the journey, inside and outside the healthcare context. We investigate the holistic PX by crossing the perspectives of multiple participants: patients, healthcare professionals and ICs. Research questions: RQ1. How do the experiences of chronically ill patients manifest throughout their journey? RQ2. How do different touchpoints influence the experience of chronically ill patients throughout the journey? RQ3. How can the experience of chronically ill patients be managed to generate service delivery improvements and well-being outcomes?
Unit of analysis	People´s interactions within multiple touchpoints across the journey
Research strategy and design	Qualitative research strategy IPA – Interpretative Phenomenological analysis

Data collection	Primary data collection: — Total of 38 participants recruited from Hospital of Braga — 40 Individual in-depth interviews with T1D/ESRF patients (n=19); HCPs (n=15) and ICs of ESRF patients (n=4). — 1 Focus group with nutritionists responsible for supervising T1D patients (n=5) — 6 patient diaries developed by T1D patients (n=3) and ESRD patients (n=3) and discussed in post-diaries follow-up interviews. Additional sources of data for triangulation: — Non-participant observation (n= 3hours) of the informative session on RRTs (nephrology service). — Text-based document analysis (n=20) mostly selected from the institutional website of the Hospital of Braga Additional sources of data for generating managerial implications — Best practices collection — Netnography
Data analysis	— Qualitative data analysis through thematic analysis – using NVivo. — Multiple correspondence analysis to explore salient relationships through qualitative variables using the IBM SPSS Statistics (Version 29).

Source: Authors' elaboration

4.5. FINDINGS

4.5.1. Results from primary data collection – Themes and subthemes

This section presents the main themes and subthemes that emerged from data analysis (from the most to the least mentioned).

4.5.1.1. Theme 1 - Interactions with the processes, staff, and servicescape

Our primary data reveal that the most frequent and overarching theme encompasses the interactions with the hospital processes, staff, and servicescape (brand-owned touchpoints). From this theme, six subthemes emerged: (1) drivers of ineffectiveness of care and internal processes, (2) positive interactions between patients and HCPs, (3) drivers of effectiveness of care and internal processes, (4) negative interactions between patients and HCPs, (5) negative interactions with servicescape, and (6) positive interactions with servicescape. The mentioned touchpoints occur during the care service delivery/service encounter stage and are specially evoked by the HCPs. A synthesis of theme 1 is presented in the Table 4.10.

4.5.1.1.1. Subtheme 1. Drivers of ineffectiveness of care and internal processes

4.5.1.1.1.1. Lack of timeliness / excessive waiting times

Even though most informants mentioned the increasing waiting times, this topic was emphasized by ESRF patients regarding the scheduling of outpatient medical appointments and exams. Additionally, due to delays and excessive waiting times, some ESRF patients decided to seek treatment at private hospitals where they can utilize their private health insurance benefits. The nephrology team also emphasises this fact and assumes it is challenging to meet adequate and efficient response times in the nephrology services,

> *We have patients who complain about the waiting time for their first appointment. For example, the family doctor asked for an appointment in January, and it is March or April, and it still has not been booked. We cannot respond as we would like. Because if we have extra appointments, and if we have 5 or 6 more subsequent patients, which is what I usually have, that is 100 extra minutes of appointments, there will be delays... There is no way now to increase appointment times unless we use external providers or if the service increases in size, which would be ideal). Patients do not complain about how we work or*

anything, not often, but with waiting times, there are many complaints. We get complaints from patients who arrive for their appointment at 2 pm and are seen at 3 pm or 4 pm) (Nephrologist 3).

Secondly, waiting times are also excessive to obtain care in the emergency department, outpatient appointments, making exams and getting medication from the hospital pharmacy,

Having a massive queue to get medicines from the pharmacy of the hopsital does not make sense. They deal with people who have appointments and there should be a queue to pick up medicines with appointments and another for people without appointments. For example, I come here (hospital), and I have a quick appointment, and then I wait 2 hours to pick up a medicine that I could not leave without (Antoine, ESRF patient).

4.5.1.1.1.2. Poor access and communication with the hospital

The contact with the hospital is challenging – a global perception among most of the informants. The most expressive limitation concerns the lack of response from the telephone system. Moreover, there is not even an automated telephone system, which means that only the general number is available to accommodate all the possible contact attempts, which results in a lack of response capacity from the hospital,

The worst thing about the hospital is that we cannot get in touch. If there is a problem, I must go to the hospital. (Rosale, ESRF patient).

It is impossible to call the hospital here. Recently, I called 108 times—all morning. The music was always playing, and nobody answered. It would be essential to have someone who could guide us; otherwise, we get very nervous (Cliston, ESRF patient).

Therefore, the impossibility of contacting the hospital forces patients to travel to the hospital (e.g., older patients from distant cities) just to fix administrative problems and schedule or cancel medical appointments. Nevertheless, even contact with the physician inside the hospital is a challenge for patients,

The physical access to the doctor is complicated here. When the patient needs one at a time that's not on the agenda, he/she comes here, and the secretariat sends him/her to the nurses. And then nurses contact the doctor to see if the patient needs to be seen or if they can help (Endocrinologist 3).

Another problem – especially mentioned by HCPs (endocrinologists) is the lack of e-mail responsiveness. Not all the HCPs feel comfortable providing e-mail or other direct contact to patients, as they think patients would probably abuse contact with physicians. On the other hand, HCPs also manifest that ensuring good responsiveness by e-mail is quite challenging. This is because they receive thousands of e-mails daily since there are no administrative services by departments/units for filtering and following up on the messages.

> *I think there is an abuse of email use in this hospital. Coming on holiday and finding 200 e-mails, imagine what that is like. Then you lose the purpose of e-mail, which is to contact you quickly and rapidly* (Endocrinologist 1).

Moreover, due to this lack of accessible and direct access, HCPs (nephrologists and endocrinologists) state that patients try to find alternative and informal communication channels, such as social media platforms, to communicate with HCPs.

4.5.1.1.1.3. Lack of resources and weak response capacity

From the perspective of HCPs – nephrologists and endocrinologists – the lack of human and physical resources in the Hospital of Braga constitutes the primary driver of internal inefficiencies. Regarding the lack of human resources, the hospital lacks a health workforce or staff in specific service areas, such as mental health services (psychology and psychiatry) and other support services, such as nutrition and social services. Mental health services are highly relevant for chronic conditions such as ESRF and T1D. Patients with ESRF, particularly, face several challenges when they are confronted with RRTs or Conservative Management for Kidney Failure (CMKF). In addition, these patients might develop depression during this stage or even before, when they need to drastically change their food habits (e.g., enrolling on a low-protein diet) and when they start to lack productivity at work due to fatigue. Therefore, support from mental health services seems essential,

> *Psychology would be fundamental here to have more support. Some patients cannot be productive, who are unemployed or who are depressed. We do not have a very comprehensive psychology response here. I am not aware of a psychologist who supports nephrology here. All those resources that could collaborate with us would be significant* (Nephrologist 2).

T1D patients face several difficulties during the daily discovery and management of their condition. For example, many young T1D patients show strong resistance and denial when they discover their disease. In addition, many adult T1D develop physical complications (e.g., diabetic foot

comorbidities) and are in a lot of pain and difficulty in dealing with a sense of imminent or possible loss of a limb. Lastly, some female T1D patients start to develop eating disorders, and others feel a strong sense of tiredness since they need to manage several things, including food, insulin administration and exercise, technologies, and other insulin supplies. Hence, psychology would offer valuable support to these patients throughout their journey.

In addition, in terms of health workforce it would be essential to provide the hospital with more social workers and to have auxiliaries/administrative staff to help the patients with the hospital ticket system. Some older patients suffer particularly with this support gap as they get confused, get lost, and may even lose their turn for the medical appointment,

> *Because even the social worker's support here is difficult, they do not have much time to come. The social worker's role is to recognise situations that require social intervention, sometimes special support for the informal caregiver, to understand if it is a patient who is often at home alone* (Nurse 1, nephrology service).

> *Sometimes, an assistant explains to the patients how to use the ticket system, but sometimes, not. When we pass the machine's door to take tickets, we are immediately questioned because there are many doubts, which creates some delays. Sometimes, the doctor accepts or does not accept* (Nurse 1, endocrinology service).

Still focusing on human resources, HCPs also mention the inadequate resource allocation/recruitment criteria and retention efforts. Participants highlight that current admission criteria neglect other vital variables and skills. In other words, following this strategy, there is no guarantee of a perfect match between health workforce profiles and the specific needs of the medical services,

> *How the services integrate the new specialists is an issue. The interns take an exam, they get a mark, vacancies come up, they fill the vacancies based on the mark and the options they choose. But the services need people with specific profiles and characteristics. They may not even have such a high mark, but they may have specific skills that are not covered; it is not easy to ask for vacancies with criteria. New specialists are placed according to their grade, ignoring the needs of the service. The hospital's resources must be adapted to the needs, which is not always the case. Hiring professionals - doctors, nurses, auxiliaries, medical staff - is centralised and difficult. It would be desirable if the administrations had the autonomy to talk to the services and, in a discussed vision, understand the dimension*

that the service or a certain area needs to have and allocate resources to it. This goes beyond nephrology. (Nephrologist 3).

Not only is recruitment an issue but also the retention of the health workforce. The actual poor work conditions of the hospital create demotivation in these professionals, who tend to go to private care institutions,

> *There is not a doctor in the service who does not do something else outside. So, 40 hours here, plus extra hours outside, and that is it. There is a shortage of doctors and nurses. Many nurses work in dialysis clinics or on the wards in private hospitals. There is little time left for the family* (Nephrologist 3).

The last human-related aspect mentioned was the lack of academic training and research focus felt by HCPs, both in nephrology and endocrinology services,

> *I am a very academic, and I miss a different structure here. It is still seen as an accessory task and not included in the timetable. No formal time is allocated to this function, and it should be valued differently. As a university hospital, especially in endocrinology, we have very little representation here, for example, in students' academic training. The students spend time here in consultation, but in terms of theoretical training, they are still given by professionals from other areas. They spend two weeks here, which is very reductive. In endocrinology, we still do not have the relationship I think we deserve with the medical school here at University of Minho* (Endocrinologist 1).
>
> *We have a service that is ambitious, still new and has not yet achieved everything it needs to achieve. We must bring quality to what we do and accompany the differentiation of the whole service in its aspects - clinical but also academic (a step that has not yet been well realised), liaising with the medical school, the academic clinical council and everyone else)* (Nephrologist 3).

Regarding physical resources, the lack of physical rooms and equipment (e.g., computers) is another severe problem that HCPs identified. Quite often, physicians do not have room to conduct extra medical appointments or to respond to a growing demand,

> *The biggest problem is the low speed of response and capacity to respond due to the lack of physical space (I mean, consulting rooms). It forces us to waste 1/3 of our working time adjusting. It is super stressful. These adjustments are in terms of space, conditions, and how we carry out our daily activities. I have a team, I have patients, and I do not have space. Sometimes I have a room free because my colleague is absent, and when I need*

that room free, it is often already occupied because rooms are rare in this hospital. Moreover, I cannot make extra appointments. In other words, I always have a waiting list of patients that get longer daily (Endocrinologist 3).

Access to medical appointments is also tricky, as resources for patients with low mobility are still lacking,

I believe there should be improvements for elderly individuals when they come for their appointments. In particular, access should be made even easier. Sometimes, the elevator wait is too long, and even the priority elevator is occupied by people who do not require it. Perhaps there could be more accessibility measures implemented, such as eliminating the need to navigate through the hospital to reach an appointment. Personally, I often have to request a wheelchair to assist my loved one. For instance, when I come alone, I have to park the car, retrieve the wheelchair, bring it to the appointment, then return it to the car, and finally, return the wheelchair (Informal caregiver of an ESRF patient).

Other resources, such as time, were also mentioned by HCPs. There is a need for more time for preparing and conducting medical appointments. For example, when dealing with patients with T1D and CKD, it becomes incredibly challenging to respect the "short" consultation time, as these patients present HCPs with several issues that need to be treated and managed during the consultation.

4.5.1.1.1.4. Lack of customised care approach

T1D Patients, particularly, mention the need to receive an individualised and personalised care plan, as they often tend to feel the opposite – to receive standardised plans and a mainstream approach when interacting with HCPs, namely, dietitians. Some T1D patients strongly enhanced this idea,

I tried nutrition once. I even asked the doctor to send me to nutrition because I doubted reading the sugars on packaging labels. They did not tell me anything about it at the consultation. At the appointment, I wasn't even allowed to talk; I was just told, "Here is the plan, and you are going to eat this, this and this". She wanted me to eat a lot at once, and I was trying to explain that my stomach could not digest everything. She did not allow me to talk much or explain why I was there and my doubts. The problem is that they do not try to adapt what they recommend to our reality and needs; they think they know everything and that it is based on "as I say, I know best". There is no time, no energy, no motivation.

Doctors need to be aware of this. It is not just books and knowing how to analyse images; you must know how to interpret people and their lives. Let's adapt. (Amandine, T1D patient).

Other situations related to the lack of personalisation are mentioned by T1D patients, for example, when nurses make an overall examination of T1D patients before their medical appointments and use a general script for all patients,

Before the appointment, when you go to the Nurse's room, you should take care to look at the patient's profile and see what stage they are at, and not ask basic questions that do not fit the patient's situation. Before the consultation, I always used to see the Nurse I had known for years. But today, for example, I had a new nurse, and it was the first time I had seen her. She asked me a few questions. I do not know what she saw in the chart, but if she did not, she should have. I have not been diabetic for a year or months; I have been diabetic for 26 years, and she started asking questions like, "Oh, and where do you take your insulin?" and "do you change needles?" in other words, questions you would ask someone who has been diagnosed recently, not in my case I am not talking about having a personalised speech here, but a more adapted one (Amandine, T1D patient).

4.5.1.1.1.5. Issues with the organisation of services

In the view of HCPs (endo/neph), there are important issues related to the organisation of services. The first Is the importance of conducting multidisciplinary consultations,

Working in multidisciplinary groups is necessary. We end up giving consultations in a very isolated way. Despite having a fantastic connection with the nephrology team, the truth is that everyone only knows what is going on inside their office. And no doubt, a multidisciplinary consultation could have a different impact (Nutritionist 1, nephrology service).

I think there is an opportunity in the future to have a multidisciplinary team that meets. There is not yet this multidisciplinary component. It would be more advantageous if we all knew each other. Also, I have patients being followed up in psychology, but I do not know the colleague who is following them (Endocrinologist 2).

Other service-related aspects are specifically mentioned by nephrologists, such as (1) the clarification session about RRTs and (2) the organisation of dialysis unit care. Regarding the first, HCPs mentioned the lack of follow-up with ESRF patients after the clarification session about RRTs. They often occur at one point at a time without any subsequent session or follow-up for patient

reports on what technique/therapy was selected. Moreover, a large gap of time can occur between the clarification session and the next visit to the doctor, leading to the patient forgetting what he or she has heard,

> *There is one consultation that we no longer do, which is the pre-dialysis consultation. Patients would go to this appointment and then have another consultation with the Nurse (me) and the doctor, where we would ask the patient what they thought of the informative session. If they had any doubts, we could better guide the patient in a personalised conversation because this consultation is individual/personalised. The patient is supposed to decide about the RRT in this consultation, whereas in the informative session, the patient listens and receives information. This pre-dialysis appointment made sense because it happened almost immediately after the informative session, a month later or so. Without this pre-dialysis consultation, what happens is that they go to their doctor's appointment, maybe some months after the informative session, and they have already forgotten half of what they have heard. The doctor might not even approach them about the appointment. We do not know if the doctor will see if the patient has attended the informative session. The patient may still be there and still taking a few months to go on dialysis, so it depends greatly on what the doctor does with that information and if he gives them space to ask questions (Nurse 1, nephrology service).*

Regarding the dialysis unit care, HCPs mentioned that the dialysis room is used at the same time for both dialysis patients and inpatients, which creates entropies within the service,

Also, nursing rotating shifts is another issue directly reported by HCPs from both endocrinology and nephrology. The fact that nurses are constantly rotating between services creates inter and intra-team conflicts,

> *Every day I must look at the timetable to see where I´m going to be (at which service). It is demotivating! Here, things constantly change from one week to the next. There are technological changes, things come out on the market constantly, and the organisation is always changing workwise. At first, I thought, "Is it worth studying endocrinology so much? What am I going to study? I cannot specialize because I am traveling through several services each day. Moreover, this area needs a lot, and the T1D patient with a pump knows a lot. We must know more than they do* (Nurse 1, endocrinology unit).

> *I am in a hospital, so I must have the right people working with me. I have nutritionists and nurses. Suppose the Nurse I have available is multi-skilled and can analyse diabetes-*

related technology data. In that case, he/she will speed up many of these things and at least teach the patients about technology. If I have a nurse who drops from time to time, today he/she is here, tomorrow he/she is in surgery, and then in orthopaedics, it is complicated. One of the service's requests was to have a group of nurses effectively trained who could ensure that consultations took place during the week. The answer they gave was "yes, whenever possible". However, "my qualified Nurse" often does other activities on other services. So, I lose my resources (Endocrinologist 3).

4.5.1.1.1.6. Lack of smooth and seamless service delivery

The main driver of the lack of smooth and seamless care service delivery is identified by the HCPs (especially nephrologists) as the excessive bureaucracies, blocks, and rigidity of the Hospital of Braga. Nephrologists emphasise that the rigid operation of the outpatients' appointments (booking centre) creates limitations and lacks autonomy among HCPs,

There are blockages in the organisation of the secretariat, which takes up too much of the consultation and does not allow us to do things that should be easy. The doctors do not have enough autonomy to change their agendas for outpatient appointments. I want to book patients, and the appointment is automatically blocked for many days, which makes no sense; it is blocked for two months. You cannot book it before the holidays are approved, which takes a long time and causes unnecessary chaos. (Nephrologist 1).

Additionally, the difficulty of internal coordination between services and HCPs also impairs the delivery of care services (e.g., limits the proactivity of physicians and causes delays in clinical decision-making),

Sometimes, there are difficulties if something extra is needed, like an analysis or a referral to the emergency service, the difficulty in getting this done. There are coordination difficulties. It is fine when I must ask for favours if there are cooperative people; if not, we have a problem. Moreover, the request for help from other specialities is not quick enough. For example, I want a urology appointment to investigate a urological problem, and the patient may have to wait several months. If I need an ultrasound scan quickly, radiology gives late support and delays everything. Sometimes, I must find alternative ways, like asking patients who go to the family doctor to request an ultrasound through the family doctor. The hospital is not responding promptly. There is not always the fluidity I would like (Nephrologist 2).

Difficulties of coordination between hospital services and other external entities (e.g., other public hospitals and primary care) are mentioned and described by HCPs (Nephrologists) and ESRF patients. Firstly, more protocols with other public hospitals should exist to facilitate the life of patients and avoid them having to travel to the Hospital of Braga just to make blood analyses. This is emphasised as a problem which is not exclusive to Braga's Hospital but to the whole public national health service,

> *Some patients from Viana and Valence are very far away and need complementary tests. We are only authorised to order tests carried out within the hospital structure - a biochemical test, an imaging test, or an ultrasound - I can only order them inside. The structure cannot always cope with this excess of requests, and it's very inconvenient for the patient to come here from far away just to take blood and do some analyses* (Nephrologist 3).

From the HCP's view, problems with internal communication negatively affect the smoothness and seamlessness of care services delivery. Some of those internal communication issues come from the absence of professional mobile phones for HCPs to communicate with each other,

> *In the hospital where I worked for so long, we all had a service phone for the direct contact of all the professionals. If I wanted to speak to Dr X from the X service, who was responsible for patient X, I would call her/him from my service number to her/his service number, which made communication much more accessible. There is no such thing here. It is all through personal numbers* (Nephrologist 1).

Another central aspect identified by endocrinologists, is the excessive use of papers and manual procedures (e.g., letters to patients notifying them about medical appointments) instead of benefiting from the process's automation and technologies,

> *Many bureaucratic blockages do not make sense, such as prescriptions that are still very manual, paperwork, and a series of procedures to do simple things which could be improved. When prescribing certain medicines, I sometimes need two or three pieces of paper that are then signed, instead of creating approval platforms straight away that are online, as happens in other hospitals* (Endocrinologist 1).

4.5.1.1.2. Subtheme 2. Positive interactions (HCPs towards patients)

4.5.1.1.2.1. Support delivery

The informational support was the support type mostly mentioned by endocrinologists and perceived by T1D patients, followed by emotional support and psychosocial support. These types of support were expressed essentially during the service care encounters, even though the long-term psychosocial support was also referred to as a type of support provided over/for the course of the patient's condition. The informational support is mostly associated with referrals to other internal services, such as nutrition.

T1D patients also mentioned the capacity of endocrinologists to provide detailed information to them, related to the diet and medication management, by creating strategies and guiding them in coping with new flexible schemes of insulin administration and with hypos and hyperglycemias (treatment and symptoms management),

> *The approach to T1D has changed a lot in recent years. We approach healthy eating in our consultations but do not set up a plan if the patient is not overweight. We do food education, and, above all, we focus more on HC counting* (Nutritionist 1, endocrinology service).

> *At the consultation, we (me and the doctor) analyse all the graphs and the values. They also talk to us to explain what to do if there is hyper or hypo; They remind you of everything; they always ask which needles we use for the pump, they always check that we have everything we need, etc. They remind you of the most necessary things in everyday life.* (Victoriah, T1D patient).

The information about technology management is another item critical to T1D patients, as they frequently need to manage technologies and devices to control glycemic values, insulin administration, carbohydrate intake and other parameters. T1D patients recognise the medical team's strong orientation towards technology and the help provided in managing and using these same tools/devices,

> *I came from a hospital with a lot of technology and innovation, and I felt that I added value to the patients by coming from a different background (...) Moreover, the fact that I like technology and try at home to keep up to date in this area makes people curious. I involve the patients often because they have full access to the information. Often, they come to the consultation asking questions they already know the answer to, but they just want to test whether we know it* (Endocrinologist 1).

Here, there is more technology, more involvement, more closeness. Technology helps a lot. My doctor encourages me to use technology more and more (Julianne, T1D patient).

In the case of nephrology, informational support is mainly expressed through referrals to other services. For example, it is also quite common to refer ESRF patients to assist in the informative session about RRTs, which include dialysis (hemodialysis and peritoneal dialysis), CMKF, and kidney transplant. ESRF patients and nephrologists also mentioned the long-term informational support, reporting the use protocols for follow-ups and a medication administration record for the patients to use at home.

Overall, regarding emotional support, HCPs (endo/neph) recognise the need to be interested in patients (listening and helping them), show proactivity and searching for solutions, act as a driving force of compliance and positive reinforcement, and show awareness of the social and economic condition of patients and their overwhelming condition. They specifically emphasise the need to show empathy, kindness, proximity, respect and build trust and confidence. In such circumstances, the relationship established between physicians and patients becomes like a friendship,

The truth is that we already have a very close relationship with them; it is almost like a friendship (Nutritionist 1, endocrinology service)

We are like two friends talking (Marylin, T1D patient).

We provide a service in the most dignified way that can be understood—the care, the affection, the empathy (Nephrologist 3)

Lastly, within the domain of psychosocial support, HCPs mainly mentioned referrals to mental health services, such as psychology and psychiatry. Long-term psychosocial support is also expressed through the effort of HCPs to refer patients to other additional sources of information or community groups to help them cope with their disease over time,

Whenever I notice that there is a need for support, I recommend psychotherapy (Endocrinologist 2).

We refer some bibliographical references or websites in more interesting cases. Sometimes, not all the information they research is reliable. An endocrinologist who wants to access it can because all the documents have been approved and revised. There is much information, not just on diabetes but on all areas. And then there are the apps and websites that every professional knows about and recommends. Some various tools and guides are provided (Nutritionist 1, endocrinology service).

I recently went on the radio and have already given some patients the link to the podcast. I was interviewed by the University of Minho radio station, and as I explained a few things about kidney disease, I gave the link to some of them (Nephrologist 2).

4.5.1.1.2.2. Availability

T1D patients explain the highest availability of HCPs (after medical appointments) in two ways. The first is inviting patients to go to the hospital whenever needed. Physicians (nurses and doctors) explain that the hospital has "open doors" to them in case of need or that they can call them if they have questions or doubts. The second way is the highest responsiveness by e-mail when patients put questions or doubts regarding the treatment,

I have no complaints, only positive aspects: the doctor's concern, her availability, there are few like her. She is always telling me that if I have any problems, I can call her or send her an e-mail) (Dominic, T1D patient).

4.5.1.1.2.3. Medical, technical competence

HCPs (endo/neph) highlight their technical and transversal skills, such as academic and clinical competencies, previous professional background and experience, multi-tasking capacity, collaboration, proactivity, and willingness to evolve,

I have a group that is interested, collaborative, keen to do things and make progress. I recognise that I have an excellent team and an asset. I am pleased about that (Endocrinologist 3)

In this service, the professionals have diverse experiences and areas of interest. We have excellent colleagues in nephro-clinics who provide internal and inpatient support; we have excellent colleagues in the technical area, in catheterisation, in biopsies, and very good in palliative care (Nephrologist 3).

4.5.1.1.2.4. Involvement of patients and informal caregivers (ICs) in treatment decision-making

This topic highlights the efforts of HCPs (endo/neph) in putting the patients at the centre of their care, which means involving them in their conditions and therapeutical plan (e.g., understanding the disease, the cause of the symptoms, constant questioning, dealing with technologies, whether the case, and developing critical thinking). Otherwise, the errors and frustration could increase,

decreasing adherence to treatment. This effort of involving patients should be adopted as a long-term strategy, employed with consistency over time, very carefully and progressively,

> *In my consultation, I try to include the patient at the centre of the consultation. This is a bit of a buzzword, but for me, getting patients to look at the figures, explain, and ask questions is important. I insist a lot on therapeutic education in the consultation itself; in chronic diseases, in diabetes, the patients themselves always must make decisions, so you must take advantage of the consultation for that. Otherwise, the person is consumed with managing their condition* (Endocrinologist 1).

This involvement is not only relevant for T1D patients, who need to constantly interpret values, take actions, and make decisions about their treatment, but also for ESRF patients who need, at the end stage of their disease, to select one therapy of renal replacement,

> *I had a situation with a man at an informative session about RRTs and he did not even seem to be listening. In the end, his daughter said he was going to do hemodialysis. A few months later, he did have to start hemodialysis, but he had always been angry and frustrated about it. He was in his 70s and used to be very active. One day, I told him to rethink the technique and decide for himself. He effectively changed his technique to the PD and became much happier with his day-to-day life. It is an interesting case showing that people fear the unknown and must do it for themselves. Moreover, that gives them responsibility* (Nurse 1, nephrology services).

The involvement of ICs is also promoted, as they are present at all medical appointments. For ESRF patients, ICs are fundamental as they are often physically and cognitively vulnerable and have a limited ability to capture and understand the received information

> *All the information I give in the consultation, the patient takes in writing. Generally, when patients have the support of a child, or a family member, the teaching is passed on to the patient. However, it is all facilitated by the ICs (...) If the patient comes alone, and if I see that they have difficulty fully understanding the message, I suggest that they always come with informal caregiver to the next appointment* (Nutritionist 1, nephrology service).

4.5.1.1.3. Subtheme 3. Drivers of effectiveness of care and internal processes

4.5.1.1.3.1. Organisation and differentiation of care units and services

The nephrology and endocrinology services are mentioned as good examples and practices of management and organisation. Regarding the nephrology service, the organisation of the information session on RRTs is particularly mentioned as the nurses present all the relevant information in a clear manner and these sessions allows patients to visit the HD room and, therefore, experience the reality of dialysis,

> *We already use audiovisual materials and videos that show how the technique is done. The nurses take the patients to the peritoneal dialysis (PD) rooms, where other patients are doing the technique, and that serves as a counterpoint; they talk about how comfortable and easy it is to do it. When it comes to HD, they also go to the treatment room* (Nephrologist 3).

Also, nephrologists mention the strong and growing support of specific and differentiated medical consultations which provide direct support to ESRF patients, such as nutrition (for patients with general kidney pathologies), pre-dialysis nutrition-nephrology appointment (for patients who already have a progressive disease), advanced kidney disease consultation (for ESRF patients) and peritoneal dialysis (PD) appointments (aimed to assess whether patients have the physical and cognitive skills to go for a selected RRT). In the future, there is the goal of implementing a consultation for CMKF,

> *A CMKF consultation must be directed for patients with advanced chronic illnesses who are not candidates for RRTs and who will require a different kind of monitoring such as clinical follow-up, analyses, and medication, in conjunction with palliative care, social services or internal medicine* (Nephrologist 3).

The endocrinology team also emphasises the existence of differentiated consultations, like the multidisciplinary support consultations for T1D with a pump in which the patient is seen on the same day by a doctor, nurse, and nutritionist. This is a step forward in patient care, which also involves excellent coordination (each doctor is paired with a nutritionist). In addition to the multidisciplinary consultations, there are refresher training sessions for adults.

4.5.1.1.3.2. Timeliness – reduced waiting times

In this dimension, some T1D and ESRF report that they experienced reduced waiting times for accessing outpatient appointments (in nephrology and endocrinology) and scheduling medical exams,

> *The appointments here have always been on time, today I was even telling my wife that the doctor would be at the door ready to see us (laughs). When you come to these places, and you have seen straight away, it is incredible* (Ray, ESRF patient).

4.5.1.1.3.3. Access to care and communication with the HCPs

HCPs (endo/neph) report the easier access to the HCPs through the use of (1) e-mail or giving personal contacts, (2) telehealth and (3) chats. Regarding the first, some HCPs provide institutional e-mails and personal contact information to T1D/ESRF patients as they need extra support over time. However, this is an individual decision and not a formal hospital practice,

> *The patients have my telephone number. They also have a professional e-mail address, but I prefer to give out my telephone number* (Nurse 1, endocrinology service)

Secondly, non-face-to-face medical consultations using telehealth is already recognised in the endocrinology community as a positive consequence of the COVID-19 pandemic.

> *There is one good thing that the pandemic has brought: it has created opportunities for telehealth and online consultations. It has brought advantages to the patient who does not have to go there; it is also easier because it is quicker* (Nurse 2, endocrinology services).

Lastly, efforts are still being made to create chats to articulate the medical team with the patient. When the patient arrives at the hospital, the front officer can use the chat to contact the physicians and nurses, ask questions, and clarify some points, among others,

> *We are setting up chats to see if we can articulate and interact with the whole team; when the patient arrives at the desk, the front officer must contact the doctor or Nurse through the chat. We have already got the chat, but few points are still missing* (Nurse 2, endocrinology services).

4.5.1.1.3.4. Individualised / customised care approach

The dietitians responsible for supervising T1D and ESRF patients strongly manifest the efforts done to provide personalised care and support. The diet plan should be adapted not only to the patient's condition but also to their lifestyle and preferences.

Patients strongly reprove the non-consideration of these factors. For example, in the case of T1D patients, the benefits of the new flexible insulin therapy by carbohydrate counting are widely recognised in nutrition services and such approach can be used with patients to give them more autonomy and flexibility with their meals and food.

> *Today, patients have a much more flexible approach to eating than before. If you count the HC correctly, it may not even make any difference to their glycemic control. Moreover, they become calmer, and this approach is interesting. They even see that they have a more flexible diet, that they do not always have to eat at the same time, the same way, as they used to, depending on their treatment, but particularly with the counts, and that they even have better control* (Endocrinologist 1).

Regarding the ESRF patients, the approach should also be individualised., as quite often, very restrictive nutritional plans create resistance and demotivation in patients, who end up giving up appointments

> *All teaching in this disease must always be very personalised because we do not all eat the same things and the same as each other. In the old days, even before my training, there was much talk about hyperkaliemia, cutting tomatoes and potatoes or bananas. My practice is not drastically cutting them out as It affects the patient's quality of life. In short, the behaviour should be ideal but not restrictive, respecting each person's tastes and individuality because the forbidden fruit is always the most desirable. Therefore, I cannot tell a patient who eats tomatoes daily that they can never eat tomatoes again. I will not adhere to the therapy and will not attend my next appointment* (Nurse, nephrology service).

4.5.1.1.3.5. Standardised processes and protocols

The standardisation of processes has been mentioned mostly by endocrinologist, as a factor that improves internal efficiency. Prominent examples of standardisation regarding T1D patients include the creation of performance protocols (especially in the nutrition service) and patients' visits to the nursing unit before the endocrinology consultation. During this visit to the nurse, all procedures were also standardised. Patients perform a series of activities that optimise the medical consultation, such as weighing, measuring blood pressure, and reviewing lessons about insulin, technologies, apps, and CGMs,

> *The most important thing is undoubtedly to have our actions protocolised, to have procedures so that each one can understand the other's language. We all collect data in the same way. As a director, one of my roles is to audit patients' medical files. I periodically check whether the protocols are being followed because it is very harmonious to work in this way rather than each having its own method and way of working. For example, for patients who are transferred from paediatrics to adults. It is important to have everything standardized* (Nutritionist 4, endocrinology service).

4.5.1.1.3.6. Patient satisfaction measures

There is a perception by the HCPs (endo/neph) that the patient's overall satisfaction with the endocrinology and nephrology services is positive,

> *The perception of the care provided by the hospital to these patients is very positive. Even in nephrology, there is a high level of satisfaction* (Nutritionist 1, nephrology service).

4.5.1.1.3.7. Smooth and seamless delivery of care – care coordination efforts

Nephrologists, in particular, also refer to the continuous efforts to articulate the interactions between the Hospital of Braga and external entities, such as primary care and family doctors. The development of closer ties with primary care and the establishment of training programs with family doctors aims to improve the access and the quality of health services for the overall population,

> O*ne of the things I am trying to do with Viana do Castelo is to go there and talk, set up meetings. It is for us to get out of the hospital, and there is even a project called "the hospital goes to the street" which is for us to go to the family doctors and have consultations with them there* (Nephrologist 1).

4.5.1.1.4. Subtheme 4. Negative interactions between patients and HCPs

4.5.1.1.4.1. Communication barriers with patients

From the HCP's perspective, the most critical communication barrier with patients is their high vulnerability (emotional and physical). Emotional vulnerability is mainly linked to disease issues, such as conflicts dealing with the diagnosis, difficulties in managing the condition and its many complications, and the fear and myths associated with the disease. In the case of T1D, most difficulties come from managing their condition at a daily basis, which is very complex and encompasses many tasks such as monitoring glycemic values, administrating insulin, calculating insulin rations and carbohydrate intakes, and managing exercise, sports, and nutrition,

> *The first consultation is more about familiarisation, because I notice more resistance on arrival, and it is also a disease associated with much denial. I think it is associated with a huge emotional burden, a huge stigma. Since most of the population is very young, children and young adults do not have the skills to deal with all this. It creates some adaptive changes that are not necessarily good, which become increasingly difficult to deconstruct throughout life* (Endocrinologist 2).

Also, due to the high complexity and burden associated with T1D, female patients suffering from this disease tend to develop eating disorders, such as anorexia.

In the case of ESRF patients, the main difficulties and concerns in managing their condition are associated with the nutritional and diet plan (which is the most severe and complex to follow) and the fears and myths associated with the dialysis techniques,

> *Understanding why dialysis is necessary is one of the main problems. In other cases, it is about dealing with this information, which is sometimes emotionally painful for those who do understand. Life changes a bit. Some people have many myths about dialysis. They are terrified of dialysis, and they have only heard a neighbour or relative talking about it. They immediately become terrified and paralysed; they do not even want to hear anything else* (Nephrologist 1).
>
> *Of all the diets associated with the disease, the pre-dialysis diet is the most difficult to comply with. It is the most senseless; it is low in salt, requires restricting fluids, and in summer, it is tough; those with hyperkaliemia must demineralise certain foods in two glasses of water, making it even more senseless. However, as it is a tough diet, they quickly lose motivation* (Nutritionist 1, Nephrologist service).

The emotional vulnerability of patients can also be explained by hospital-related motives (e.g., waiting times, errors with medical appointments, or HCPs turnover) or personal-related motives,

> *We always have some patients (outliers) who always say bad things about everything, but they are usually isolated people or people who have had very negative experiences and very complex lives, and it is a bit like externalising everything* (Endocrinologist 1).

Physical and cognitive vulnerability can be mostly expressed in ESRF patients who can develop physical and cognitive complications, such as age-related hearing loss and difficulties with comprehension of their disease characteristics and treatments. The difficulties in the communication with patients also increase when they are not accompanied by their ICs,

> *In terms of communication, another problem is that some people cannot hear. There is much deafness in nephrology. They have had drugs that make them deaf. They do not hear, and what they do hear, they do not understand; it is tough to get the person to absorb the message and back off the language* (Nephrologist 2).
>
> *And then they come alone, and I cannot give them all the information, so there is no doubt that a patient with an informal caregiver, the responsibility is shared"* Nurse 1, Nephrology service).

These comprehension problems are particularly evident in some older T1D patients,

> *What we do before patients go to the consultation is always measure their weight and blood pressure and do a brief review of insulin administration. For example, one day I taught a diabetic couple how to administer insulin, and they were super calm and doing everything right. After two days, they came here to ask for help because their insulin levels were still too high. It is frustrating. So, let us do it again!* (Nurse 1, endocrinology service).

The second main obstacle to communication is the low health literacy and knowledge about their condition, treatments, and therapies. This aspect is particularly evident in the case of ESRF patients who do not know what the kidney function is, have wrong perceptions about what is a healthy nutritional plan and frequently make errors with their medication,

> *Health literacy is low. Patients do not know what they are coming for; they do not know what nephrology is, and they do not know much about kidney problems. Then there is the problem of therapy, where patients do not know what the drugs are for, and sometimes they do not have things well organised, and they make mistakes; they do not comply with the medication properly. Medication management and adherence is undoubtedly a very*

critical point. People do not know why it is essential and sometimes do not do it properly. It is tough to change habits (Nephrologist 2).

Another critical obstacle identified by HCPs relates to the heterogeneity of patients in terms of age, socio-economic conditions, and old habits, and even personality. Such variety makes the medical appointments more complex to manage and applies to T1D and ESRF patients,

At one end of the spectrum there are very educated people – generally younger people - who have different backgrounds and want to know a lot. Then there are more anxious people who want to know minor details in a stressful manner (Nephrologist 2).

Other less-mentioned factors were (1) the higher rate of HCP turnover and patient no-shows and the (2) the technology used during medical appointments, such as PCs and health information systems (HIS). Regarding the first, the high turnover of HCPs within the endocrinology and nephrology services creates additional difficulties in the involvement of patients. As each physician has specific therapeutic strategies and approaches to deal with patients, the patients feel frustrated when physicians change and, therefore, tend to skip medical appointments. The second aspect is related to the technology which can be a physical barrier between the physician and the patient. Sometimes, physicians waste a lot of time dealing with technical problems, information overload, and even searching for information on these platforms, which can prevent a more active dialogue and conversation with the patient.

4.5.1.1.4.2. Lack of support delivery

HCPs identified three main types of support that are particularly challenging to deliver to patients. The first is informational support **-** helping patients with disease education and managing medication and technologies because of the time consumption. This issue is particularly relevant for endocrinologists and nurses responsible for delivering care to T1D patients,

In addition to medical consultation, we must teach technology, how to deal with technology, receive the data, think, analyze, and take a therapeutic attitude. And even a non-face-to-face consultation is no less time-consuming than a face-to-face one. And even then, it is an overload (Endocrinologist 1).

Furthermore, when it comes to informational support, providing recommendations for specific apps and technologies poses a challenge for endocrinologists, given the rapid evolution of technology which demands constant updates and ongoing learning.

The second type of support that is still lacking is emotional support. This topic is reported by patients (ESRF/T1D) and covers the lack of empathy, respect and humanity of HCPs towards patients and relatives. Some of these situations happened with auxiliary, administrative services or even nurses while interacting with older people with visible physical limitations,

> *We cannot treat people like a number, we must treat people like human beings (...) they (people in Hospital of Braga) are not that kind to people* (Carol, T1D patient)
>
> *Every time I pass the reception desk, it is a trauma for me. Some people cannot hear and cannot see. That is difficult for people who are 80 or 90. Moreover, the people attending do not have the patience to deal with them. My stress about going to the hospital is having to see these things. Moreover, now, I am taking a course in elderly care, and that makes me think even more and get angrier* (Marylin, T1D patient).

In this context, the absence of emotional support is evident in the behavior of HCPs who disregard their patients, failing to consider their opinions and perspectives and instead adopting a paternalistic stance. Paternalism in a healthcare setting refers to situations where physicians or other HCPs make decisions on behalf of patients without their explicit consent, under the belief that these decisions are in the patients' best interests,

> *I was told I had chronic kidney disease and had to have a biopsy. A doctor saw me. I did not like it very much. I asked him why he was doing this and that, and he just looked at his computer, telling me what to take. He gave me a medication - corticoids - in a very high quantity - and I started to feel unwell and called the hospital in the meantime, but no one would answer me. In the meantime, as I was working in Germany I decided to go to hospital there where a nephrologist looked at my analyses and weaned me off the corticoids. Here, the doctor did not answer any questions; he just prescribed. All I knew was that I had to take the pills* (Daniyal, ESRF patient).

Lastly, regarding the lack of psychosocial support, even though HCPs are aware of its importance, they emphasize that there are not enough resources to provide it. They report the lack of time and human resources to conduct collective patient meetings or create educative materials and content in this domain. This type of support is critical during the post-consumption of care, where patients are engaged in a process of knowledge enhancement, searching for peer support, and daily managing their condition,

> *We even tried with the nursing team to create the same language and even group sessions, especially for transition and pump patients, precisely to standardize the language. We are*

so absorbed in our care activity that there is no time to create nice content to give to patients, to create a YouTube channel with various themed videos, to have support for printing more appealing written material and not that black and white photocopy. We do not have much time to carry out these important tasks (Endocrinologist 1).

4.5.1.1.4.3. Medical malpractice or lack of technical competence

This topic covers various examples of medical malpractice reported by patients, such as improper medication or dosage, premature discharge, and disregarding or not taking appropriate patient history,

Being diabetic and coming to the hospital to be treated not for diabetes but for other problems is complicated. I had a surgery on my mouth, and I was fasting when my diabetes was 400. And I said, "I need to take my injection" and they said: "No, it had to be the hospital insulins"! If I have my equipment, why will I use the hospital insulins? A nurse even turns to me and says, "Oh, your levels are too high," I said, "Yes, they are, with the food you gave me. I always say that I am diabetic, and the person must see all the medication I am taking! I think they have got it wrong (Carol, T1D patient).

4.5.1.1.5. Subtheme 5. Positive interactions with servicescape

4.5.1.1.5.1. Hospital environment and infrastructures

Regarding the physical environment and infrastructures, patients (T1D/ESRF) associate the hospital with a new, beautiful, modern, and robust building providing cleanliness, comfortable and familiar environment,

I like the hospital; it is like a shopping centre (laughs) (Doug, T1D patient).

HCPs mainly mention the positive aspects concerning the hospital infrastructure such as the proper work conditions for internal staff,

In terms of infrastructure, compared to other hospitals I've worked in, here it is perfect; we have ideal working conditions, large rooms, and a bright hospital, and that is very important. We spend most of our day here; most of us work a 40-hour week, and a hospital with good conditions improves the working environment (Endocrinologist, 2).

4.5.1.1.6. Subtheme 6. Negative interactions with servicescape

4.5.1.1.6.1. Hospital environment and infrastructures

Patients (T1D/ESRF) have reported several negative aspects regarding the hospital infrastructure, primarily concerning the increased charges for car parking. Additionally, other negative factors were highlighted, including challenges related to complex pathways within the facility for patients, and concerns about cleanliness and hygiene standards. For example, a specific incident involving a nurse was reported,

> *I had blood test just before the COVID-19 pandemic began. Upon arrival, I encountered a nurse who had just finished drawing blood from another patient and then approached me. I jokingly asked, "Did you lose your gloves?" as I noticed he had not worn gloves or disinfected his hands. His response was rather brusque: "Sit down," he ordered. Surprised by his tone, I persisted, "Aren't you going to disinfect your hands?" to which he replied, "No." Subsequently, I patiently awaited the opening of the complaints center to address the situation* (Amandine, T1D patient).

4.5.1.1.6.2. Poor quality and inadequacy of food and beverages

Patients (ESRF/T1D) often express concerns beyond just the taste of the food. They frequently mention the unpleasant smell of the plastic wrapping around the food and the mismatch between the meals provided and their physical condition,

> *For instance, in the case of my 89-year-old mother, certain foods are simply not suitable for her to eat, such as a raw apple. It's unrealistic to expect her to consume it in that state; instead, it needs to be prepared in a baked or boiled form to be manageable for her. I hope better standards can be improved here* (Carol, T1D patient).

4.5.1.1.7. What really matters to patients?

After identifying the critical touchpoints in patients' journey with T1D and ESRF, we sought to understand what matters most to patients within the hospital. Specifically, patients were asked to prioritize the factors that contribute to a positive experience within the hospital environment. Their responses shed light on key touchpoints within the hospital experience that hold significant weight in their overall perceptions. Firstly, T1D patients emphasized the moment of service encounter and interactions with healthcare professionals (HCPs) as pivotal for a positive experience. They highlighted the importance of HCPs demonstrating (1) education, respect, and kindness, (2) the ability to actively listen and allow patients to express themselves freely, and (3) proactive problem-solving and assistance. Additionally, within the realm of interactions with HCPs, they stressed the importance of emotional support and fostering trusting relationships to instill a sense of security. ESRF patients, in turn, emphasized the effectiveness of care services and internal processes, focusing on reducing waiting times for outpatient appointments and exams. Regarding the atmosphere and service environment, T1D patients emphasized the significance of overall cleanliness and the affordability of car parking charges. All patients expressed confidence in recommending the hospital to friends and family, underscoring their positive overall perceptions of the institution.

Table 4. 10– Synthesis of Theme 1.

Theme I. Interactions with the hospital processes, staff and servicescape
Brand sphere (brand-owned touchpoints) mostly during service encounters
6 subthemes; n=38 (100%)

	Predominantly view	Focus		Main stage of the journey
		General	Specific	
Subtheme 1. Drivers of ineffectiveness of care and internal processes				
Lack of timeliness / excessive waiting times	P (ESRF) / HCPs (neph)	X	X	During service encounters
Poor access and communication with hospital	P (ESRF) / HCPs (endo); ICs	X		During service encounters
Lack of resources and weak response capacity	HCP (neph/endo)	X	X	During service encounters
Lack of customized care approach	P (T1D)		X	During service encounters
Issues with organisation of services	HCP (neph/endo)		X	During service encounters
Lack of smooth and seamless service delivery	HCP (neph/endo), P(ESRF)		X	During service encounters
Subtheme 2. Positive interactions (HCPs towards patients)				
Support delivery (informational, emotional and psychosocial)	HCPs (endo/neph); P(T1D/ESRF)		X	During service encounters
Availability	HCPs (endo); P(T1D)		X	During service encounters
Medical technical competence	HCPs (endo/neph)		X	During service encounters
Involvement of patients and ICs in the treatment decision making	HCPs (endo/neph)		X	During service encounters
Subtheme 3. Drivers of effectiveness of care and internal processes				
Organisation and differentiation of services services	HCP (neph/endo)		X	During service encounters
Timeliness / reduced waiting times	P (T1D/ESRF)	X	X	During service encounters
Access to care and communication with the HCPs	HCP (neph/endo)	X	X	During service encounters
Individualized / customized care approach	HCP (neph/endo)		X	During service encounters

Standardized processes and protocols	HCP (endo)		X	During service encounters
Patient satisfaction measures	HCP (neph/endo)		X	During service encounters
Smooth and seamless service delivery - care coordination efforts	HCP (neph)		X	During service encounters
Subtheme 4. Negative interactions between patients and HCPs				
Communication barriers with patients	HCPs (endo/neph)		X	During service encounters
Lack of support delivery (technical, emotional and psychosocial)	P (T1D/ESRF), HCPs (endo/neph)	X	X	During service encounters
Medical malpractice and lack of technical competence	P(T1D)		X	During service encounters
Subtheme 5. Positive interactions with servicescape				
Hospital environment and infrastructures	HCPs (endo), P(ESRF/T1D)	X		During service encounters
Subtheme 6. Negative interactions with servicescape				
Hospital environment and infrastructures	P (T1D/ESRF); HCPs (neph); ICs	X		During service encounters
Poor quality and adequation of food and beverages	P (T1D/ESRF)	X		During service encounters

Source: Authors' elaboration

4.5.1.2. Theme 2 – The role of patients in care and self-management

The second most prevalent theme centers on the patient's perspective, highlighting their initial symptoms, concerns, coping strategies, and accomplishments over time throughout their journey with the disease (patient-owned touchpoints). Within this theme, six subthemes emerge, including (1) daily challenges associated with the disease, (2) adjusting life to the chronic illness, (3) symptoms awareness and searching for care, (4) negative emotions and attitudes towards the condition, and (5) positive attitudes towards the condition. These touchpoints occur beyond the hospital setting, during the self-management of care, and are particularly emphasized by patients. A synthesis of theme 2 is presented in Table 4.11.

4.5.1.2.1. Subtheme 1. Daily challenges associated with the disease

4.5.1.2.1.1. Lifestyle changes

Almost all participants have identified the main challenges that patients face when attempting to take an active role in managing their disease. These challenges include dealing with (1) physical activity and sports nutrition, (2) eating habits and nutrition, (3) technologies, (4) medication, and (5) intimate relationships.

Regarding the first challenge (1) physical activity and sports, T1D patients often encounter uncertainties about what they should eat before, during, and after exercise to maintain stable blood sugar levels. Many individuals have experienced fear and trauma related to physical activity due to previous negative experiences, such as hypoglycemia. Consequently, these apprehensions and traumas associated with physical activity can lead to demotivation and a persistent preoccupation with their disease,

> *Sport reminds me that I am diabetic because it gives me hypos. When I go for a walk, it is always at a low level, and then I think, 'Thank you for reminding me that I am diabetic' – laughs."* (Julianne, T1D patient).

> *Some patients who used to engage in regular physical activity, such as running or gym workouts, may hesitate to continue due to past experiences of experiencing sudden drops in blood sugar levels (hypoglycemia) during exercise. Others may avoid physical activity altogether after experiencing episodes of hyperglycemia, leading to confusion about the impact of exercise on blood sugar levels. This uncertainty often leaves patients feeling*

embarrassed to ask questions or seek clarification from HCPs. Sometimes they prefer to go to the Facebook group to ask. It is essential to teach them. That is why the relationship with the doctor is significant, and we only find out many things over time during consultations (Endocrinologist 2).

The second challenge (2) is nutrition, especially for T1D patients as it requires them to acquire new habits and routines for calculating insulin-to-carb rations and meal insulin dosages. It is a habit that many patients neglect and, hence, they end up making random estimates. The lack of motivation to weigh food and calculate HC also derives from the Portuguese culture, which, compared to other cultures, needs to keep evolving on eating control habits. Eating out can also discourage sufferers as they do not control what food comes in or how it is composed, which makes measuring and weighing difficult. Finally, the myths involved in diabetes (e.g., they must eat every 3 hours and food suitable for people with diabetes) also contribute to the demotivation of these patients,

What concerns them most is their diet. There's this misconception about "diabetic food," which is actually just regular food. In other words, it is a myth that has been perpetuated. There's also the misconception that, as a diabetic, you have to eat every three hours, which is not true either. It is challenging to go to the restaurants, especially when meals are already prepared. In such situations, one of three scenarios typically occurs: either the person attempts to make do with what's available, or they opt not to eat because they are unsure of the content, or they simply rationalize it by thinking "once won't hurt." This ambiguity around food choices exacerbates the problem for diabetic individuals (Endocrinologist 2).

Still on eating and nutrition habits, patients (T1D) highlighted their difficulty in correctly reading the packaging labels (for example, knowing how to analyze the CH values per 100g). Some mention having doubts about how to interpret packaging and labels. The diet is also very rigorous for ESRD patients, due to the restrictions in terms of salt and protein. The options are limited and tasteless, which makes it very difficult for these patients to follow the plan. Therefore, the help of the nutritionist here is essential,

I attempted to seek nutritional guidance at one point. I specifically asked my doctor to refer me to a nutritionist because I had concerns about interpreting food labels. Many packages display information about carbohydrates (HC) and 'of which sugars.' My question was which one of these values I should prioritize in managing the equivalent insulin units (Amandine, T1D patient).

The third challenge (3) is technology management. T1D patients' condition implies adaptation to a vast kit of devices (CGMS, insulin pumps, and carbohydrate calculation apps). In general, the devices also present some limitations for patients, such as the accuracy of the results/indicators, the management of the notifications throughout the day, possible skin reactions to the devices and infections, and technical problems,

> *The disadvantage of the pump is sleeping with it; it is uncomfortable. The other limitation is that it is an electronic device; it can fail. I have already had a fault and had to fix it (Doug, T1D patient).*

The fourth challenge (4) pertains to medication management, which presents ongoing issues for both T1D and ESRF patients along their healthcare journey. For individuals with T1D, managing medication involves not only administering insulin manually or through a pump but also the meticulous task of counting carbohydrates, often aided by available apps. On the other hand, ESRF patients face the task of managing a substantial volume of medication, leading to challenges such as forgetfulness, medication mix-ups, and errors,

> *The patient must learn numerous dietary rules, as well as various regulations concerning insulin treatment* (Endocrinologist 3).

> *Many individuals express dissatisfaction with the substantial amount of medication they must take, which can be overwhelming. In some cases, especially with CMKF we may need to consider de-prescribing medications. This not only impacts the patient and their family but also contributes to the patient's fatigue. One of my priorities is to assess and discontinue medications that are no longer beneficial or necessary. It's important to be mindful of the prognosis, as it may be poorer in some cases* (Nephrologist 1).

The last challenge (5), in the view of HCPs (endo/neph), is how the chronic condition affects several areas of personal life, namely intimate and affective relationships. The lack of normalization of the disease still means that some patients do not share with their girlfriends/boyfriends that they have the disease.

> *Having End-Stage Renal Disease (ESRD) can significantly impact both physical and sexual aspects of life, and these effects are often challenging to reverse. However, it is possible to provide support and assistance to help individuals lead as normal a life as possible under the circumstances* (Nephrologist 3).

The perception of T1D has evolved significantly over the past decade, yet some parents have not kept pace with these changes, which can have negative consequences. It's surprising to see that individuals with T1D often choose not to disclose their condition to their romantic partners. This lack of disclosure can be difficult to comprehend, given the importance of open communication and mutual understanding in any relationship (Endocrinologist 1).

4.5.1.2.2. Subtheme 2. Adjusting life to the chronic illness

4.5.1.2.2.1. Seeking for physical and mental well-being

Patients seek to enhance their physical and mental well-being while maintaining a healthy identity. They engage in activities and hobbies that serve as momentary distractions, allowing them to forget about their condition. For T1D patients, sports, physical exercise, and hiking are popular choices, along with activities like acupuncture, reading, and watching movies or series. Some even express that they "almost forget" they have the disease because they prioritize staying active. ESRF patients, on the other hand, often go to the internet and spend time with family. Additionally, both ESRF and T1D patients recognize therapeutic benefits from the companionship of animals.

4.5.1.2.2.2. Developing coping strategies

Due to their chronic condition, many T1D patients develop autonomy and self-sufficiency in managing their disease and controlling symptoms. Some have established consistent routines for glucose measurement, carbohydrate calculation, and insulin administration, whether through traditional methods or with the support of an insulin pump. This allows them to anticipate scenarios and employ preventive strategies effectively. Additionally, some patients aim to normalize the management of their disease, openly carrying out treatments in front of others. This proactive approach to responsibility and practical learning about the disease may contribute to reducing hospital admissions for decompensation. In the patients' perception, insulin pumps offer better long-term disease control and greater convenience. These proactive initiatives and strategies employed by T1D patients can lead to improved clinical indicators of well-being and quality of life.

Similarly, ESRF patients also implement strategies to optimize their medication management. Given the large quantity of medication they must take daily, they develop methods to prevent forgetting or incorrectly taking pills,

> *I take 11 tablets a day. I bought a box divided into days - Monday to Sunday - and phases of the day - morning, noon, afternoon, evening, and that is it, I arrange them like that* (Daniyal, ESRF patient).

4.5.1.2.2.3. Seeking contact with others/information

Some patients, both with ESRF and T1D actively seek second medical opinions for various reasons. This may include validating diagnoses, exploring alternative treatments, gathering additional information about their disease, and seeking technical support for managing medical devices involved in their treatment. This search for information often takes place outside hospital boundaries. One of the most significant changes identified in the patient diaries and discussed in follow-up interview was the change in attitude towards seeking information about the disease. For example, in the first-round interview, a patient with T1D reported not having any interest in searching and knowing more about her disease. Six months later, the same patient revealed a drastic change in her attitude, having even searched for treatments and solutions in alternative medicine, namely in acupuncture and Magnetic Resonance Imaging (MRI[8]). These treatments are not used as a substitution of the traditional ones but as a complement which also enhances the health outcomes,

> *When you are ill, you look for everything you can. I have been to acupuncture; I have been to many things. you lose much money but learn more. You do not use alternative medicine to replace what you have or are given here. It is a compliment. You prevent what might happen. If I have diabetes, I know that I am likely to have many more illnesses. You try to find something that will help you in the other direction because nothing will cure you. I have even had some success stories from people who have tried alternative medicine. When I started going to alternative medicine, I was also a bit afraid that the doctor would think you were doing it against her or going against what she told me. But it is just a compliment. I think it is important for a T1D patient to seek opinions from other*

[8] - MRI is a non-invasive method of treating various conditions. It is a type of therapy used in holistic or complementary medicine which uses a machine to measure the frequency of energy wavelengths coming from the body

endocrinologists and to look for complementary therapies and alternative medicine. People must be open-minded about new options (Victoria, T1D patient).

4.5.1.2.2.4. Becoming experts in their condition

Patients, especially those with T1D, keep on organizing and interpreting their clinical data, particularly their blood glucose values. This daily management of glycemic control is a fundamental aspect of their lives. To optimize their interactions with HCPs, patients maintained meticulous records of their values through medical devices that provide real-time access to this information. Prior to this technological revolution, patients relied solely on manual methods for monitoring blood glucose levels, which were prone to potential inaccuracies or deliberate modifications. With the introduction of Continuous Glucose Monitors (CGMs) and their widespread adoption, many patients now benefit from automated data storage within these devices. This shift eliminates the need for manual record-keeping as historical data is seamlessly stored and accessible for analysis during consultations.

Hence, these medical devices promote the patient progress, increase treatment adherence, convenience, transparency and the effectiveness of service encounters. These advanced technologies provide HCPs with real-time access to data and results, as well as a comprehensive history of the patient's glucose values. The ability to monitor glucose levels continuously allows for timely interventions and adjustments to treatment plans, ultimately leading to better outcomes for patients with T1D. Moreover, these technological advancements have brought greater autonomy in disease management for patients. With CGMs and insulin pumps, individuals with T1D can make informed decisions about their insulin dosing and lifestyle choices, resulting in improved control over their condition and overall health. Moreover, CGMs are discreet, practical and allow greater flexibility and freedom to the patient, who does not have to resort to blood strips and all the associated procedures. This accuracy, convenience, and accessibility (affordable price) explain the greater adherence to these technologies and devices.

Nevertheless, despite the significant advantages of diabetes-related technologies and devices, one important limitation was mentioned by HCPs, namely, the technological revolution that must go beyond the service provider's control. From the perspective of endocrinologists, patients' power and autonomy can escalate, which becomes a threat, primarily because of the lack of medical control over such applications and devices.

4.5.1.2.3. Subtheme 3. Symptoms awareness and searching for care

The presence of noticeable symptomatology is frequently reported by both T1D and ESRF patients. In the case of T1D patients, initial symptoms commonly include excessive thirst, frequent urination, significant weight loss, and persistent fatigue. Some individuals may also experience episodes of diabetic ketoacidosis, characterized by symptoms such as nausea, vomiting, and severe abdominal pain, marking the onset of their journey with the condition. Additional symptoms occasionally reported by T1D patients, albeit less frequently, encompass excessive hunger, dry mouth, severe muscle pain and weakness, nausea, vomiting, breathing difficulties, abdominal discomfort, and distinctive odor in urine. These symptoms typically expressed acutely and served as crucial indicators prompting medical attention.

In contrast, the symptomatology of ESRF often presents differently, characterized by its silent progression until reaching an advanced stage. Symptoms such as profound fatigue and swelling in the face, hands, and feet tend to manifest more prominently as the disease progresses. Consequently, some patients may only become aware of their condition during hospital visits for unrelated reasons, where tests or physical examinations reveal indicators such as high blood pressure and protein loss in urine (proteinuria). This delayed recognition underscores the insidious nature of renal failure and the importance of proactive medical evaluation in its detection and management.

4.5.1.2.4. Subtheme 4. Negative attitudes and emotions towards disease

4.5.1.2.4.1. Feelings of revolt and tiredness; fears and myths

Upon receiving their diagnosis, patients commonly experience a range of intense emotions, with shock, revolt, and fear being frequently reported. Shock is particularly prevalent among T1D patients, especially those diagnosed during childhood or adolescence, who often initially believe the condition to be transient or curable. This misconception contributes to feelings of deep sadness as they confront the reality of a lifelong illness. HCPs emphasize that patients also experience negative emotions throughout their illness management journey. The predominant emotion reported is fatigue, stemming from the myriad daily challenges patients face. For T1D patients, these challenges include navigating dietary restrictions, adhering to exercise routines, and managing medication regimens. In contrast, ESRF patients encounter significant dietary limitations,

particularly during the pre-dialysis stages, which exacerbate feelings of frustration and limitation. HCPs also refer to fears and myths expressed by many patients with both pathologies. In the case of ESRF, the fear of starting RRTs results from the negative experiences of friends or colleagues. T1D patients, in contrast, can show fears related to hypoglycemia and others of hyperglycemia.

4.5.1.2.4.2. Refusing to accept the disease and developing obsessions

Managing a chronic illness that persists throughout life without a cure presents significant emotional challenges. Many patients find it difficult to accept this reality, and resistance or denial is a common response. Some individuals consciously choose to ignore or avoid treating the disease, while others may do so due to a lack of understanding of the complexities involved,

> *T1D is a disease that, if left untreated, may not lead to survival. Some do not care, do not understand, or if they do understand, do not do it, and have frequent decompensations and frequent visits to the emergency room, which can lead to serious complications* (Endocrinologist 1).

In the case of ESRF patients, resistance and refusal of treatment happen mainly when confronted with RRTs, which will affect their lives in many different areas.

Another concerning phenomenon observed among T1D patients is the development of obsessive behaviors and mental illnesses, particularly evident in cases of eating disorders among young women. Some individuals, particularly those with a focus on weight control, may develop opportunistic attitudes toward their illness, exploiting the relationship between insulin management and weight loss,

> *Some women realize that if they do not give insulin, they lose weight. Some do not eat HC to give the minimum amount of insulin, which jeopardizes the growth of their babies. This It is increasingly seen in young adults and even pregnant women* (Nutritionist 4, endocrinology service).

Depression is a prevalent condition among ESRF patients, as noted by the nephrologists, in particular. The debilitating effects of ESRF, including extreme fatigue and diminished strength resulting from kidney function decline, often leave patients unable to maintain productivity or employment. This loss of function and independence can contribute significantly to feelings of despair and hopelessness.

4.5.1.2.5. Subtheme 5. Positive attitudes towards disease

4.5.1.2.5.1. Acceptance, adoption of a new positive perspective

In the journey of living with a chronic condition like T1D, patients' attitudes can undergo a significant transformation, particularly after initially grappling with denial. As patients come to terms with their diagnosis and accept their condition, a shift in mindset occurs, characterized by determination and resilience in managing and controlling their symptoms. This change in attitude is often driven by an awareness of the importance of cooperating in treatment and symptom management. Patients who undergo this mindset shift often cite previous hospitalizations and health complications stemming from denial as pivotal moments that spurred them to take charge of their health with a positive and proactive approach. Embracing an open and flexible mindset becomes critical. Furthermore, the process of relativizing the disease plays a crucial role in fostering acceptance. By comparing their condition to other more severe physical or psychological ailments, patients gain perspective and diminish the impact of their illness, empowering them to navigate their health journey with resilience and optimism,

> *If I had to choose a disease, I'd choose diabetes. It's not just because I've been used to it since I was little; it helps me eat a balanced diet. Within the spectrum of problems, diabetes will be the best* (Amandine, T1D patient).

Table 4.11– Synthesis of theme 2.

Theme II. The role of patient in care and self-management
Patient sphere
(patient-owned touchpoints) mostly in post-care encounters
5 subthemes; n=33 (86,8%)

	Predominantly view	Focus		Main stage of the journey
		General	Specific	
Subtheme 1. Daily challenges associated with the disease				
Lifestyle changes	P(T1D/ESRF); HCPs (endo/neph)		X	Post service encounters
Subtheme 2. Adjusting life to the chronic illness				
Seeking for physical and mental well-being	P(T1D/ESRF)		X	Post service encounters
Developing coping strategies	P(T1D/ESRF)		X	Post service encounters
Seek contact with others/information	P(T1D/ESRF)		X	Post service encounters
Becoming experts in their disease	P(T1D); HCPs (endo)		X	Post service encounters
Subtheme 3. Symptoms awareness and searching for care	HCPs (neph), P(ESRF/T1D)		X	Pre service encounters
Subtheme 4. Negative emotions and attitudes towards disease				
Feelings of revolt and tiredness, fears and myths	P(T1D/ESRF); HCPs (endo/neph)		X	Post service encounters
Refusing to accept the disease and developing mental diseases / obsessions	HCPs (endo/neph)		X	Post service encounters
Subtheme 5. Positive attitudes towards disease				
Acceptance, adoption of a new positive perspective	P (T1D/ESRF)		X	Post service encounters

Source: Authors' elaboration

4.5.1.3. Theme 3. The influences from the social circle

The third most frequent theme focuses on how social actors (family, friends, peers, and others) (social-owned touchpoints) influence the patients' perceptions, choices, and experiences throughout their journey. Indeed, the theme "the influences from social circle" encompasses four subthemes such as (1) the lack of support; (2) support delivery; (3) the role of OHCs and patient groups; and (4) the changing role of ICs. Overall, this theme entails touchpoints that mainly occur outside hospital boundaries during the post-consumption of care services. A synthesis of theme 3 is presented in the Table 4.12.

4.5.1.3.1. Subtheme 1. Lack of support

The patients' family, friends, and social circle can negatively influence their experience and perception of the disease, as well as affect their adherence to treatment. The leading cause is related, according to the T1D patients and endocrinologists, to the higher level of disinformation and stigma associated with T1D. For example, at the work level, misinformation discourages T1D patients from talking about their disease, and some choose to hide their condition from their managers. As such, T1D patients and their HCPs report that some managers explicitly state that they do not employ people with diabetes. The condition itself can affect patients in the performance of their tasks and lead them to be less productive, which can make them even more embarrassed and afraid of losing their jobs,

> *That is why there are people who we think are defaulters and who do not care about diabetes, and if we go exploring, in the workplace, people do not even know that he/she has diabetes, and so they do not take insulin in the workplace because people don't know that they have the disease* (Endocrinologist 2).

In the context of education, there is also a lot of misinformation and stigma associated with diabetes. The discovery of diabetes at younger ages is subject to a lot of stress. It is sometimes associated with bullying by peers. Even in high school or higher education, the lack of knowledge and information from the teaching staff about the disease can lead to students with T1D being misunderstood regarding their physiological needs and the practice of high-level physical exercise,

> *I remember a time when someone said to me, 'You are not going out to eat,' and I was so shocked that I nearly fainted because I needed to eat. I responded, 'Well then, I'd rather leave because I have to eat.' It's frustrating because sometimes teachers or people in authority assume things can wait, but it is not that simple for someone with a condition*

like mine. Some people just need to be more informed. Younger individuals seem to better understand these issues, but it can be more challenging for older professors, especially those aged 60 or over (Marylin, T1D patient).

Even at school level, the exercise is not very well structured. It is important to discuss this: people with diabetes can and should do high-level physical exercise. They must know what to do; we must teach them. It is important to teach them, and some are embarrassed to ask (Endocrinologist 2).

According to T1D patients, their friends and peers can be potent blockers of progression and adherence to diabetes therapy. Diabetes is still strongly associated with physical and psychological limitations, which does not allow everyday life for those with the disease. Thus, a fictitious idea is created that it is difficult for diabetics to develop effective romantic relationships,

I recall a conversation with friends where they expressed disbelief about how someone with diabetes, particularly while using an insulin pump, could engage in sexual activity. They questioned the logistics and comfort level of having sex with a pump attached, expressing their inability to envision such a scenario (Victoriah, T1D patient).

Finally, endocrinologists state that family members and people living with chronically ill persons are not always capable enough to allow and to understand their specific dietary and treatment needs. Sometimes cultural habits and poor health literacy lead relatives to block treatment and patient motivation.

4.5.1.3.2. Subtheme 2. Support delivery

Even though the main subtheme was the lack of support from the social circle, family and friends can provide instrumental support, such as assistance with activities of daily living such as nutrition and medications. They are also a source of emotional support for patients by developing the ability to cope with their chronic conditions in the long term,

On a personal level, I do not feel much difference because I think the people I have around me are wonderful. They (family and friends) have always been very understanding and helpful (Carol, T1D patient).

For patients with ESRF, the instrumental support provided by family members and ICs plays a crucial role, particularly in medication management. Given the extensive medication regimen associated with this type of illness, assistance from family and ICs is fundamental in ensuring proper adherence and administration of medications.

4.5.1.3.3. Subtheme 3. The role of OHCs and patient groups

4.5.1.3.3.1. Perceived limitations on current SNSs and online groups

Patients, especially T1D patients, report not having much interest in participating or engaging in virtual/online groups (e.g., Facebook groups). The main reasons are related to the fact that they do not like or want to talk about their disease with someone who is not an expert in the field. There is a perception of a lack of usefulness and relevance of the content usually shared in online groups. Finally, other people's defeatist and negative attitudes tend to be detrimental when they get into these dynamics,

> *I remember joining a Facebook group back then, although I cannot recall the name. It was quite an eye-opening experience. Many members often vented their frustrations, whether it was about malfunctioning sensors or difficulty troubleshooting issues. I noticed a pattern where people relied heavily on the group for advice on insulin dosages based on their meals, instead of consulting with healthcare professionals specialized in diabetes management. It was disheartening to see how some members labeled themselves as "poor things" because of their T1D. In those moments, I couldn't help but feel grateful for "only" having diabetes* (Amandine, T1D patient).

4.5.1.3.3.2. Perceived usefulness of patient groups and online health communities (OHCs) managed by the professional care services

Overall, patients (T1D/ESRF) perceive the virtual patient groups and OHCs managed by the hospital services and its partners as useful and supportive activities at a psychosocial level and informational level. First, these initiatives allow the sharing of experiences and the guidance of newly diagnosed patients, therefore improving their well-being and feelings of social integration. Second, these approaches can inform about new launches, apps, technologies, innovating treatments, among others. Even for some ESRFs, these activities present several advantages, such as meeting someone in the same condition, feeling understood and exchanging information.

> *I think that it is essential to put people who cope well with the disease in contact with people who do not cope so well. It is trying to show that person that there are people with the same problem, the same age, with the same situation* (Victoriah, T1D patient)

> *I have never personally known anyone who shares the same illness as me, but I imagine it would be quite interesting. There is a certain camaraderie in exchanging experiences and*

perspectives with others facing similar health challenges. It is easy to forget that we're not alone in our struggles. I remember one particular day when I attended a psychology consultation with fellow patients from other hospitals. There were about 10 or 11 of us gathered together. The experience was quite uplifting, and I left feeling filled with laughter and a sense of connection. Moments like these remind us of the importance of community and the shared journey we're on (Rosaire, ESRF patient).

4.5.1.3.4. Subtheme 4. The challenging role of ICs

4.5.1.3.4.1. Emotional burden due to the lack of support and resources

This subtheme focuses on the indispensable role of ICs in providing practical support to ESRF patients over time. While ICs play a crucial role in assisting patients, it is important to recognize that they can also experience emotional and physical burdens, which are amplified by the lack of resources. In addition to offering practical assistance, ICs are tasked with monitoring medication, a responsibility that becomes particularly pronounced within the ESRF patient group. This dual role places significant demands on ICs, highlighting the complex dynamics involved in caring for individuals with chronic illnesses like ESRF,

Caring for my father, who weighs a lot of weight, is incredibly demanding and not easy at all. We often learn through our own experiences, and while we may see demonstrations on TV about caregiving techniques, doing it is a whole different story. It requires a lot of physical and emotional energy. Sometimes, there are training sessions for caregivers in homes and social centers, but it's still challenging. As the sole caregiver for my parents, I do not have anyone else to rely on. Now, with my own health problems, there are no breaks, no Sundays, no rest days. It's a day-by-day struggle, and some days, it feels like the weight of the world is on my shoulders. Somehow, we find the strength to keep going, but it's hard to pinpoint where it comes from. We become deeply attached to our loved ones, and their sadness or distress immediately becomes our concern and worry.

Table 4. 12 - Synthesis of theme 3.

Theme III. The influences of the social circle
Social sphere (social-owned touchpoints) mostly in post-service encounters
4 subthemes; n=32 (84,2%)

	Predominantly view	Focus		Main stage of the journey
		General	Specific	
Subtheme 1. Lack of support due to the high level of stigma and disinformation	P(T1D); HCPs (endo)		X	Post service encounters
Subtheme 2. Support delivery	P(T1D/ESRF), ICs		X	Post service encounters
Subtheme 3. The role of OHCs and patient groups				
Perceived limitations in the current SNSs (e.g., Facebook groups) and online groups	P(T1D/ESRF)		X	Post service encounters
Perceived usefulness of patient groups and OHCs managed by the hospital services	P(T1D/ESRF)		X	Post service encounters
Subtheme 4. The challenging role of ICs due to the lack of support and resources	ICs		X	Post service encounters

Source: Authors' elaboration

4.5.1.4. Theme 4. The external influences and dynamics

The fourth theme concerns external influences/dynamics. This sphere entails both the positive and the negative influences of externalities and past experiences of other PXs throughout their journey. Indeed, this theme encompasses two main subthemes: (1) the negative and positive consequences of the COVID-19 pandemic and (2) the negative influences of past experiences from others. Most of the mentioned touchpoints exert influence during the consumption of care services. A synthesis of theme 4 is presented in Table 4.13.

4.5.1.4.1. Subtheme 1. Negative and positive consequences of COVID-19

4.5.1.4.1.1. Difficult access to care and restrictive safety measures

With the advent of COVID-19, medical appointment cancellations were successive, which led to many patients decompensating and hospitalization ratios increasing:

> *Covid has spoilt everything. I lost a significant number of patients. In these cancellations, the patients think it was us and it's the appointment centre that manages them. I believe many patient files have been lost, and I can't find them again. I'm not just talking about nutrition. I've accompanied patients who, since 2020, have never been able to get a nephrology appointment again* (Nutritionist 1, nephrology services).

From the perspective of T1D patients, the restrictive measures imposed by the pandemic affected many patients who were hospitalized and went to outpatient appointments with their ICs.

4.5.1.4.1.2. The potentialities of telehealth

One of the advantages of the COVID-19 pandemic was the creation and development of telehealth. Endocrinologists emphasized the positive feedback from patients about telehealth during the pandemic and that it has become a relevant medical consultation format to use today and in the future.

4.5.1.4.2. Subtheme 2. Negative influences of past experiences from others on decision-making and treatment adherence

Based on the nephrologists' view, the past experiences of peers prove to be strongly critical and negatively influence ESRF patients in decision-making and adherence to RRTs. Indeed, patients in pre-dialysis are very reluctant to perform any of the RRTs just because they have had negative

examples from family, friends or colleagues. The strategy seems to be, therefore, the continuous health education as well as the use of success stories to share with ESRF patients,

> *I believe one of the greatest challenges lies in the reluctance of many patients to discuss or confront certain myths and taboos surrounding their condition. For example, there's often a misconception stemming from anecdotes, such as a neighbor's negative experience with hemodialysis (HD), leading to unwarranted fears and hesitations. Patients need to understand that the issues their neighbor faced weren't solely attributed to dialysis and that dialysis itself wasn't the cause of their neighbor's death. Rather, it's crucial to recognize that the neighbor likely had other underlying health complications, such as diabetes, and that dialysis was a life-saving intervention. Without dialysis, their neighbor would have likely succumbed to their condition much earlier. Therefore, addressing these misconceptions and providing accurate information is vital to empower patients and alleviate unnecessary fears* (Nephrologist 1).

Table 4. 13– Synthesis of theme 4

Theme IV. External influences/Dynamics
External influences / dynamics touchpoints mostly during service encounters; 2 subthemes; n=15 (39,5%)

	Predominantly view	Focus		Main stage of the journey
Subtheme 1. Negative and positive Consequences of COVID-19		General	Specific	
Difficult access to care and restrictive safety measures	P(T1D/ESRF); ICs	X		During service encounters
The potentialities of the telehealth	HCP (neph/endo); ICs	X		During service encounters
Subtheme 2. Negative influences of past experiences from others on decision-making and treatment adherence	HCP (neph)		X	During service encounters

Source: Authors' elaboration

4.5.1.5. Theme 5. Interactions with technology

The last theme "Interactions with technology" encompasses interactions with hospital information systems and technologies (partner-owned touchpoints). This theme encompasses one subtheme: the disadvantages of hospital information technologies. The interactions with these touchpoints occur during service encounters. A synthesis of theme 5 is presented in Table 4.14.

4.5.1.5.1. Subtheme 1. Disadvantages of the hospital information systems

4.5.1.5.1.1. Poor functioning of the ticket system

One of the main problems HCPs – endocrinologists – identified related to the ticketing system at reception is that it does not identify the nursing rooms where T1D patients need to go before their endocrinology appointment. There is so far no way around this problem, which creates confusion and stress for patients and nurses,

> *There is a logistical challenge in coordinating patient appointments with the nurse's office and the actual appointment location, leading to confusion and delays for patients, especially those with motor difficulties. Despite efforts to address this issue, including discussions with the IT team and attempts to implement solutions such as an app for patient notifications, the problem persists and has resulted in frustration and inconvenience for both staff and patients* (Nurse 1, endocrinology services).

4.5.1.5.1.2. Health information systems slow-loading and not user-friendly

Nephrologists, in particular, have identified various incompatibilities and limitations within the health information system that hinder their workflow and efficiency. One significant challenge is the difficulty in accessing essential patient information, such as test dates and medical history, leading to wasted time, especially during medical appointments. This inefficiency not only affects the quality of time with patients but also prolongs the duration of medical appointments, contributing to frustration among both healthcare professionals and patients.

Table 4. 14. Synthesis of theme 5.

Theme V. Interactions with technology
Partner sphere (partner-owned touchpoints) mostly in pre, during and post-service encounters
1 subtheme; n=5 (13,1%)

	Predominantly view	Focus		Main stage of the journey
		General	Specific	
Subtheme 1. Disadvantages of the hospital information systems				
Poor functioning of the ticket system	HCP (endo)	X		During service encounters
Health information systems slow loading and not user-friendly	HCP (neph)	X		During service encounters

Source: Authors' elaboration

4.5.2. Systematizing results from primary data collection – Proposed patient journey models

Based on the findings, we propose two patient journey models delineating the experiences of individuals with two distinct medical conditions: T1D and ESRF. These models delineate patients' experiences across three distinct phases of their healthcare journey, encompassing key interactions within five spheres/categories of touchpoints. They synthesize the diverse perspectives of participants, enabling the identification of converging elements as well as unique and distinctive viewpoints within each participant group. Both patient journey models exhibit considerable depth, particularly during and after service encounters. In these stages, individuals with T1D and ESRF engage with multiple touchpoints and stakeholders both within and beyond the confines of the hospital. Overall, these conclusions, especially those related to convergent views, offer valuable insights into PX priority areas for intervention and the allocation of future efforts.

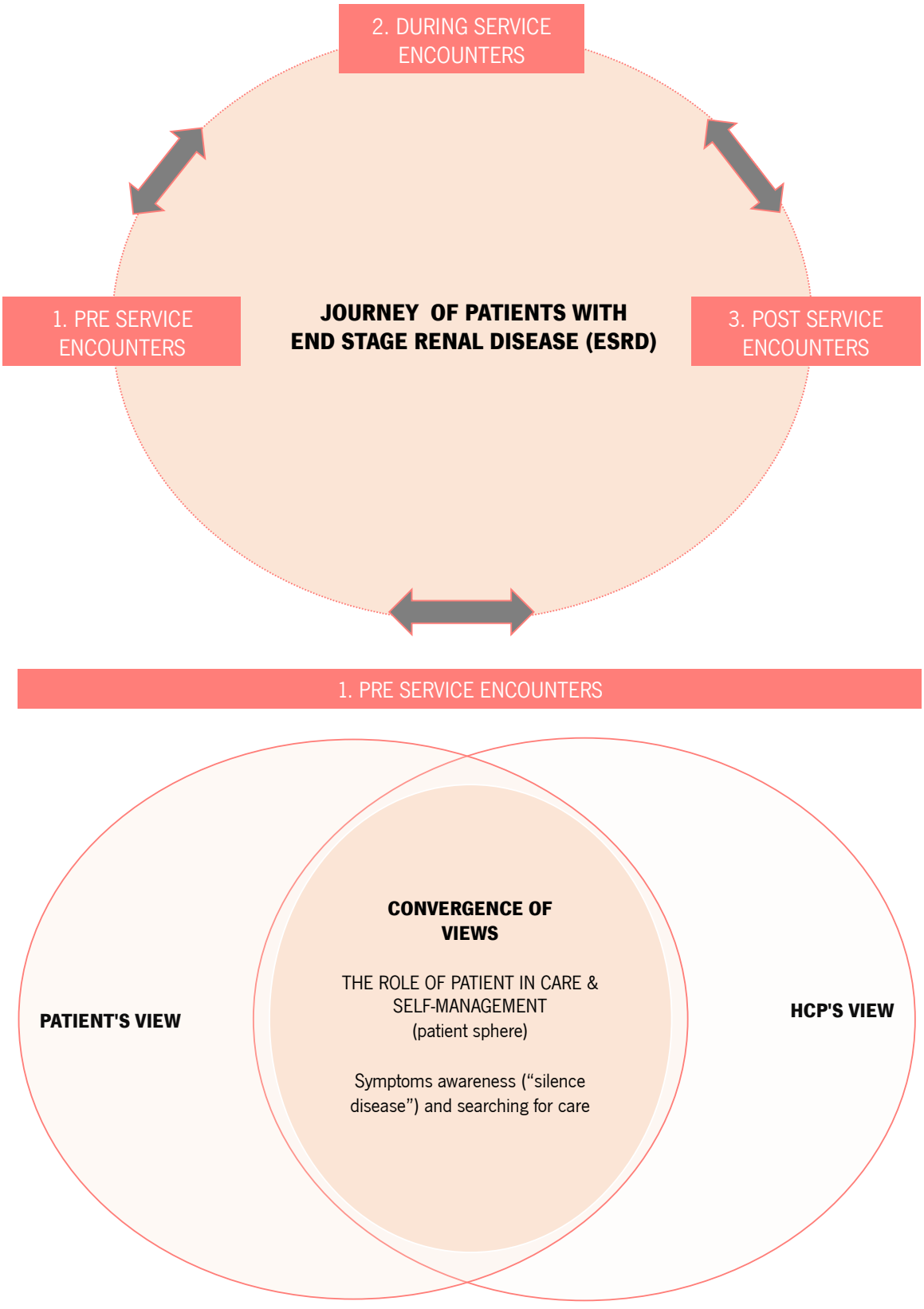
4.5.2.1. Proposed patient journey model for End-Stage Renal Failure (ESRF) with integrated participant perspectives

In the pre-service encounter phase of the ESRF patient journey (see Figure 4.1), we underscore the significant alignment between perspectives of patients and HCPs (we include here nephrologists, nurses, nutritionists and also other internal staff such as auxiliaries) concerning the recognition of Chronic Kidney Disease (CKD) as a silent disease, with a challenging diagnosis due to its asymptomatic nature. During the service encounter phase, several converging viewpoints are notable, including: (1) identifying process inefficiencies such as timeliness issues, access and coordination difficulties; (2) positive interactions with HCPs, including the efforts in the provision of informational, emotional, and psychosocial support; (3) positive interactions with the hospital's servicescape, encompassing environmental aesthetics; and (4) negative interactions with the servicescape, such as car parking charges and complex hospital pathways. A salient commonality among all participants – ESRF patients, HCPs, and ICs – is the challenge of inadequate access to care and communication with the hospital. Lastly, in the post-service encounter phase, both patients and HCPs converge on the daily challenges associated with the diseases, including lifestyle changes (e.g., nutrition/eating habits, medication management). Patients and ICs also converge on the critical role of the immediate social network in providing practical and emotional support to ESRF patients, also underscoring the need for both technical assistance (e.g., medication management).

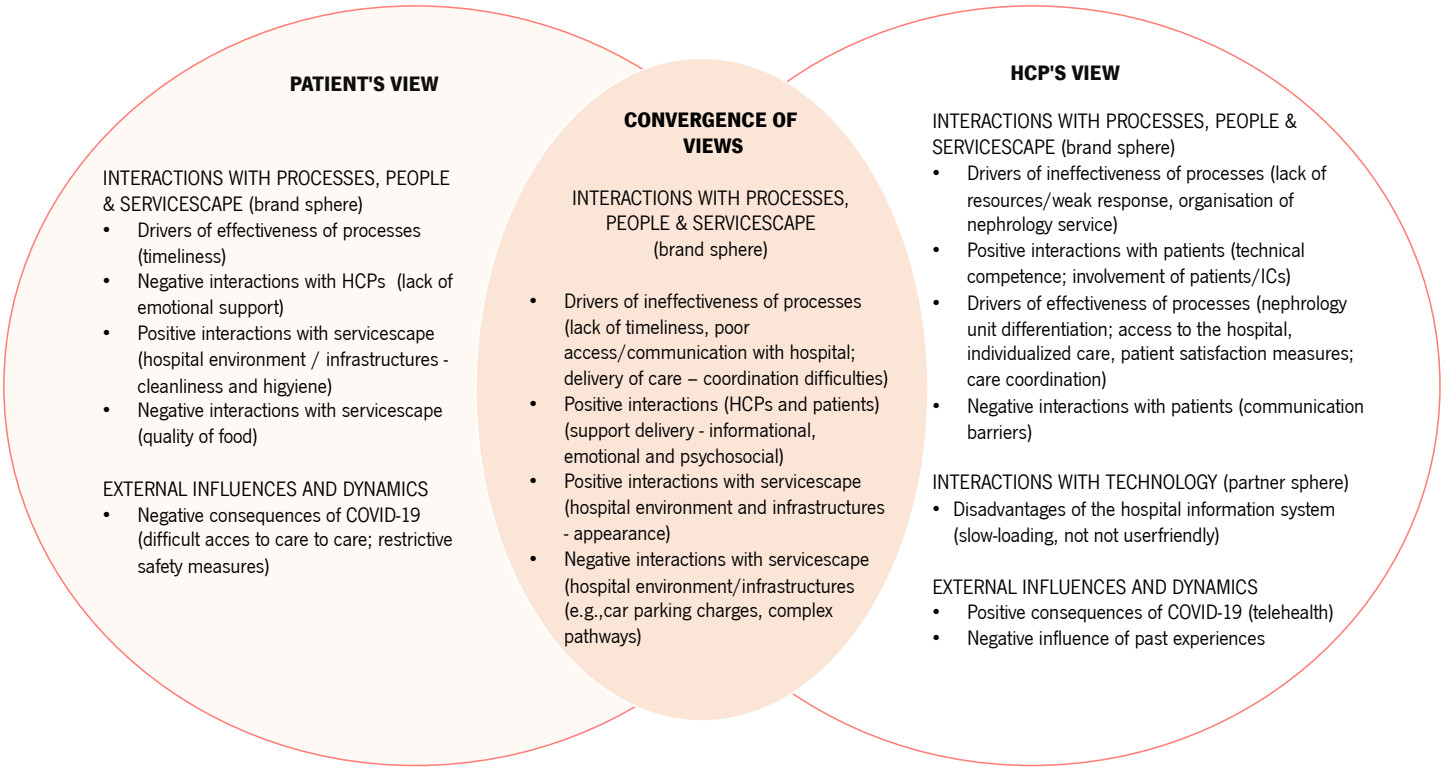
4.5.2.2. Proposed patient journey model for Type-1 Diabetes (T1D) with integrated participant perspectives

Regarding the journey of T1D (Figure 4.2), our investigation revealed a convergence of perspectives among patients and HCPs (we include here endocrinologists, nurses, nutritionists, and auxiliary staff) concerning the recognition of specific symptoms and the search of medical care. T1D is characterized by prominent symptoms that often result in hospitalizations for affected individuals. During the service encounter stage, notable alignment of viewpoints was observed regarding interactions with processes, staff, and the servicescape, within the hospital sphere. Specifically, there was consensus on: (1) positive interactions between HCPs and patients, emphasizing the delivery of comprehensive support encompassing technical expertise, information, emotional reassurance, and psychosocial guidance; (2) positive interactions with the servicescape, highlighting the favorable attributes of hospital environments and infrastructures, particularly in terms of appearance. Transitioning to the post-encounter phase of service, significant convergence of perspectives between patients and HCPs was noted regarding: (1) the daily challenges associated with T1D management, encompassing dietary and nutritional adjustments, physical activity engagement, technology utilization, and management of intimate relationships; (2) the experience of negative emotions towards the disease, including feelings of frustration, fatigue, and various fears and misconceptions, and (3) the patients as becoming experts in their own condition based on the support of diabetes-related technologies. Both patients and HCPs also shared concerns about the adverse impact of societal attitudes and misinformation, contributing to stigma and misconceptions surrounding the disease.

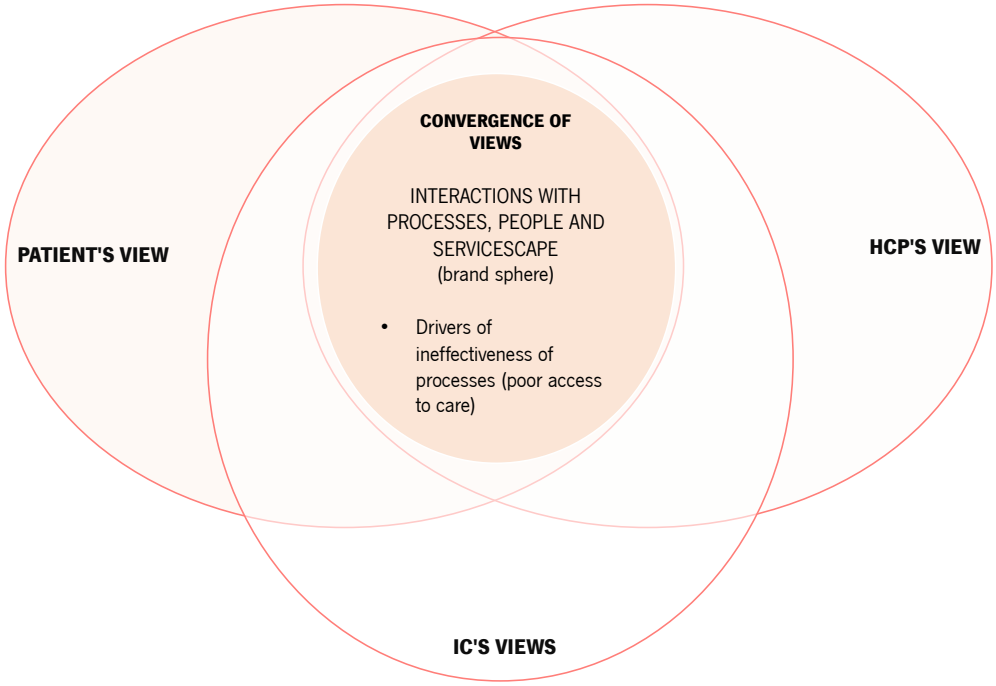
Figure 4.1- Proposed patient journey model for End-Stage Renal Failure (ESRF) with integrated participant perspectives



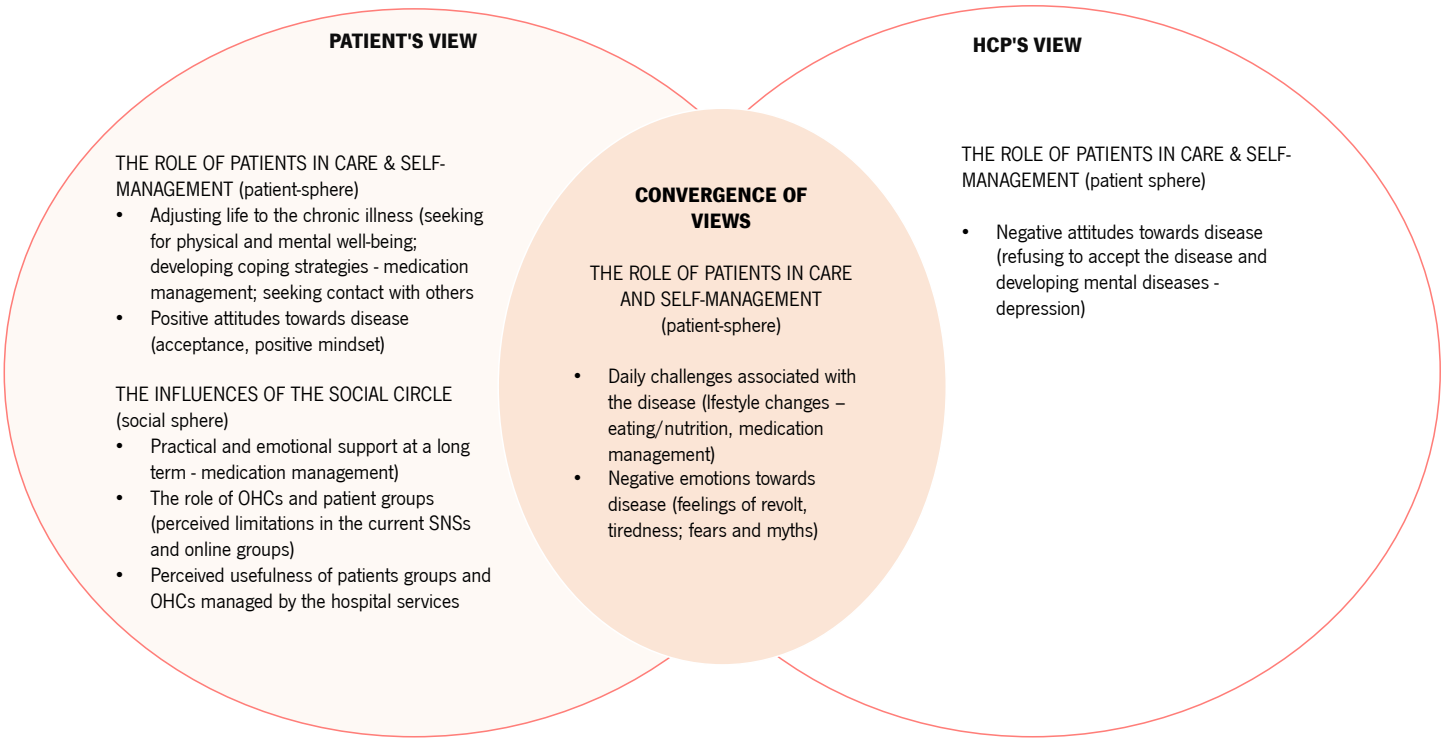
2. DURING SERVICE ENCOUNTERS



2. DURING SERVICE ENCOUNTERS

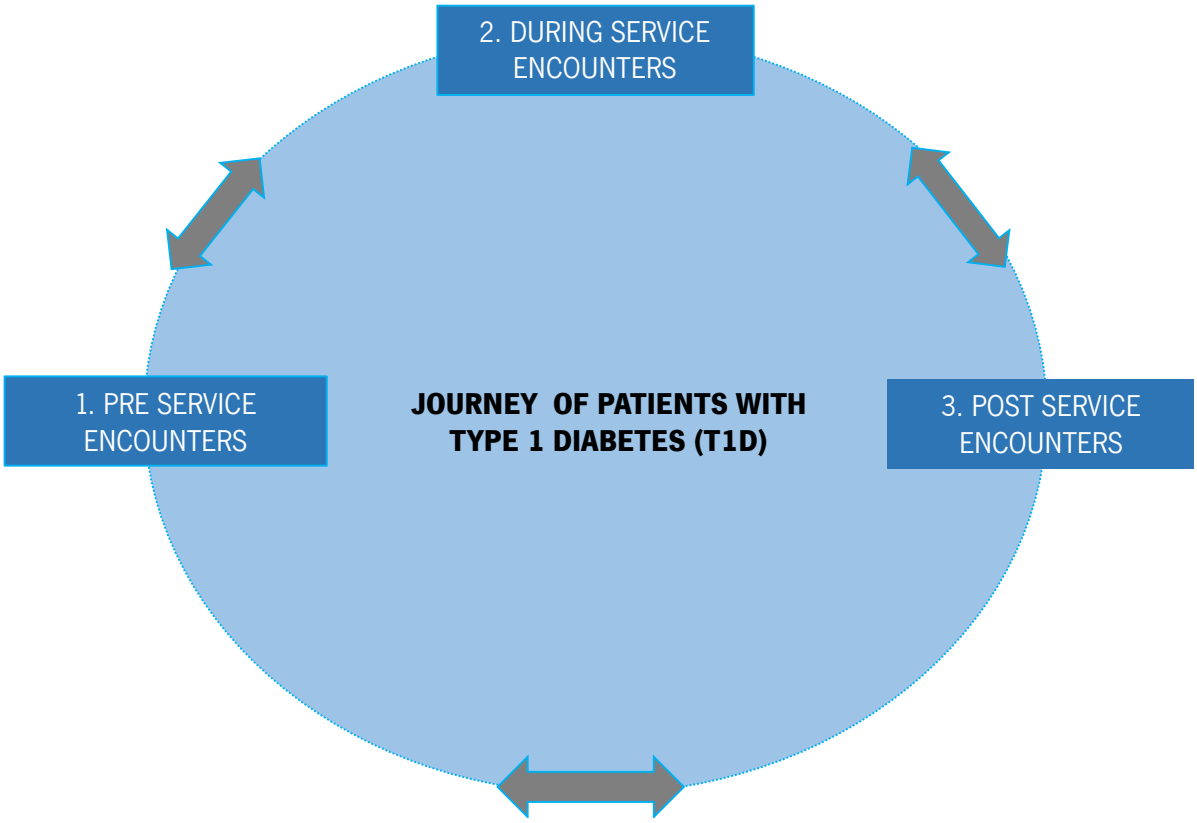


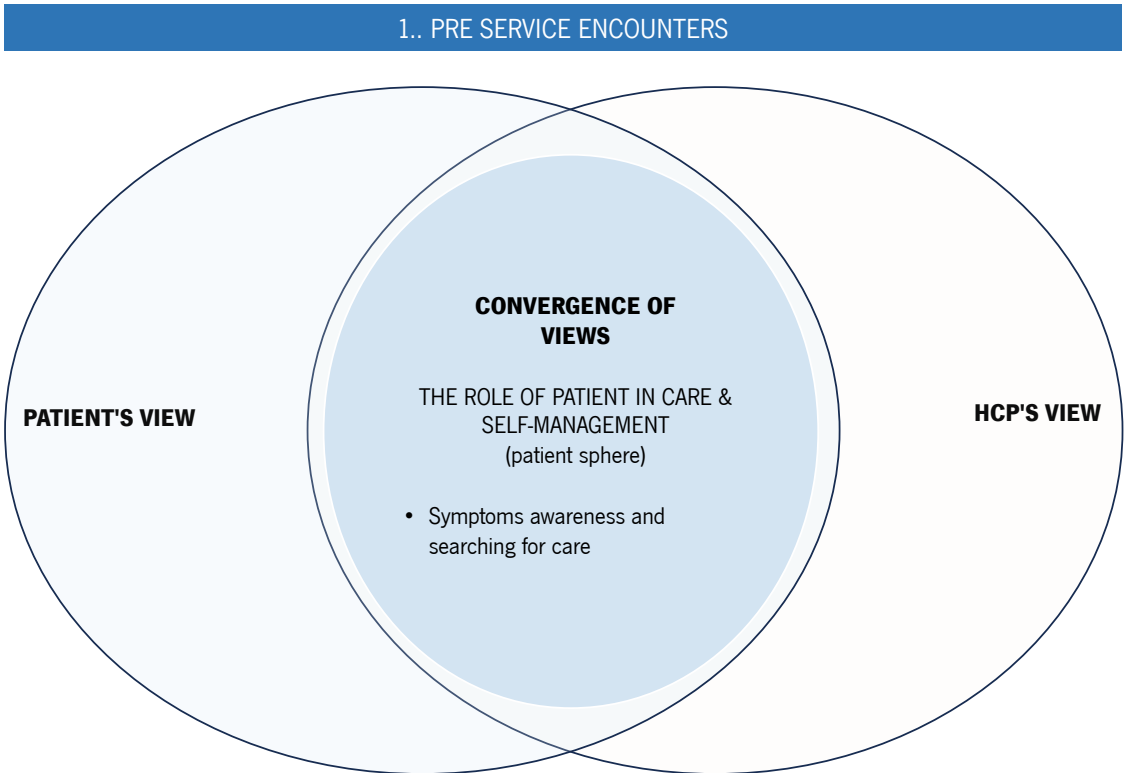
3. POST SERVICE ENCOUNTERS



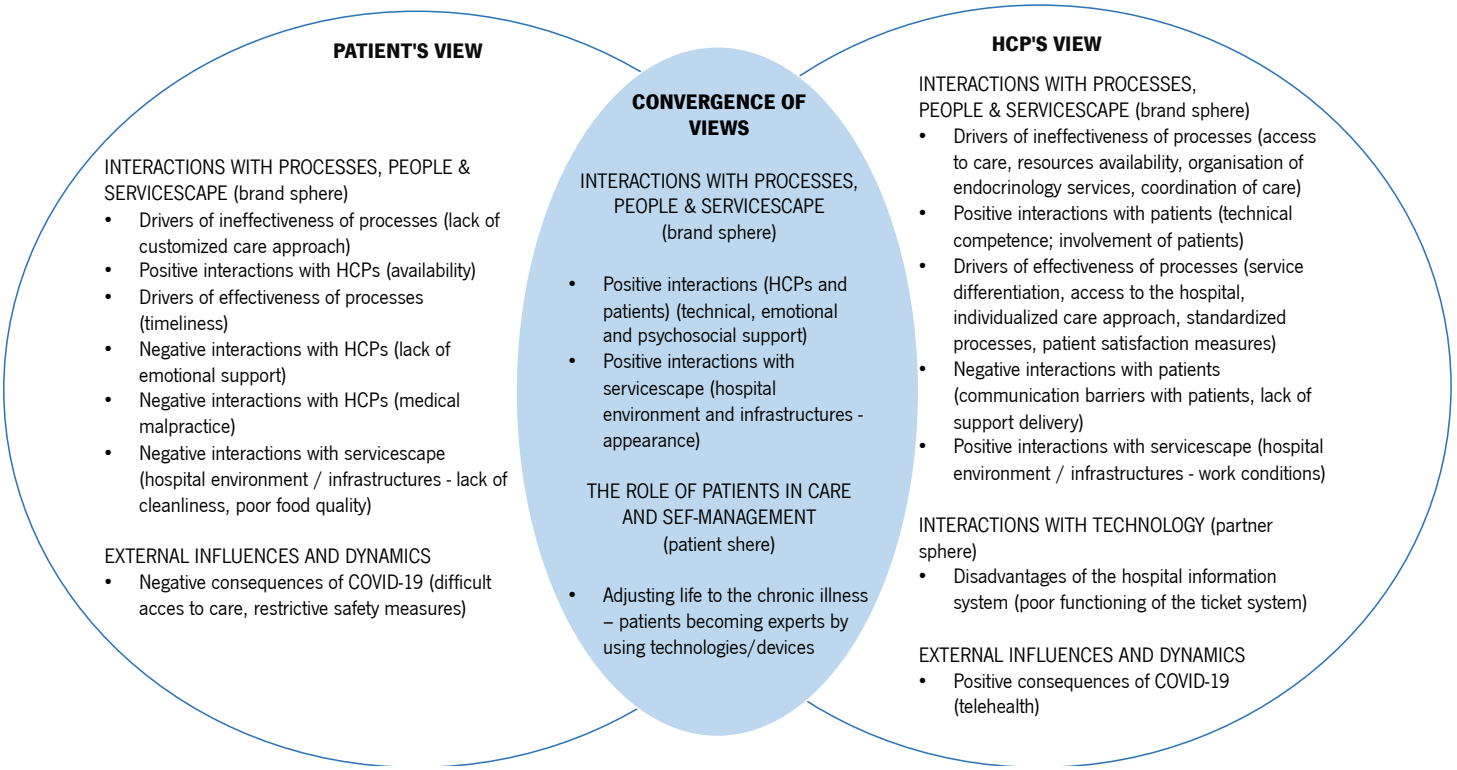
Source: Authors' elaboration

Figure 4.2 - Proposed patient journey model for Type 1 Diabetes (T1D) with integrated participant perspectives

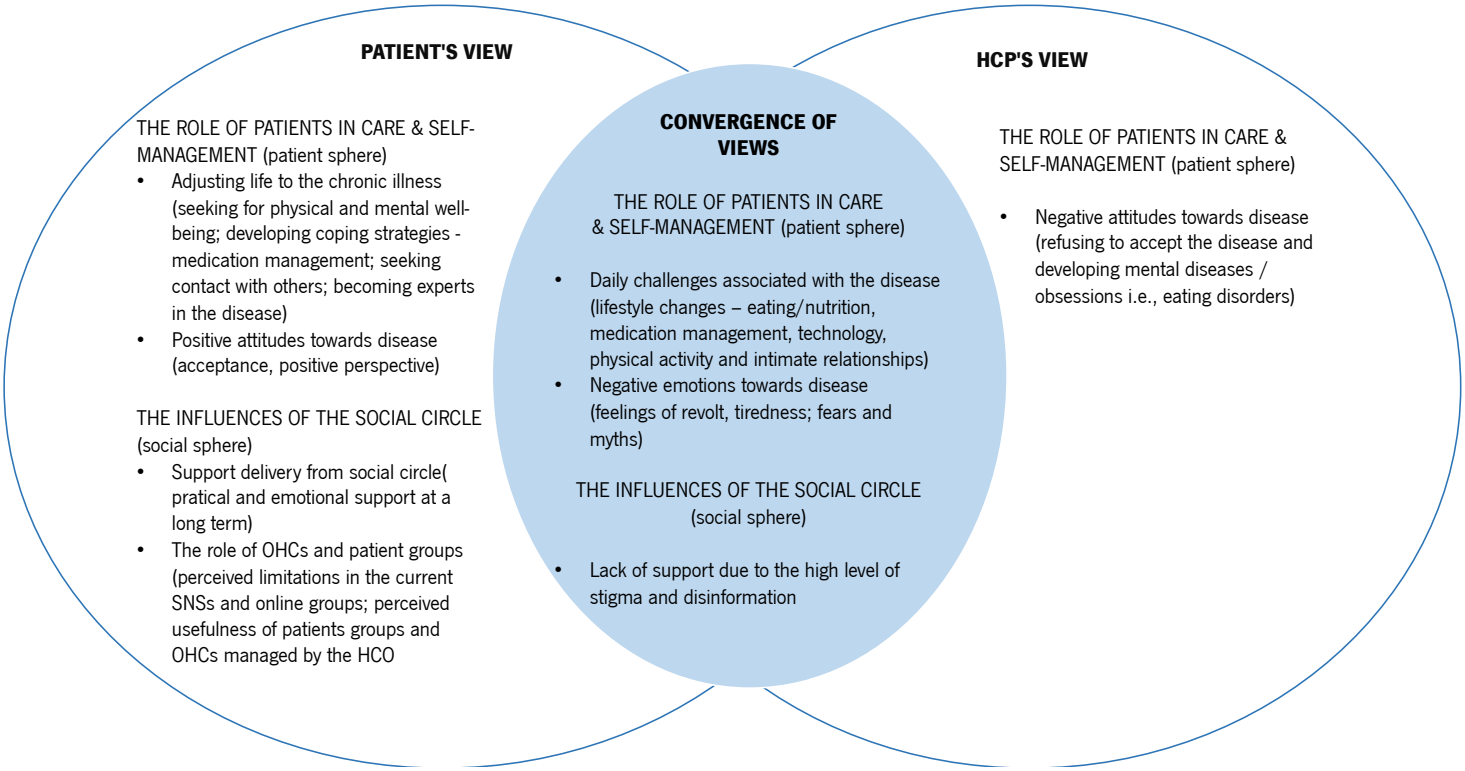




2. DURING SERVICE ENCOUNTERS



3. POST SERVICE ENCOUNTERS



Source: Authors' elaboration

4.5.3. Results from the additional data collection

We employed two complementary methods to triangulate our interview data: non-participatory observation and text-based document analysis. Our findings aligned with the interview results in various dimensions concerning brand, patient, and partner-owned touchpoints. In the subsequent subsections, we present these findings in detail and summarize our analysis in Table 4.15.

4.5.3.1. Non-participant observation study

Non-participatory observation explored a series of strengths and limitations related to the organisation of the information session on RRTs, within the nephrology service of the Hospital of Braga. Regarding the main strengths, the analysis highlighted the communication skills of the nurse responsible for conducting the session. The nurse was generally dynamic, empathetic, friendly and attentive to the group. She immediately questioned if the patients had difficulties in seeing or hearing. She generated a lot of comfort and intimacy among the group, even during the visit to the hemodialysis (HD) room. The whole communication process was facilitated by various factors, including the following: (1) clear communication with direct messages; (2) empathy - the nurse's understanding of the situations experienced by the patients enabled the development of a relationship of help, trust and openness to answer questions; (3) non-verbal communication - correct posture, with appropriate body expression, a smile, and eye contact enabled the reduction of the psychological distance between those involved; (4) active listening - the ability to listen to others and allow them to express their doubts or questions. The messages were conveyed with plenty of room for questions and answers. There was always a summary at the end of each chapter, and the language was well-adapted to the target audience. The nurse used an expository and demonstrative method, showing patients HD and peritoneal dialysis (PD) materials. She immediately clarified the patients' questions and used an interrogative method, asking the patients themselves about the topics and involving them in the session. When it came to informing patients and their ICs, the following aspects were checked: the provision of pertinent information tailored to the needs and doubts of family members and patients; the provision of explicit content using simple, objective language tailored to the level of understanding of the recipients and, lastly, the creation of a moment to clarify any doubts and ensure that the message was passed on correctly. The involvement of the ICs was also well done. They were part of the session; some were attentive, writing personal notes on a personal pad. In summary, active listening, empathy and clarity were all mentioned in the interviews and reiterated in the observation session.

Although these aspects were transpired in the interviews, the observation data provided additional depth and richness to our understanding. Hence, our observation unveiled two specific limitations regarding the conduction of the informative session on RRTs: (1) the lack of informative and educative resources and materials delivered to patients during the session and (2) the lack of effectiveness of the invitation process of patients and their ICs for the session. Regarding fhe first aspect, the PPT presentation supporting the session was not physically distributed to the patients and ICs. Also, the videos did not work. A set of A5 manuals (General Regulation from the Direção Geral de Saúde – DGS) was scattered around the table to give to each patient. The printing was of low qualitydraft and black and white, which made it difficult to read and visualize the images. The A5 manuals also contained too much technical information about the RRTs (therefore, misappropriated for such an audience) that needed reading and understanding.

Regarding the second aspect, improvements can be done in the recruitment of patients and their ICs. More specifically, we found that the patients needed to know the purpose of the session - so they had not been informed beforehand when the session was booked. Indeed, the patients thought this session was just another routine appointment. Also, the nurse had a sheet with preliminary information about the patients, namely, their names and ages. We found no additional relevant information about the patients on that sheet. More detailed information about each patient should be provided to allow the nurse to adapt and customize her discourse. Furthermore, even though some ICs were present at the session, they were not formally invited. Their presence in these sessions is essential to ensure that decisions about RRTs are discussed and shared among the patient and their family.

In summary, while our interview data provided valuable insights, the observational component of our study offered nuanced depth and context, highlighting both strengths and areas for improvement in the organisation of the information session on RRTs. These findings overall underscore the importance of enhancing the provision of tangible resources, and improving in the invitation process for patients and ICs as their active participation is essential to the development of a shared decision-making process regarding RRTs.

4.5.3.2. Documental (text-based) study

4.5.3.2.1. Findings pertaining to the investigated chronic conditions and corresponding healthcare services

The documental analysis shed light on some domains that converge with the data collected in the interviews. Regarding the interactions with HCPs (brand-owned touchpoints), the analysis highlighted the support delivery (emotional and informational) to T1D patients is a critical aspect and this was also highlighted in the interviews. The informational support is delivered through workshops and group meetings that allow the sharing of information and experiences among insulin pump patients. Moreover, the analysis identifies information and technical support guidelines delivered for patients with T1D and ESRF through the website (e.g. clinical information department, information manuals on diseases and specific services, materials and written information about T1D and ESRF). However, both groups of patients (T1D and ESRF) interviewed seemed unaware of such practical information support.

The second main domain pertains to the challenges that T1D patients face throughout their journey, such as the difficulties in adapting their lifestyle to the disease (patient-owned touchpoints) For example, the fear of hypoglycemia and other symptoms associated with physical exercise is also covered by the text-based document analysis.

Lastly, the analysis also emphasized the technological dimension, namely diabetes-related technology such as CGMs and insulin pumps, in controlling symptoms and the disease. The analysis also identified some limitations felt by T1D patients related with the use of insulin pumps (hypoglycemia, ketoacidosis, poor flexibility, among others), which were not mentioned in the interviews.

4.5.3.2.2. Findings pertaining to the general hospital context and services

While our primary focus in text-based document analysis centered on selecting documents pertaining to key dimensions of PX within the context of the chronic diseases under investigation - T1D and ESRF - our analysis also unveiled additional dimensions relevant to the hospital services. Specifically, we identified aspects concerning the efficiency or inefficiency of processes, as well as the strengths and limitations of interactions with healthcare professional teams and the hospital environment. By analysing each of these dimensions, we expect to draw parallels with findings from our interview data.

Firstly, various aspects related to the drivers of the ineffectiveness of care and internal processes emerged. The pervasive issue of inadequate resources and limited response capacity stands out among these aspects, which is indicative of the hospital's struggle to keep pace with the escalating demands of its geographical area. The Hospital of Braga, serving as a central and primary care facility for a large geographical region, faces significant challenges in meeting response time standards across various medical specialties due to physical and human resources constraints. Our analysis further highlights into other relevant factors, including difficulties in accessing care services, administrative inefficiencies leading to bureaucratic blockages, technological inadequacies, lack of patient-centric focus, and concerns regarding patient safety and security.

Conversely, our examination also highlighted factors contributing to exemplary performance and effectiveness in internal processes. These include strategic investments and enhancements in specialized services such as nutrition and psychology, although the latter remains under-resourced. Additionally, improved coordination with external stakeholders, exemplified by collaborative initiatives with health centers and academic institutions, reflects a positive trend in service delivery. However, the findings of the interviews underscore the persistent challenges in coordination, particularly between primary healthcare units and the hospital, which demand ongoing efforts to strengthen collaboration. Similarly, while the hospital's academic reputation and collaborations with academic institutions are acknowledged, our interviews underscore the need for further enhancement in this area.

Furthermore, our analysis highlights additional insights, including the hospital's quality management practices, the advantages of the transition to a Public Business Entity (EPE) model from a Public-Private Partnership (PPP), and favorable patient satisfaction ratings. Additionally, commendable practices in patient-healthcare professional interactions, such as initiatives promoting patient involvement in therapeutic decisions and caregiver training programs, underscore the hospital's commitment to humanizing healthcare. However, our interviews highlighted a discrepancy between institutional initiatives and caregiver perceptions of support. Moreover, external dynamics, notably the impacts of the COVID-19 pandemic, are elucidated, highlighting both adverse effects, such as delays in medical services, and positive outcomes, including the adoption and efficacy of telehealth solutions in managing demand.

Table 4. 15. Data triangulation scheme

Brand sphere - Interactions with the hospital processes, staff and environment - subthemes			
	Drivers of ineffectiveness of care and internal processes	Drivers of effectiveness of care and internal processes	Positive interactions between patients and HCPs
	Issues with the organisation and differentiation of nephrology service (informative session on RRTs): (1) lack of educative and informative resources and materials delivered to patients during the session; (2) the lack of effectiveness of the invitation process of patients and their ICs for the session.	Organisation and differentiation of nephrology service (informative session on RRTs): (1) Nurse communication skills and (2) demonstrative component of the session (visit to the HD and PD rooms)	HCPs ensure the delivery of emotional and informational support to T1D and ESRF patients
Non-participant observation	√	√	
Text-based document analysis			√
Interviews		√	√

Patient sphere - The role of patients in care and self-management - subthemes	
	Daily challenges associated with the disease
	— Lifestyle changes for T1D patients - physical activity/sports - fear, myths and stigma
Non-participant observation	
Text-based document analysis	√
Interviews	√
	Adjusting life to the chronic illness
	— Disavdvantages of diabetes-related technology (Insulin pumps)
Non-participant observation	
Text-based document analysis	√
Interviews	√
Legend:	
Convergence of findings were identified	

Source: Authors' elaboration

4.5.4. Results of the Multiple Correspondence Analysis - MCA

Clinical, general lifestyle, physical and experience characterization of the MCA study sample (n = 19) is presented in Table 4.16. A two-dimension MCA solution was considered the most adequate from the MCA analysis. The first and second dimensions presented are, respectively, eigenvalue, 3.396 and 2.319; inertia, 0.283 and 0.193; and Cronbach's alpha, 0.770 and 0.620.

While the commonly acknowledged Cronbach's alpha is 0.70, a lower value is deemed suitable in exploratory studies (Johnson & Wichern, 2007), as a diminished alpha score could stem from factors such as a reduced number of research questions or heterogeneous constructs. In this context, we are addressing diverse constructs to depict a two-dimensional view of the data, and the methodological approach was carried out assuming this limitation.

Discrimination measures (Table 4.17 and Figure 4.3) and a joint plot of category points (Figure 4.4) were obtained. All discrimination measures were below 0.9 with a maximum value of 0.816 (type of disease/condition) for the first dimension and 0.541 (alcohol consumption) for the second dimension. The most discriminant variables for dimension 1 hierarchically were the type of disease/condition, age class, social stigma, and smoking habits; regarding dimension 2, the most discriminant variables were alcohol consumption, and dealing with lifestyle challenges. The variables education level and physical activity presented relevant and similar discrimination measures in both dimensions. From the results and their graphical visualization, dimension 1 was termed "Type of chronic condition, Age, Lifestyle and Social Stigma" and the second dimension "Lifestyle and Daily challenges dealing with the disease" (see Figure 4.4 and 4.5) From data analysis, for the first dimension, having T1D and an unhealthy lifestyle (as indicated by the smoking habits) were associated with stronger perceptions of social stigma, while unhealthy lifestyle (as indicated by the drinking habits) appeared to be associated with more challenges in dealing with the disease in second dimension.

In dimension 1, the type of disease correlated (transformed variables) significantly with age (r = 0.689, P < 0.001), and smoking habits (r = -0.645, P < 0.001). In dimension 2, no significant correlations were found. Education level correlated significantly with physical activity (r = 0.673, P < 0.001). Only correlations above 0.30 were considered to have meaningful practical significance.

Table 4.16 - Sociodemographic, general lifestyle, clinical and experience characterization of the sample

	Count	Column n (%)
Sociodemogrpahic characteristics		
Gender		
Male	11	58%
Female	8	42%
Total	19	100%
Age		
18-49 years	10	53%
50+ years	9	47%
Total	19	100%
Location		
Braga district	15	79%
Other north locations	4	21%
Total	19	100%
Level of education		
Higher Education	7	37%
Basic Primary school	7	37%
High school	5	26%
Total	19	100%
Employment status		
Non-active	14	74%
Active	5	26%
Total	19	100%
Clinical characteristics		
Disease /chronic condition		
T1D	10	53%
CRF	9	47%
Total	19	100%
Lifestyle		
Smoker habits		
Regular smoker	6	32%
Non-smoker	13	68%

Drinking habits		
Regular driking	6	32%
Residual drinking	4	21%
No alcohol	9	47%
Total	19	100%
Physical actiivity habits		
No physical activity	8	42%
Residual physical activity	4	21%
Regular physical activity	7	37%
Total	19	100%
Experiences		
LACK OF TIMELINESS		
Yes	10	53%
No	9	47%
Total	19	100%
DAILY CHALLENGES DEALING WITH THE DISEASE		
Yes	10	53%
No	9	47%
Total	19	100%
SOCIAL STIGMA		
Yes	10	53%
No	9	47%
Total	19	100%

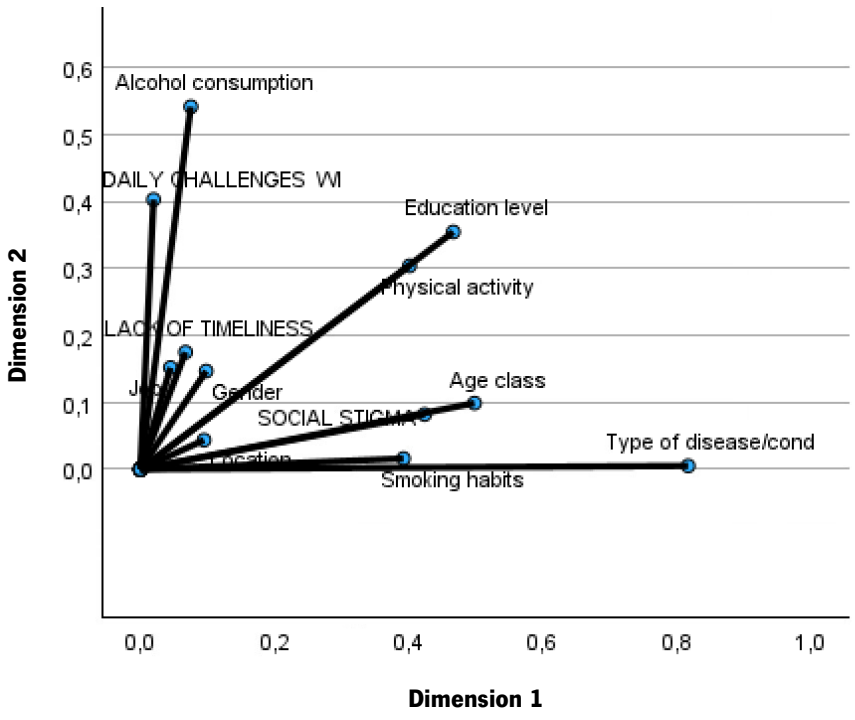
Source: Authors' elaboration

Table 4. 17 - MCA dimensions discrimination measures

	MCA dimension		Mean
	1	2	
Age class	.498	.099	.298
Gender	.098	.146	.122
Location	.095	.043	.069
Education level	.466	.354	.410
Job	.045	.152	.098
Smoking habits	.392	.016	.204
Alcohol consumption	.075	.541	.308
Physical activity	.401	.304	.352
Type of disease/condition	.816	.005	.411
Experience dimension – DAILY CHALLENGES DEALING WITH THE DISEASE	.020	.403	.211
Experience dimension - LACK OF TIMELINESS	.067	.175	.121
Experience dimension - SOCIAL STIGMA	.424	.082	.253
Total ative	3,398	2,319	2,858
% Variance	28,314	19,325	23,819

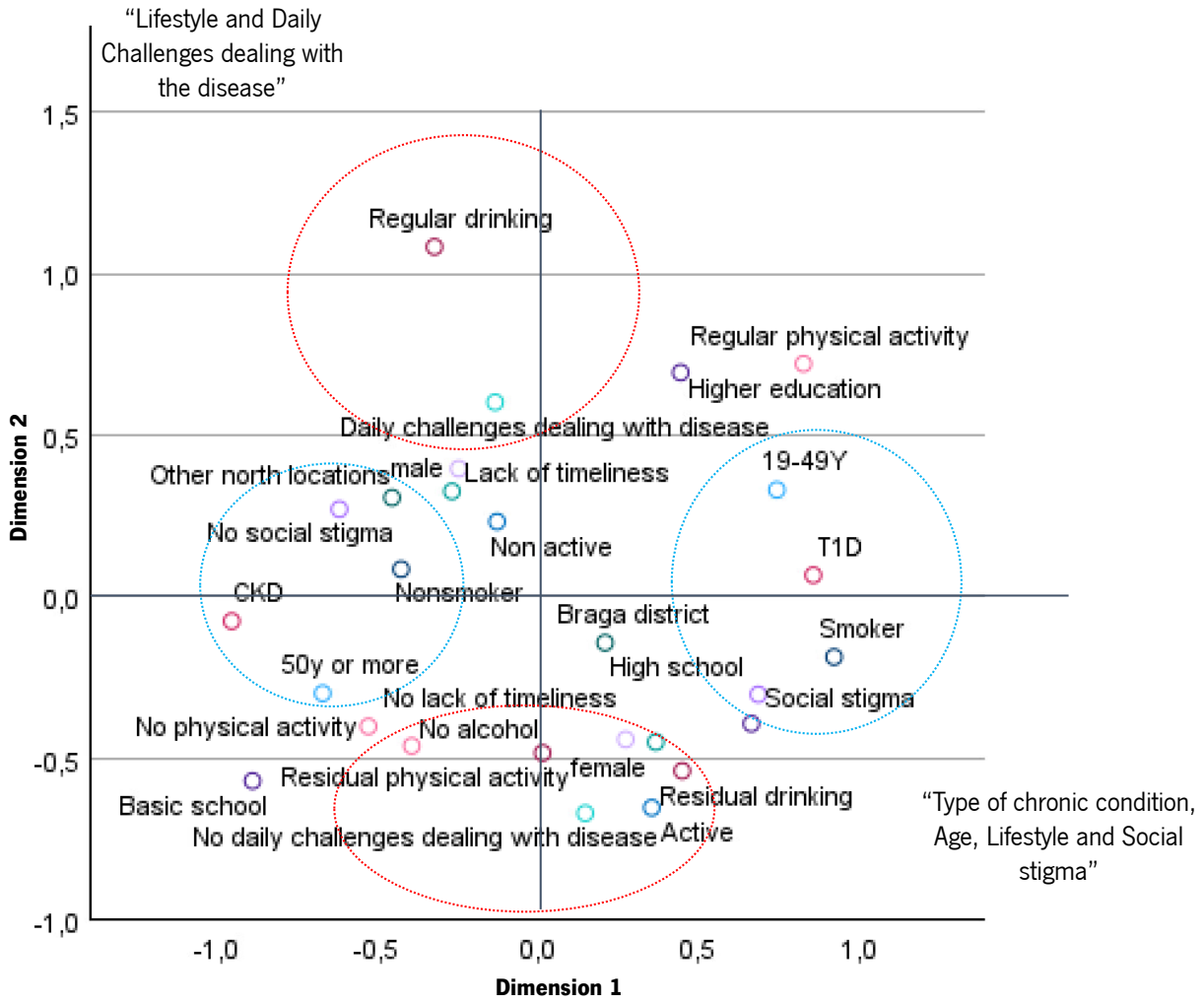
Source: Authors' elaboration based on graphical representations generated from SPSS Statistics software

Figure 4. 3 - Graphical representation of MCA dimensions discrimination measures



Source: Graphical representation generated from SPSS Statistics software (V.29)

Figure 4.4 - Joint plot of category points

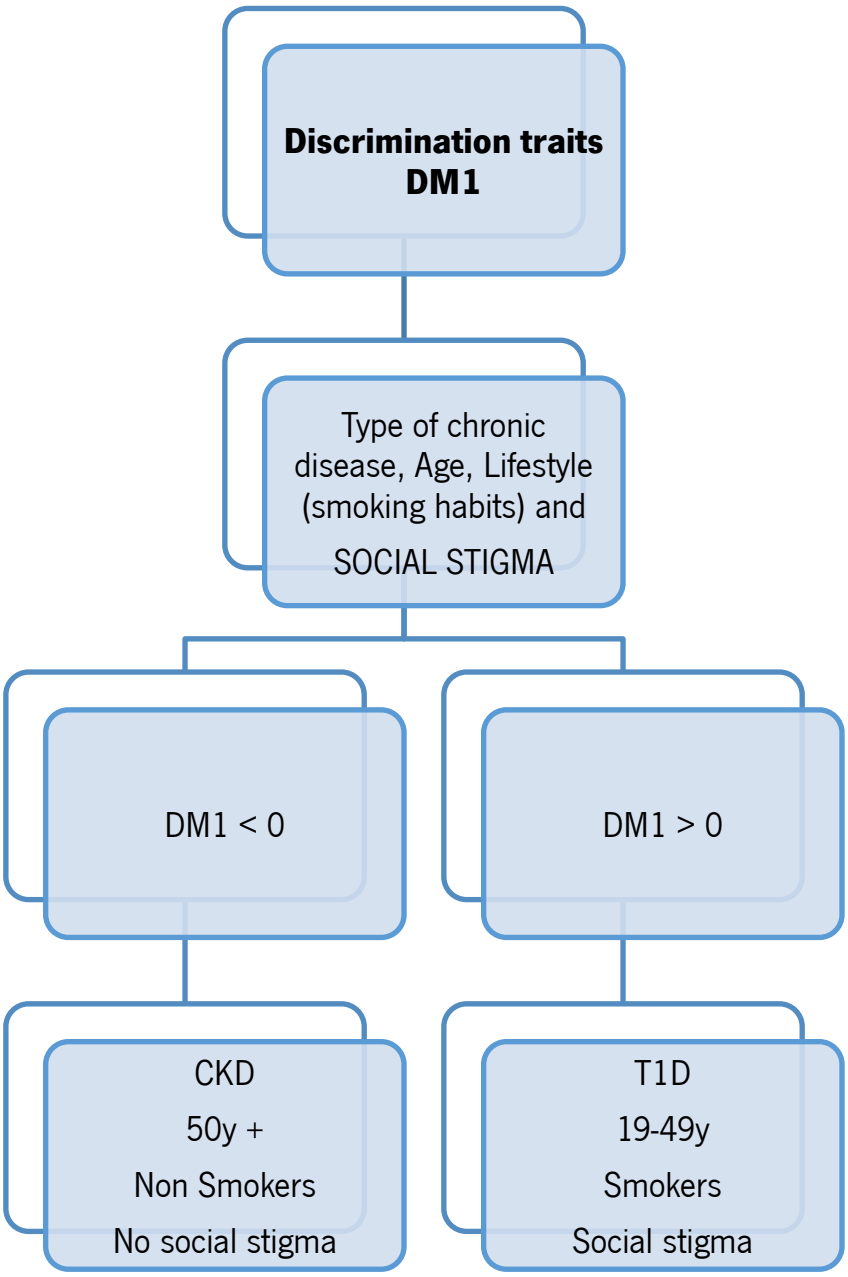


Source: Graphical representation generated from SPSS Statistics software (V.29)

Legend:

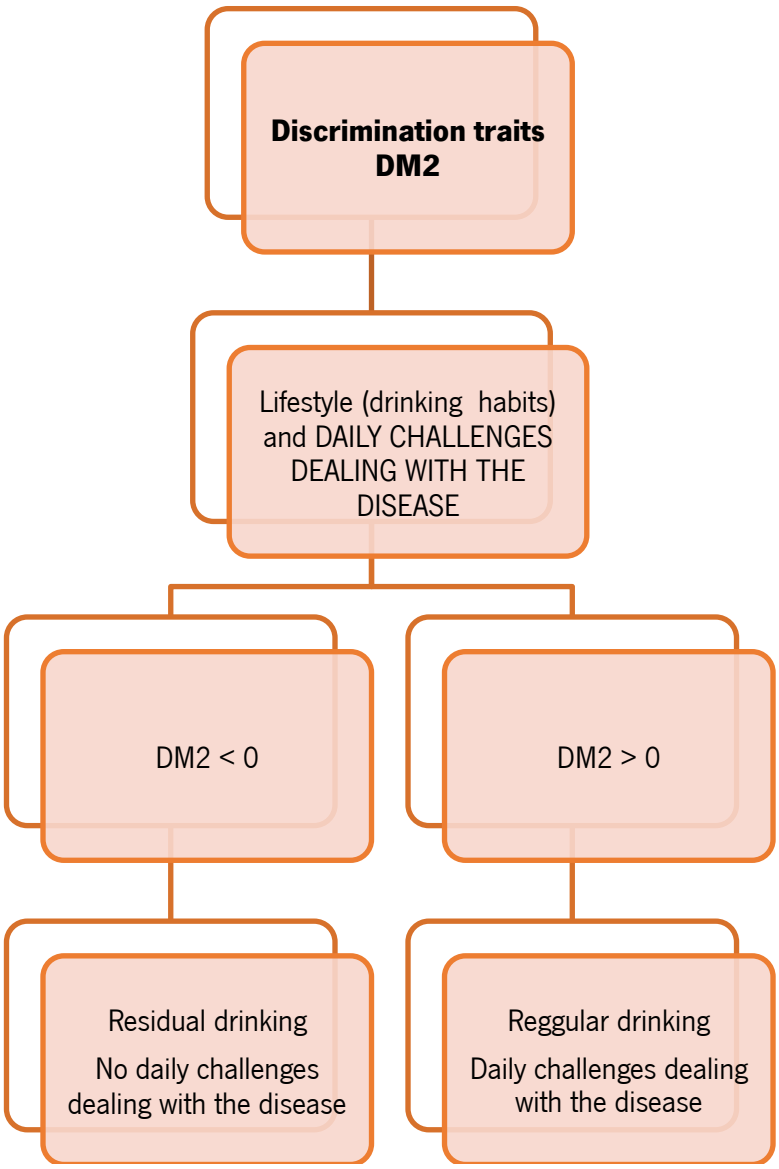


Figure 4.5 - Positive and negative centroid coordinates for dimension 1



Source: Authors' elaboration

Figure 4. 6- Positive and negative centroid coordinates for dimension 2



Source: Authors' elaboration

4.6. DISCUSSION

4.6.1. Theoretical implications

4.6.1.1. Empirical evidence on a key focus area

This research addresses the calls for comprehensive examination of PX across the patient's journey with a particular focus on vulnerable consumers such as chronically ill patients, as advocated by (Davies et al., 2023). From a theoretical perspective, this study represents the first application of the "Process Model for Customer Journey and Experience" (Lemon & Verhoef, 2016) within the domain of healthcare, specifically concerning chronically ill patients. It provides evidence on the holistic, social and dynamic nature of PX as it occurs throughout the patient journey (Ponsignon et al., 2018; Richardson et al., 2007). By adopting a holistic approach that encompasses the multifaceted interactions of patients across the pre-, during-, and post-care stages, this study extends beyond prior research that predominantly focuses on specific care elements within hospital settings and limited to service encounters.

Building upon empirical insights, the study presents two "patient journey maps" to depict the experiences of chronically ill patients, delineating their interactions across various touchpoints throughout their journeys. These maps underscore the pivotal role of touchpoints within brand, hospital, patient, social, partner, and external spheres at different stages of the patient journey, emphasizing their profound influence on PX. Moreover, the patient journey maps highlight the main points of convergence and divergence among patients and other participants (HCPs and ICs).

The findings underscore the relevance of the interactions with hospital processes, HCPs, and the servicescape. Specifically, enhancing care delivery effectiveness, including aspects such as timeliness, accessibility, resource availability, and coordination, emerges as a key recommendation. This study advocates for fostering meaningful patient-HCP relationships through empathy, active listening, and open communication, echoing findings from previous research (e.g., Berglund & Westerlund, 2016; Broughton et al., 2017; Vachon et al., 2017). Notably, personal relationships with HCPs are mentioned as pivotal by reports such as the Portuguese perception study on public hospitals (decoproteste).

This study elucidates the critical role of patient-owned touchpoints in shaping PX, highlighting their initial symptoms, concerns, coping strategies, and accomplishments over time throughout their journey with the disease. Despite these touchpoints lying beyond direct control of HCPs, their acknowledgment is imperative (Lemon & Verhoef, 2016) for continuous improvement of self-

management support services, particularly given the imperative for greater chronically ill patients involvement in disease self-management (Farley, 2020). Furthermore, the study sheds light on co-creation activities (McColl-Kennedy et al., 2012) undertaken by chronically ill patients, with a focus on T1D patients such as collating information (managing medical/other types of information gathered from other sources), combining complementary therapies (using supplementary medicines or therapeutic techniques), changing ways of doing things (managing lifestyle changes associated with the health condition such as sports, nutrition, employment, relationships) and undertaking activities specially designed to help cope, and engaging in cerebral activities (actively trying to maintain a positive perspective and attitude). Conversely, our study's least expressive co-creation activities are connecting and co-learning. These activities are intrinsically related to the interest in building and maintaining relationships with others and seeking and sharing information from others. Indeed, both T1D and ESRF patients showed little interest in the current habit of sharing and learning from others in current SNSs such as Facebook groups. They do not see such platforms and communities as valuable for resource integration, mainly due to the lack of useful content shared on such platforms (Kamalpour et al., 2021). However, participants recognize the utility of new future platforms managed by healthcare institutions for aggregating and disseminating relevant content and facilitating peer-to-peer support, particularly valuable for the long-term psychosocial support needs of chronically ill patients and ICs. In particular, ICs can also benefit from these platforms as they still feel unsupported by HCPs. The relevance of online health communities (OHCs) and patient groups (social-owned touchpoints) in delivering sustained support to chronically ill patients and ICs is also aligned with findings from previous studies (Kamalpour et al., 2021).

4.6.1.2. Uncovering insightful associations between qualitative variables

In this study a MCA was conducted to, upon identifying 12 categorical variables, explore relationships between sociodemographic, lifestyle, clinical and experience dimensions among our sample of chronically ill individuals (with T1D and ESRD). Thereafter, the dimensions “lack of timeliness”; “daily challenges dealing with the disease”, and “social stigma” could be explored in relation to the mixture of sociodemographic, clinical, and lifestyle aspects. Evidence of these relationships is necessary to elucidate whether particular characteristics of the chronically ill patients can be associated with their perceptions and experiences responses, throughout their journey. Furthermore, even if gender, age, location, education level, job, and clinical aspects may

remain “fixed” parameters (e.g., an individual either has or not a T1D/ESRD pathology), their combinatory effect with other more “mutable” parameters (e.g., lifestyle - physical activity, alcohol consumption, smoking habits) is of relevant interest.

From data analysis, and its graphical representation, two MCA dimensions—termed “Type of chronic condition, Age, Lifestyle (smooking habits) and Social Stigma”,” and “Lifestyle (drinking habits) and Daily challenges dealing with the disease”—were identified. For the first dimension, having T1D and an unhealthy lifestyle (as indicated by the smoking habits) were associated with stronger perceptions of social stigma, while an unhealthy lifestyle (as indicated by the drinking habits) appeared to be associated with more challenges in dealing with the disease in the second dimension. The findings of the MCA add to previous studies using this technique to uncover associations between qualitative dimensions, and, in particular, to establish associations between sociodemographic and clinical characteristics of TD1 patients and target glycated haemoglobin values (HbA1c target) (e.g., Oujidi et al. (2022). In contrast, our study addresses the associations between chronically ill individuals' sociodemographic, clinical and lifestyle aspects and their experience perceptions.

4.6.2. Practical implications

4.6.2.1. Implications for patients and informal caregivers (ICs)

Findings from this research can foster critical health outcomes for patients with chronic illnesses such as T1D and ESRF as they encompass various aspects that directly affect their daily lives. Firstly, understanding the holistic nature of the PX and the factors that most influence their experiences across their journey can improve their well-being (Doyle et al., 2013). For example, by addressing challenges related to the effectiveness of care processes (e.g., timeliness, better access and communication with the hospital/HCPs) and strengthening the relationships with HCPs, patients can enhance their well-being, despite their health condition.

In this study, the social implications for patients with chronic illnesses like T1D and ESRF and their ICs are profound and wide-ranging. Firstly, by recognizing the importance of social-owned touchpoints (e.g., peer support networks), this research highlights avenues for promoting social interactions, meaningful connections, and shared experiences that contribute to a more fulfilling and enriched life despite the challenges posed by chronic illness. Indeed, this research offers insights into opportunities for reducing social isolation through peer support networks, online communities, and patient group activities, fostering a sense of belonging and connection among

individuals facing similar challenges. Furthermore, this research sheds light on ICs' challenges and the need for additional support systems. This awareness can prompt initiatives to provide respite care, caregiver training, counselling services, and assistance to alleviate caregiver burden and promote their well-being.

4.6.2.2. Managerial Implications for HCPs and other Public Hospitals / Institutions

This study sheds light on patients' experiences with ongoing and complex conditions, specifically chronic diseases, as they navigate service systems. It uncovers significant deficiencies that demand focused managerial attention, as unaddressed issues may lead to diminished satisfaction and undesirable outcomes within the healthcare system (Xie et al., 2019). Indeed, critical touchpoints emerge at each stage of the patient journey, exerting a profound influence on their overall experience. By introducing two PX journey models tailored to specific chronic conditions, this study provides insights into how HCOs, particularly public hospitals, can enhance PXM and service delivery to chronically ill patients.

4.6.2.2.1. Improvement guidelines for the Hospital of Braga

In the subsequent subsection, we delineate recommendations to enhance PX management. Specifically, we outline a series of improvement areas tailored for the endocrinology and nephrology services at Braga Hospital and broader improvement areas encompassing the entire Braga Hospital entity, including cross-cutting public services.

4.6.2.2.1.1. Improvement guidelines for the nephrology and endocrinology services

The findings of this research also enable the delineation of a set of domains and guidelines for Braga Hospital to enhance its patient-oriented services systematically. Tables 4.18 and 4.19 meticulously organize the recommendations for improving experiences among patients with T1D and ESRF, as well as optimizing healthcare service delivery, categorizing them by the various phases of the patient journey. Most recommendations centre on two pivotal phases of the patient journey: the service encounter and the post-service encounter. In the service encounter phase, the recommendations primarily focus on optimizing processes, personnel, and physical evidence (servicescape). The recommendations outlined in the post-service encounter emphasise the importance of empowering chronic patients to manage their conditions effectively through self-management. This approach equips patients with the necessary resources, knowledge, and tools

to take an active role in their healthcare journey. Authors such as Sheridan et al. (2016) have highlighted the positive impact of self-management support on patients' physical and mental well-being, healthcare usage patterns, and clinical outcomes. Our study emphasises the role of health system factors in facilitating self-management among chronic patients. It includes providing essential information, fostering shared decision-making, offering strategies to develop skills, and providing technical and psychosocial support. To address these needs, we propose the development of a new platform dedicated to long-term support for chronic patients. This recommendation aligns with findings from previous studies, such as Vachon et al. (2017), which underscore the relevance of improving the dissemination of information to chronically ill patients, particularly regarding community-based health services. By leveraging technology and creating a dedicated platform, HCPs can enhance accessibility to essential resources and support services, empowering chronic patients to manage their conditions better and improve their overall quality of life.

Table 4. 18– Recommendations for improving experiences of T1D patients and service delivery

Stage of the journey	Domain & Goal	Detailed activities
During service encounters	Improve the interactions with the hospital processes: — Better access to care and communication with HCPs and the hospital	— To establish a dedicated telephone number within the nursing service for supporting questions and emergency contacts from T1D patients, their relatives and ICs. This initiative would requiren the implementation of a structured schedule and assignment of a designated staff member to manage the line exclusively. — To recruit a specialized administrative staff member specifically designated to support the endocrinology service. This could require (i) optimizing the interaction time between physicians and patients, (ii) developing operational tasks, (iii) solving issues of interest to the service, and (iv) optimizing the use of email, with these services being responsible for filtering emails and responding to patients.

	Improve the interactions with the hospital processes: — Organisation and differentiation of endocrinology service	— To create multidisciplinary medical consultations for patients with no insulin pumps and involving other non-medical specialties such as psychology and nutrition. — To ensure proper appointment management by concentrating all medical consultations on the same day, making it easier for the patient. — To address high turnover rates within the nursing team by guaranteeing the presence of permanent and adequately trained nursing staff members during medical consultations, offering support and appropriate advice to T1D patients.
	Improve the interactions with hospital staff / HCPs: — Strengthening relationships with T1D patients through emotional and technical support provision	— To improve communication with patients by (i) showing openness and willingness to discuss other/alternatives therapies and, thereby, increasing patients security and comfort in exposing ideas and potential solutions; (ii) focusing on active listening skills and on clarifying patient´s doubts, to ensure a greater closeness and empathy towards patients; (iii) explaining in detail illness-, and service-related contents to promote therapeutic adherence; and (iv) informing the patients about the disease's impacts on the different dimensions/areas of their life (e.g., the impacts of T1D on intimacy and romantic relationships).
	Improve the interactions with the hospital environment (servicescape) — Adequation of food and beverages to the patient's condition.	— To ensure the quality of food and beverages provided to hospitalized patients with T1D. It is imperative to pay meticulous attention to these patients dietary needs, which must be meticulously tailored to their condition. Specifically, care should be taken to avoid offering foods high in sugar, such as biscuits, as they can adversely affect blood sugar levels and exacerbate diabetic symptoms. Instead, meals should be carefully crafted to align with the dietary requirements of T1D patients, emphasizing nutritious options that support stable blood sugar levels and overall health.
Post service consumption	Improve the interactions with hospital staff / HCPs — Providing long-term psycho-social support	— To deliver long-term psychosocial support through periodical educative collective sessions (face-to-face and online) with other patients with T1D and with family members and ICs for sharing stories and experiences and promoting the feeling of social belonging and inclusion. These sessions should facilitate sharing stories and experiences, promote social belonging and inclusion, improve disease knowledge, introduce new technologies, and address fears and phobias. Nutrition- and sports-related topics, such as managing physical exercise and insulin dosages, interpreting food labels, and utilizing carbohydrate calculation apps, should also be covered in these sessions.

		— To deliver long-term psychosocial support through the patient-to-patient mentorship program. To invite a group of patient ambassadors to share best practices and success stories among peers. These ambassadors should exemplify excellence in managing their chronic condition and demonstrate high levels of empathy, responsibility, strength, and perseverance. — To deliver long-term psychosocial support through a collaborative online platform or community (e.g., *Together We Stand* platform), managed directly by service staff specifically recruited for this purpose. This platform could facilitate ongoing interaction with T1D patients outside hospital boundaries, disseminate videos and psycho-educational materials, allow for the review of educative collective session content, and share success stories from patient ambassadors to inspire others and normalize the disease. The platform could also provide the access to a "T1D handbook" to guide and inform new and current patients about the entirety of their journey. The manual could provide essential information on symptoms, treatments, available support resources, relevant technologies and a directory of valuable contacts, such as nursing helpline numbers.

Source: Authors' elaboration

Table 4.19– Recommendations for improving experiences of ESRF patients and healthcare service delivery

Stage of the journey	Domain & Goal	Detailed activities
During service encounters	Improve the interactions with the hospital processes: — Better access to care and communication with HCPs and the hospital	— To establish a dedicated telephone number within the nephrology service to support inquiries and emergency contacts from CKD/ESRF patients, as well as their relatives and ICs. This initiative would require implementing a structured schedule and assigning a designated staff member to manage the line exclusively. — To recruit a specialized administrative staff member designated to support the nephrology service by (i) optimizing the interaction time between physicians and patients, (ii) developing operational tasks, (iii) solving issues of interest to the service, and (iv) optimizing the use of email, with these services being responsible for filtering emails and responding to patients. — To promote the utilization of telehealth services for ESRF patients residing in remote areas where face-to-face assessments are not required. Additionally, to encourage telehealth consultations with family doctors to efficiently manage patient follow-up requests and triage processes. This approach aims to enhance accessibility to healthcare services for ESRF patients while streamlining communication and care coordination between HCPs.
	Improve the interactions with the hospital processes: — Organisation and differentiation of the nephrolopgy service	— To strengthen interdisciplinary collaboration by: (i) facilitating regular formal multidisciplinary meetings involving nutritionists, nurses, and psychologists to discuss cases and develop comprehensive care strategies; (b) enlisting support from psychology and social services to conduct informative sessions on RRTs; (c) developing a physical and cognitive rehabilitation program for ESRF patients, integrating physiotherapy, psychology, and psychiatry, and (d) collaborating with specialists in sports medicine, physiatry, and physiotherapy to establish a tailored physical activity program for ESRF patients. This initiative aims to mitigate sedentary lifestyles and enhance health outcomes. — To address high turnover rates within the nursing team by ensuring the presence of permanent nursing staff members within the service. — To establish a new dialysis admission appointment, inclusive of both Hemodialysis (HD) and Peritoneal Dialysis (PD) patients, involving the patient and ICs. This appointment aims to adequately prepare patients and their caregivers for the treatment beginning.

		— To optimize the organisation of the RRT informative session by: (i) inviting patients currently undergoing RRTs to share success stories, dispelling myths and fears surrounding adherence to treatment; (ii) ensuring formal invitations of patients and their ICs by a nurse responsible for explaining the session's purpose, collecting participant data, and confirming attendance; (iii) clearly identifying the information session location within the waiting room; (iv) enhancing audio-visual materials and resources during the session (e.g., to develop an educational manual specifically designed for the session, containing comprehensive information on RRT techniques and CMKF along with other essential details). This manual could be distributed to patients and ICs after educational sessions, providing them with a tangible resource to consult at home); (v) providing proper follow-up to assist patients in their decision-making process. — To optimize the organisation of the dialysis room by ensuring a smaller, dedicated space exclusively for outpatient dialysis sessions and by relocating inpatients to a larger space to accommodate their extended treatment requirements and resource needs.
	Improve the interactions with the hospital processes: — Ensuring a smooth and seamless delivery of care	— To enhance care coordination with external entities, such as primary care, by leveraging telehealth technologies. The purpose is to ensure appropriate follow-up care for patients and maintain service continuity and improve patient admission criteria by efficiently filtering referrals from primary care to the nephrology services of the hospital. — To improve care coordination with other external entities, including public hospitals of the Portuguese National Health System (SNS), day hospitals, pharmacies and imaging services, to establish a support network system. This network will allow patients to undergo examinations and blood testing in their area of residence without the need to visit the Hospital of Braga. The collaboration with local pharmacies is specifically recommended to create an open channel to clarify patient doubts about medication. Alternative collaboration options include (i) implementing protocols with a specialized team of pharmacists within the hospital to exclusively manage patients' medication (e.g., controlling medication intake, identifying potential issues, educating patients, and co-creating strategies for proper medication management) and (ii) assigning this role to a nurse, ensuring adequate resources for this function/activity. o For example, the Hospital Centre of São João (CHUSJ) and its partners, including the Order of Pharmacists, the National Association of Pharmacies (ANF), and the Association of Pharmaceutical Distributors (ADIFA), have collaborated on the innovative "Farma2care" project. This initiative aims to enhance

		patient adherence to therapy by providing convenient access to medication through local pharmacies. Patients who typically visit CHUSJ to collect their medication can now obtain it from a pharmacy of their choice within the network of available establishments. — To enhance coordination among internal services and departments responsible for supporting CKD patients, such as nephrology, otorhinolaryngology, nursing, and nutrition. Facilitate interactions between nephrologists and otorhinolaryngologists to ensure supervision of ESRD patients experiencing hearing loss. Strengthen the nurse-nutritionist relationship by allowing nurses to perform bioimpedances before nutrition consultations.
	Improve the interactions with HCPs: — Strengthening relationships with ESRF	— To enhance communication with patients by (i) demonstrating openness and willingness to discuss alternative therapies and treatments, fostering a sense of security and comfort for patients to share ideas and potential solutions; (ii) providing detailed explanations of illness- and service-related information to promote therapeutic adherence and increase patients' awareness and attendance at medical appointments; (iii) prioritizing active listening skills and addressing patient doubts, fostering greater closeness and empathy towards patients; (iv) informing patients about the disease's impacts on various life dimensions, ensuring they have a comprehensive understanding of the broader implications of their condition.
	Improve the interactions with HCPs: — Fostering the involvement of ICs of ESRF	— To enhance the active involvement of ICs, implement the following strategies such as (i) formally inviting ICs to accompany ESRD patients to both medical appointments and informative sessions on RRTs. The aim is to ensure their inclusion in the patient's healthcare journey and facilitates their participation in decision-making processes; (ii) providing clear communication about current programs designed to train and offer technical support from nurses to ICs. This communication ensures that ICs are aware of available resources and support services, empowering them to provide optimal care and assistance to ESRF patients.
	Improve the interactions with the hospital environment (servicescape) — Waiting rooms – physical evidences	— To redesign the waiting rooms by creating a welcoming and educational environment to enhance PX and empower individuals to take control of their health and well-being. The redesign process must require (i) installing displays featuring informative materials about (CKD) to educate patients and visitors about the condition, its management, and preventive measures; and (ii) integrating tension machines or blood pressure monitors to encourage patients to actively monitor their health while waiting for appointments, promoting proactive engagement in their healthcare;

Post service consumption	Improve the interactions with HCPs: — Providing long-term disease management support	— To deliver long-term psycho-social support through domiciliary visits to patients undergoing peritoneal dialysis (PD) to understand and assess specific situations as well as the effectiveness of the therapy. — To deliver long-term psycho-social support through periodic educative collective sessions, conducted in both face-to-face and online formats, for ESRF patients and their family members or ICs. The aim to foster social connections, share experiences, and promote a sense of belonging and inclusion. Care moderators must facilitate these sessions to gain patient buy-in. — To deliver long-term psycho-social support through the establishment a patient-to-patient mentorship program, in which a selected group of patient ambassadors, chosen for their exemplary management of their chronic condition, provide support and share success stories with their peers. The aim is to assist ESRD patients in choosing RRTs and provide emotional support. — To deliver long-term psychosocial support through the development of a collaborative online platform or online community (e.g., *Together We Stand* platform), managed directly by service staff specifically recruited for this purpose. This platform could facilitate ongoing interaction with ESRF patients outside hospital boundaries, disseminate videos and psycho-educational materials, allow for the review of educative collective session content, and share success stories from patient ambassadors to inspire others and normalize the disease. The platform could also provide the access to a "ESRF handbook" to guide and inform new and current patients about the entirety of their journey. The manual could provide essential information on symptoms, treatments, available support resources, relevant technologies and a directory of valuable contacts, such as nursing helpline numbers.

Source: Authors' elaboration

Based on these research findings and previous recommendations, the need to establish a comprehensive system for evaluating and measuring the experience of chronic patients is imperative. This system aims to go beyond existing metrics and indicators for assessing services and patient satisfaction by incorporating holistic evaluation criteria, including patient well-being and quality of life. For instance, IPO Porto has exemplified this approach by establishing a dedicated quality-of-life office in 2020, focusing on understanding the multidimensional impacts of illness and treatment on patients, encompassing physical, psychological, emotional, and social aspects. This office emphasizes the relevance of directly asking feedback from patients to identify their most relevant concerns and priorities. The proposed evaluation system would adopt both qualitative and quantitative methodologies. Qualitative methods involve conducting interviews and maintaining written patient records to gain deeper insights into PXs. Quantitative assessment would entail administering a PX measurement questionnaire. Essential assessment aspects include patients' perceptions of elements such as process efficiency, interpersonal interactions with HCPs, servicescape, as well as interactions and activities performed beyond the boundaries of the hospital. Initially, the evaluation system must be piloted within the nephrology and endocrinology services. Following a pilot phase, the system could be expanded to encompass other services within the hospital. To ensure the effective implementation of these measures, we recommend the organisation of co-design workshops involving a multidisciplinary team to refine and optimize the implementation of the holistic PX assessment system, ensuring alignment with the diverse needs and perspectives of the stakeholders involved.

4.6.2.2.2. Improvement guidelines for the overall hospital services

The recommendations presented in Table 4.20 are aimed at broader systemic enhancements that impact the overall experience of chronically ill patients, particularly those with T1D and ESRF. These recommendations encompass core structural services and specialised services such as nephrology and endocrinology, which are critical in managing these conditions effectively. The proposed recommendations result from insights gathered from participants, including HCPs, patients and ICs. These insights were further reinforced by collecting best practices from various sources and conducting a netnography study to analyse online discussions and experiences of patients regarding the overall services of the Hospital of Braga.

Table 4.20 – General recommendations for improving services of the Hospital of Braga

Improve the interactions with the hospital processes: — Access and communication with the hospital	— To implement an automated call centre system with specific extensions and support numbers for each department service to enhance communication and accessibility for patients, visitors, and staff.
Improve the interactions with the hospital processes: — More resources and better response capacity	— To enhance the healthcare workforce, particularly, in mental health services (psychology and psychiatry). Furthermore, recruitment efforts must be tailored to address specific needs within the healthcare services, ensuring a well-rounded and specialised workforce. — To optimise the physical infrastructure by (i) improving the availability of physical resources, including consultation rooms and offices; (ii) ensuring proper resources and equipments within consultation rooms and offices for facilitating consultations, examinations, and other medical procedures. — To review and improve the appointment management system to alleviate waiting times for patients, by giving HCPs more autonomy in scheduling outpatient appointments.
Improve the interactions with the hospital processes: — Hospital information technologies	— To advance the integration of automation and digitalisation within the services of the hospital through the following strategies: (a) Focusing on continuous Improvement of internal technological systems. It requires ongoing enhancements to existing technological infrastructure to optimise operational efficiency and support innovative solutions. Regular upgrades and maintenance ensure that internal systems remain robust and aligned with evolving healthcare needs. (b) Transition to online systems for prescriptions and patient notifications. It requires implementing online platforms for prescription management and patient communication. This shift towards digital platforms facilitates efficient prescription handling and enables timely patient notifications regarding appointments, test results, and other pertinent information. (c) Utilising artificial intelligence (AI) technologies to enhance consultations. For instance, AI-powered translation tools can facilitate real-time and automatic transcription of consultations, generating comprehensive written records in real time, which enhances the accuracy and accessibility of patient information. (d) Optimisation of patient entry and reception systems. It requires enhancing patient entry, sign-in, and reception processes through technological solutions. Streamlining these processes with automated systems reduces waiting times, minimises administrative burdens, and enhances patient satisfaction. Regarding digitalisation and automation processes, we provide some examples of good practices, namely: (i) IPO-Porto with the *Qtime Project,* which consists of dematerialising requests for analyses, integrating them with the hospital's entire

	clinical process and allowing for a reduction in patient waiting times for collection, immediate scheduling of analyses, greater efficiency, safety, productivity, increased patient satisfaction, optimisation of agendas and a reduction in costs with consumables. (ii) IPO-Porto with the *Bem-Me-Ker Kiosks*. Implementing automated check-in kiosks expedites patient registration and streamlines continuity of care processes. It is an automated solution for managing the relationship with patients on arrival (check-in), departure (check-out), and continuity of care (future visits, care at home, preparations). Electronic cards with associated pins have been designed for patients, allowing them to use the kiosks more quickly and guaranteeing security standards in their access. (iii) IPO-Porto and São João with the development of patient-centric applications (e.g., "IPO Bem Me Ker" and "My São João") facilitate seamless access to essential healthcare services and information for patients. These apps enable patients to conveniently access their appointment schedules, health reports, payment options, and exam preparations and receive important notifications.
Improve the interactions with the HCPs: Fostering training and development of front office	— To expand humanisation beyond the doctor-patient relationship to encompass the approach of assistants and front desk staff. This requires to focus on the empathy and respect in all interactions within the healthcare environment, not limited to doctor-patient interactions. Therefore, promoting training and education for administrative staff is a fundamental strategy to cultivate empathy, improve interpersonal skills, foster a deeper understanding of patient needs, effective communication techniques, and strategies for handling challenging situations with sensitivity and professionalism.

Source: Authors' elaboration

4.6.3. Implications for Public Policymakers

In light of our research findings, it is imperative for public policymakers to recognize that achieving sustainable social integration for individuals with chronic illnesses necessitates ongoing, efficacious interventions to facilitate access to diverse facets of society. This endeavor entails orchestrating collaboration among different service systems, including but not limited to healthcare, social care, and education, in order to support chronically ill patients, their ICs, and families in navigating the complexities of educational, developmental, and occupational pathways.

Regarding T1D, the results highlight the need to increase education and health literacy on T1D in the community, schools, and even in higher education institutions (HEIs). For example, the current

scenario in Portugal is still not very promising. For example, in a study carried out with a sample of young Portuguese people, the presence of a chronic illness was associated with lower overall satisfaction and a less positive perception of the school environment. This is yet another indication of the relevance and urgency of the support and supervision of teaching and auxiliary staff to fill gaps in integration and satisfaction with school (Direção-Geral da Saúde., 2019). Therefore, aligning with the best international practices (e.g., the Government of New Brunswick developed the "Handbook for Type 1 Diabetes Management in Schools), schools and HEIs must continue to be the target of a program of more information and training. Lectures, events, and dissemination of information about T1D are fundamental to ensure adequate integration of these children in the school and social community and avoid social stigma (Government of New Brunswick 2008). This research also shows that there is also a need for more excellent protection of T1D patients who often feel unsafe and discriminated against in their workplaces. The hiding of their diagnosis is motivated by the fear of losing their jobs. Therefore, the importance of safeguarding these patients' positions in the workplace is suggested. In this domain, the American Diabetes Association (ADA - American Diabetes Association, 2024) emphasises practice recommendations on employment of people with diabetes by highlighting their rights on the job and how to avoid discrimination at work. Our findings also highlight the link between T1D patients and social stigma. Similarly, recent studies have also shed light on the link between stigmatization and T1D. For instance, Sińska et al. (2023) investigated factors influencing perceived stigma among T1D patients. They found that a significant portion of T1D individuals experience stigma, which can directly impact diabetes management and treatment adherence. Consequently, addressing stigma is crucial for supporting individuals with T1D. Effective measures to counteract stigma and provide support to T1D individuals are essential. Therefore, raising public awareness and disseminating knowledge about diabetes can help reduce stigma. Including anti-stigma messages in prevention programs can educate the public about the potential consequences of mistreating individuals with T1D (Sińska et al., 2023). These efforts create a more supportive environment for T1D patients and facilitate better management of their condition.

Regarding CKD, this research manifests the need to deliver prevention services that keep people well and diagnose diseases early. The absence of symptoms in the early stages of the disease is why CKD is known as a silent disease (Whaley-Connell et al., 2011). This initial lack of signs or the downplaying of some symptoms is due to the kidneys' ability to adapt to the progressive loss of their function, which means signs only appear when the disease is already at an advanced stage.

In Portugal, the overall scenario is discouraging. The 2019 Annual Report of the Portuguese Society of Nephrology's Chronic Kidney Disease Registry Office shows that the incidence of patients starting renal function replacement therapy (RRT) remains high - 260 per million inhabitants. Portugal is still at the top of Europe and the world. For the second year running, the prevalence of patients on RRT has exceeded 2,000 per million inhabitants (SPN - Sociedade Portuguesa de Nefrologia, 2019) While the National Health Service (Serviço Nacional de Saúde – SNS) can boast of giving all patients access to treatment for advanced chronic kidney disease and dialysis, it must do more to prevent it. There is little knowledge about the disease. Surgery ends up being an option for some, often dependent on a long waiting list. Until then, most of the 13,000 patients (86%) undergoing treatment go to a hemodialysis centre thrice a week. A minority undergoes peritoneal dialysis, a lesser-known technique, usually done at home, giving patients greater autonomy (Ascensão, 2023). Therefore, we need to draw up guidelines to improve the prevention and treatment of kidney disease and define such actions on chronic kidney disease in the National Health Plan 2030. According to the Centers for Disease Control and Prevention (CDC, 2021) effective strategies for disease prevention must emphasize the following key points (1) managing and controlling risk factors such as diabetes and hypertension, which are known contributors to the onset and progression of the disease; (2) early detection and treatment of any kidney disease to mitigate its impact and progression; (3) regular health check-ups to monitor and manage potential risk factors and complications associated with the disease; (4) adherence to prescribed treatment regimens for diabetes and hypertension to optimize disease management and control; (5) maintenance of a healthy weight to reduce the burden on the kidneys and minimize associated risks; (6) adoption of a nutritious diet with reduced salt and protein intake to support overall kidney health; (7) engagement in physical activity tailored to individual capabilities and lifestyle to promote cardiovascular health and mitigate risk factors; (8) abstinence from smoking, as tobacco use exacerbates kidney-related complications and accelerates disease progression; and (9) moderation of alcohol consumption to minimize adverse effects on kidney function and overall health. By implementing appropriate interventions and fostering strong connections between community and clinical settings, it is possible to prevent or slow down the progression of kidney disease, mitigate complications, and reduce the demand for extensive healthcare services (CDC, 2021).

4.7. LIMITATIONS AND FUTURE RESEARCH AVENUES

4.7.1. Methdological advancements

This study centred on exploring the experiences of individuals living with chronic illnesses, with a specific emphasis on two conditions: T1D and ESRD. The study allowed the development of two patient journey models tailored to these chronic conditions within a Portuguese public hospital setting. An important aspect to consider is that data collection occurred immediately following the Covid-19 pandemic. This contextual factor may have influenced individuals' perceptions, as the hospital and healthcare professionals were still readjusting and recovering from the pandemic during the data collection period. Therefore, it would be crucial to replicate this study at Braga Hospital, seizing the opportunity to expand it to include other areas of interest or medical specialities.

Second, while the findings may offer valuable insights applicable to other public healthcare institutions, future research should aim to replicate the study across a broader spectrum of public hospitals and private healthcare facilities, both nationally and internationally, with multi-country studies enabling cross-cultural comparisons and insights. Such endeavours would facilitate comparative analyses, identifying areas for overarching interventions applicable to both institution types and specific interventions tailored to the unique realities of each healthcare setting.

Third, there remains a critical need for future research to expand the scope of inquiry to encompass the PX and apply the proposed models to other prevalent chronic or long-term conditions, such as cancer patients with cardiac comorbidities or individuals with mental illnesses.

Fourth, another noteworthy aspect is the predominantly cross-sectional nature of our study, supplemented by a longitudinal component tracking changes in patients' experiences over six months. However, the absence of significant changes in patient perceptions, habits, or experiences suggests the importance of adopting a more extended longitudinal methodology in future studies (Caruana et al., 2015), spanning at least 12 months. This prolonged timeframe would provide a more comprehensive understanding of the dynamics and evolution of the PX across different stages of the chronic illness journey.

Lastly, while our research investigates PX's qualitative nature and dynamics throughout the patient's journey, it falls short of establishing conclusive statistical relationships between components of the theoretical framework identified. Hence, future research should prioritise two key areas: (1) operationalising the framework into measurable constructs to enable quantitative

assessment of PX throughout the journey (Swallmeh et al., 2018) and (2) conducting studies to explore the relationships between improvements in patient journey models and resultant health outcomes, encompassing aspects such as well-being, quality of life, and clinical outcomes (Doyle et al., 2013). These research priorities are integral to advancing our understanding of the PX in chronic illness management and informing targeted interventions to enhance patient outcomes effectively.

4.7.2. Emerging research priorities across the journey

Based on these research findings, we identify some guidance for service researchers and critical questions across all stges of the service journey.

4.7.2.1. Pre-service encounter stage

Patients typically identify their symptoms in the pre-service encounter stage and search for care. Hence, it is imperative to gain a deeper understanding of the pivotal role that digital marketing techniques play in enabling hospitals and HCOs to effectively engage with and reach their target audience. In today's digital age, healthcare consumers are more proactive about their health and seek out information online before making healthcare decisions. With easy internet access, patients now can conduct thorough research on symptoms, treatments, and healthcare professionals, often relying on online reviews and ratings to inform their choices. Consequently, it is critical for HCPs to establish a robust online presence (Maas et al., 2023). Although adopting digital strategies for communication and patient attraction is more commonly associated with private institutions, it is equally pertinent for public healthcare institutions to embrace these approaches. Digital marketing offers several advantages over traditional marketing strategies. It empowers HCPs to take advantage of diverse online platforms such as websites, social media channels, and search engines to engage with patients and showcase their distinctive clinical services and offerings. By integrating digital marketing strategies into their practices, HCOs can effectively connect with patients, enhance brand visibility, foster growth within the healthcare industry, and maintain patient engagement across various stages of their healthcare journey. Therefore, considering the unique needs of chronically ill patients, future research endeavors must address several critical research questions: (1) How can digital marketing help public hospitals optimise their websites for search engines? (2) How can digital marketing help public hospitals reduce risk perceptions and build trust in chronically ill patients through video content and social media?

4.7.2.2. The service encounter stage

This research underscores the significant role of interactions within processes and their capacity to shape and influence the PX. Specifically, it sheds light on a spectrum of drivers contributing to the ineffectiveness of internal and healthcare processes within the Hospital of Braga, subsequently impacting the PX adversely. Among these drivers are challenges in coordinating internally and externally with other healthcare entities, impeding the seamless flow and transition between healthcare services. Therefore, a key research question is: (1) How can public hospitals optimise care coordination through partnerships with primary care institutions?

Moreover, deficiencies in digitalisation, bureaucratic hurdles, and manual procedures were identified as additional barriers to process fluidity, consequently impacting patients' overall perceptions. Hence, future research endeavours could concentrate on: (1) How can hospitals leverage technological tools to automate internal processes effectively? (2) How can digital marketing help public hospitals strengthen chronically ill patients' relationships with clinicians? (3) How can digital marketing help public hospitals personalise communication and add convenience for chronically ill patients?

This research also shows that interactions with HCPs were critical to the positive experiences of chronically ill patients. However, this topic deserves continued attention in future research, as we are still transitioning from a paternalistic to a collaborative stance in the healthcare sector. Thus, relational medicine and the role of empathy, active listening and patient involvement in strengthening relationships between all stakeholders should be further investigated (Berry et al., 2022). Also, the importance of involving family and ICs in strengthening these relationships and on the well-being of all parties should be highlighted here. As this study shows, ICs feel weakened and often lack access to resources and help from HCPs. Therefore, future research questions will include (1) How can ICs and families of chronically ill patients be effectively involved in the healthcare team without disrupting the patient-provider relationship? (2) How can ICs and families of chronically ill patients benefit from education and training to cocreate value in partnership with clinicians?

4.7.2.3. The post-service encounter stage

Our findings show a salient manifestation from patients and HCPs on the importance of self-management in chronic illness. Self-management encompasses a spectrum of strategies, decisions, and daily actions patients undertake to navigate and cope with their chronic conditions

over an extended period. Given the inherent vulnerability associated with chronic illnesses, individuals often encounter challenges in effectively self-managing various aspects, including symptom management, medication adherence, and lifestyle adjustments such as adapting physical activity and nutrition habits. However, the limited time and resources available for interaction during physician-patient encounters make delivering sustained and appropriate support particularly challenging. Therefore, there is a need for service researchers to further investigate the role of HCPs in contributing to and leveraging self-management strategies among chronically ill patients (Donald et al., 2018). This study underscores the imperative of addressing this gap and advocates for continuously developing online platforms to support patients. Such platforms enhance treatment and therapy adherence, bolster overall well-being, and optimise health outcomes. Additionally, these platforms foster a sense of community by facilitating the exchange of experiences among individuals dealing with similar conditions. Therefore, one pertinent research question could be: (1) How can HCOs benefit from collaborative platforms for providing sustained long-term support, thereby enhancing the self-management strategies employed by individuals dealing with chronic illnesses?

CHAPTER 5 - CONCLUSIONS

CHAPTER 5. CONCLUSIONS

The domain of patient experience (PX) represents a relatively recent field in healthcare service and marketing research, demonstrating considerable promise for future exploration. With its diverse and expanding body of research, PX has firmly established itself at the core of contemporary healthcare discourse.

In the following sections, we pesent an overview of the main findings from this investigation by addressing each research question. Afterwards, we discuss the main implications of this study, involving a explanation of the research outputs and contributions at various levels (theoretical, methodological and practical). Lastly, we conclude this chapter by identifying the main limitations and delineating potential avenues for future research.

5.1. Main findings

RQ1. How does the holistic PX occurs throughout the journey?

We conducted an extensive literature review on the topic (Essay I) to answer the first research question. We propose to go beyond the most common perspective on PX, which is the healthcare service provider perspective. Such a perspective primarily revolves around the organisational viewpoint, assuming that services primarily focus on enhancing various dimensions of service quality to craft a tailored care experience for the patient. According to this view, PX can be conceptualised as a multidimensional construct representing both the patients' experiences of care and the feedback received from patients about those experiences with domains/elements of care, including, for example, respect, information and communication, physical comfort, emotional support, and access to care.

We propose to continue the discussion on PX by demonstrating the usefulness of a novel, holistic and dynamic PX view based on the patient's journey. This approach assumes the perspective of the patient is the main one to take into account. It recognises that PX is holistic and dynamic concept, consisting of the patient's journey over time and across multiple touchpoints. The patient journey represents a map of the steps patients take as they progress through different stages of a disease. Thus, the patient journey unfolds across multiple service cycles and is very iterative in nature. More specifically, the patient journey consists of patient interactions, so-called touchpoints,

with several actors (including HCPs) distributed over three stages: pre-service, during, and post-service encounters.

Pre-service encounters typically encompass the symptoms awareness and the search for care. Service encounters include the moments of truth, that is, the moments of interactions between patients and healthcare organisations/providers, typically including interactions with the staff, processes and servicescape. Post-service encounters start when patients leave the hospital/clinical setting to self-manage their condition at home.

Patient journeys facilitate the exchange and exploration of information between patients and clinicians, going beyond medical aspects to encompass emotional, psychological, social, and other pertinent factors influencing patients' daily lives. In other words, they are proposed as essential tools to document PXs inside and outside organisational boundaries. Hence,PX should be assessed as a continuous journey rather than as distinct episodes of care received from a specific program, service, or provider. As previously mentioned, touchpoints are critical components of the patient's journey. In this research, we assume touchpoints as clusters of experiential elements that facilitate the service experiences and as being classified into five main categories based on the subject that manages and controls them: the company/healthcare provider (brand-owned touchpoints), a business partner (partner owned touchpoints), the customer/patient (patient-owned touchpoints), or external factors (e.g. a peer, the environment).

Building upon our demonstration of the potential of a holistic PX approach, our research advances towards its application in specific research contexts, mainly focusing on vulnerable healthcare consumers. The rationale is that patient journeys are valuable tools designed to gather comprehensive insights into patients' experiences across various medical domains, including those affected by chronic diseases. Therefore, we developed a Patient Experience Journey Model for Chronic Conditions, which depicts the experience of chronically ill patients through different stages and touchpoints over time. In the pre-service encounter phase, touchpoints include the influences of digital marketing (brand-owned touchpoints), patients recognising symptoms and initiating decision-making (patient-owned touchpoints), influences from family and friends (social/external-owned touchpoints), and availability of medical insurance for selecting care providers (partner-owned touchpoints), and external influences/dynamics such past experiences from others.

During service encounters, touchpoints encompass interactions with HCPs and care processes (brand-owned touchpoints), interactions with software systems (partner-owned), patients' development of feelings, emotions, and attitudes during diagnosis and treatments (patient-owned

touchpoints), and external influences/dynamics like crises and others' experiences, which can influence the service encounter experiences.

In the post-service encounter phase, touchpoints include long-term support from HCPs (brand-owned), interactions with electronic devices and self-management practices from patients to deal with the condition (patient-owned), the influence and support from family and peers (social-owned touchpoints), and external influences/ dynamics such as past experiences from others.

Following the development of a comprehensive PX model spanning the whole journey within the context of chronic conditions, our objective shifted towards empirically investigating the experiences and well-being of chronically ill patients, specifically those with Type 1 Diabetes (T1D) and End-Stage Renal Failure (ESRF) (Essay II).

To achieve this, we conducted a netnography analysis of 186 discussion threads sourced from two prominent international Online Health Communities (OHCs) dedicated to T1D and ESRF patients, respectively. In the first stage (pre-service encounters), patients reported in the OHCs identifying the symptoms and needing to explore them better. In the second stage (during service encounters), patients reported multiple outpatient consultations and interactions with HCOs and HCPs to receive the diagnosis and follow the prescribed treatments. However, patients identified issues and challenges while interacting with HCPs and the care processes. In particular, they express the need for technical competence, emotional and informational support and more adequate /effective care procedures (e.g., multidisciplinary care teams) (brand-owned touchpoints). Lastly, regarding the post-service encounter stage, patients manifest in OHCs their interactions with the social actors. Patients express in the OHCs the need for more social support, including a better understanding and comprehension of the disease from others (e.g., family, informal caregivers, and friends) (social-owned touchpoints). Also, at this stage, participants express their pivotal role in self-management by engaging in value co-creation activities (patient-owned touchpoints).

The last phase of this research (Essay III) involved a more complex empirical investigation, and the collection of multiple qualitative data sources (interviews, focus groups and diaries) from patients with T1D and ESRF, informal caregivers and HCPs in a public hospital in Portugal (n=38 participants). Based on the findings, we introduced two tailored patient journey models for the chronic conditions under investigation. These models deepen our comprehension of PXs and offer invaluable insights for future research. The empirical findings unveil the critical influences of three touchpoint spheres (brand, patient and social) crossing the three stages of the journey. At pre-service encounters, patients identify symptoms and search for care (patient-owned touchpoints).

During service encounters, the study highlights the pivotal role of interactions with processes and staff (brand-owned touchpoints). Enhancing the effectiveness of care delivery, encompassing aspects such as timeliness, improved access to care, and communication with the hospital, is imperative to foster a positive PX. Notably, access to care emerged as a critical driver of care ineffectiveness, further exacerbated by the COVID-19 pandemic.

Furthermore, HCPs establishing meaningful relationships with patients and offering support across emotional, technical, and psychosocial domains, significantly influences the experiences of chronically ill patients with T1D and ESRF. In the post-service encounters phase, patients deal with the challenges of managing daily disease-related issues, including technological devices, dietary habits, physical activity, and medication adherence. Moreover, patients must adapt their lifestyles to accommodate chronic illness, engage in activities promoting physical and mental well-being, augment knowledge, and develop coping strategies (patient-owned touchpoints). Lastly, in this stage, patients typically feel a lack of support from social circles due to the higher level of disinformation and stigma towards these diseases (social-owned touchpoints).

In conclusion, our conceptual model proposed at the first stage of research (Essay I) elucidating PX across the journey within chronic conditions sheds light on the diverse types of touchpoints that shape and impact the experiences of chronically ill patients. Through our empirical investigation (Essays II and III), we unveil the specific nuances associated with each chronic disease, identifying clusters of touchpoints that predominantly shape the experiences of chronically ill patients. Our research underscores that touchpoints related to the brand, patient, and social spheres emerge as the most critical influencers of patients' experiences with T1D and ESRD. Those specificities are illustrated within our proposed models of patient journey across the journey for the two chronic conditions under study.

By contrasting the findings from the two empirical studies (Essay II and III), we discern areas of convergence that offer valuable insights. Both studies highlight the following key aspects: (1) the imperative need to improve care effectiveness and the provision of emotional and instrumental support from HCPs within the brand sphere; (2) the role of patients in self-care and management and their efforts to engage in co-creating activities and adjusting life to the disease; and (3) the lack of social support from the social circle, denoting a critical gap within the social sphere. These convergent findings underscore pivotal areas where HCOs can enhance their management of patient experiences and drive service improvements. Additionally, both empirical studies (II and III) highlight similarities in the experience of negative emotions, particularly during the post-service

encounters phase, when patients are managing their condition independently. Specifically, while individuals with T1D report emotions such as exhaustion, frustration, and anxiety because of the lack of comprehension about the disease, patients with ESRF tend to suffer from depression.

In contrast, disparities emerged between the theoretical framework presented in Study I and the empirical findings of Study III. Notably, a point of divergence lies within the pre-service encounter phase. Our theoretical model predominantly highlights the impact of socially owned touchpoints, such as relatives, peers, or family, on the decision-making process regarding healthcare providers. However, Study III revealed a deviation from this assumption, as patients primarily relied on referrals from health centres or family doctors within their localities, thereby diminishing the perceived influence of social networks.

RQ2. How can the holistic PX across the journey be managed to enhance healthcare service delivery and generate well-being outcomes?

After understanding how PX occurs throughout the patient journey, we explored how HCOs and HCPs can better manage PX to foster improvements in service delivery and generate health outcomes such as well-being. Therefore, this research focused firstly on identifying the domains of patient experience management (PXM) in the literature review (Essay I). Three main domains of PXM were identified, namely the (1) Patient Journey and Touchpoint design, (2) Partner and Network management, and (3) Internal organisation challenges.

The empirical qualitative study involving multiple participants from the public hospital in Portugal (Essay III) proved useful for directly applying these domains to foster PXM and improve outcomes. The first domain (Patient Journey and Touchpoint design) suggests the creation of a seamless experience across touchpoints through the patient journey to create a stronger PX. Additionally, e-health tools such as apps, mobile platforms, and telehealth services are pivotal in facilitating smoother care transitions and improving service coordination among HCPs and specialists. Therefore, our empirical study recommended, for example, fostering the use of telehealth services for patients residing in remote areas where face-to-face assessments are not required. This approach aims to enhance accessibility to healthcare services, particularly for ESRF patients, while ensuring communication and care coordination between healthcare institutions (e.g., primary care and specialty care services from the Hospital of Braga).

The second domain (partner and network management) highlights the importance of mapping and analysing the patient journey while considering the broader service delivery system (e.g., online

communities, experience networks, service delivery networks, and collaborators). Therefore, in our empirical study, managerial recommendations to the hospital include, for example, extending service delivery network by developing an online platform/community managed and controlled directly by the hospital and partners to foster the delivery of long-term psychosocial support to chronically ill patients (T1D/ESRF). This platform would facilitate ongoing interaction with T1D and ESRF patients outside the hospital boundaries, enhance the PX, disseminate videos and psycho-educational materials, allow for the review of educative collective session content, and showcase success stories from patient ambassadors to inspire others and normalise the disease. It is crucial to acknowledge that this platform, either fully or partially administered by a team of healthcare professionals from the hospital and collaborating partners within a coordinated network, affords care providers a heightened sense of control and reduces patients' risk perception and uncertainty. Moreover, recommendations concerning PXM include improving care coordination with other external entities, including public hospitals of the Portuguese National Health System (SNS), day hospitals, pharmacies and imaging services, and establishing a strong and more effective support network system. Collaboration with local pharmacies is recommended explicitly to enhance medication adherence by creating an open channel to clarify patient doubts about medication or, as an alternative, by implementing protocols with a specialised team of pharmacists within the hospital to manage ESRF patients' medication exclusively.

The third and last domain (internal organisation challenges) unfolds the capabilities, resources and design system reconfigurations (e.g., physical and non-physical elements, including people/staff, environment/places, processes, and technology) that HCOs must orchestrate to develop a patient-centric focus, thereby creating stronger PXs. Moreover, internal organisation challenges include developing a multidisciplinary approach involving collaboration among various functions (e.g., Information Technologies / IT, marketing, operations, customer service, human resources) to create a strong PX response orientation. In this respect, the empirical component of this research suggests the improvement of the interactions with the hospital processes, namely of the access to care and communication with the hospital and the organisation, and a differentiation of the Endocrinology and Nephrology services, by strengthening interdisciplinarity, for instance.

In terms of interactions with health staff, it is also suggested to strengthen the communication with T1D/ESRF patients by (a) demonstrating openness and willingness to discuss alternative therapies and treatments, fostering a sense of security and comfort for patients to share ideas and potential solutions; (b) providing detailed explanations of illness- and service-related information to promote

therapeutic adherence and increase patients' awareness and attendance at medical appointments; (c) prioritising active listening skills and addressing patient doubts, fostering greater closeness and empathy towards patients; (d) informing patients about the disease's impacts on various dimensions of their life, ensuring they have a comprehensive understanding of the broader implications of their condition. Additionally, it is suggested to enhance the active involvement of informal caregivers (ICs), especially to accompany ESRD patients to both medical appointments and informative sessions on Renal Replacement Therapy (RRTs). An additional and essential factor that has culminated in actionable recommendations for the Hospital of Braga is the investment in the training and education of healthcare professionals, mainly focusing on enhancing the skills of front-office teams responsible for delivering patient care.

Lastly, the interactions with the servicescape must also be enhanced to ensure the quality of food and beverages provided to hospitalised T1D patients by paying meticulous attention to their dietary needs, which must be accurately tailored to their condition. Moreover, the redesign of waiting rooms by incorporating educational elements is also emphasised (e.g., Install displays featuring informative materials about CKD to educate patients and visitors about the condition, its management, and preventive measures).

Overall, HCOs that can skillfully manage the entire experience generate valuable outcomes. We identify ten central outcomes, falling under two major themes: (1) healthcare service-related outcomes and (2) patient-related outcomes. The health-service-related outcomes include a new model of care, effectiveness of care service delivery, strong service brand differentiation, patient loyalty, word-of-mouth, and profitability. On the other hand, patient-related outcomes encompass adherence prevention and treatment, satisfaction and safety, quality of life and well-being outcomes. Literature particularly emphasizes the link between PX improvements and the generation of well-being outcomes, which presents an opportunity to leverage transformative service research. Well-being is assumed in this research as a multidimensional construct that incorporates physical health, emotional balance, overall satisfaction with life, a sense of purpose, and social connections. Therefore, a comprehensive system for evaluating and measuring the experience of chronic patients within the hospital under study should also be established. This system aims to go beyond existing metrics and indicators for assessing services and patient satisfaction by incorporating holistic evaluation criteria, including patient-related outcomes such as well-being (physical, cognitive, affective and eudaimonic).

5.2. Main contributions

5.2.1. Research outputs

The research agenda and the results obtained gave origin to five communications at International conferences, Colloquiums and Service Research Doctoral Workshops (International Conference on Economics and Business Roads to Sustainability – ICBRS – University of Coimbra, 2023; Service Research Doctoral Workshop, FEUP, 2022; Frontiers in Service Conference, Fox School of Business - Global Institute for Artificial Intelligence & Business Analytics, 2021; EMAC 2020 Annual Conference; and 32nd EMAC Doctoral Colloquium, University of Hamburg, 2019) and to one scientific paper to be published in an international peer-reviewed scientific journal (Journal of Services Marketing). The overall research was supported by the PhD grant SFRH/BD/102853/2014 awarded by the Portuguese Foundation for Science and Technology (FCT). The work underlying this thesis also instigated several scientific contributions at various levels. The following subsection provides an overview of how these contributions relate to this thesis's essays.

5.2.2. Theoretical contributions

In this research, Essay I makes significant contributions to the academic field of PX research by examining PX as a comprehensive phenomenon occurring throughout the patient journey. It expands the understanding of PX by proposing a framework that identifies the variables influencing and resulting from PX within the patient journey. Indeed, Essay I introduced significant added value to prior studies by applying the Process Model for Customer Journey and Experience (Lemon & Verhoef, 2016) to the healthcare domain, explicitly focusing on chronic conditions. Thus, the proposed Patient Journey Model for chronic conditions underscores the holistic nature of PX, emphasizing its social and dynamic aspects (Ponsignon et al., 2018; S. Richardson et al., 2007; Silvera et al., 2017). While adopting a holistic approach encompassing patients' multifaceted interactions across pre-, during-, and post-care stages, this research goes beyond previous research, which often focuses on specific care elements within hospital settings and limited service encounters (e.g.,Makarem & Al-Amin, 2014; Mitra, 2016). By recognizing and addressing the holistic experiences of chronically ill patients, this research is expected to yield substantial outcomes for the healthcare system, including improvements in healthcare service delivery and well-being for patients, families, and informal caregivers. Therefore, this study aligns with the

objectives of transformative service research (TSR), which aims to focus on vulnerable healthcare service users, such as chronically ill individuals, and integrate consumer and service research to drive positive changes in well-being at individual, community, and systemic levels (Black & Gallan, 2015, O'Loughlin et al., 2023). Lastly, Essay I provides a research agenda for PX, which will stimulate research and knowledge development in this area.

Essay II explores the experiences and well-being dimensions reported in OHCs, contributing to recent theoretical discussions in the services marketing literature regarding the need to move beyond service-dominant logic to understand services with minimal service-provider interaction (Heinonen et al., 2010; Strandvik & Heinonen, 2015).

Finally, Essays I and IIII offer substantial suggestions and recommendations to enhance PXM, enrich the healthcare service literature, and advance knowledge in healthcare service strategy and managemen.

5.2.3. Methodological contributions

The main methodological advancements are evident in Essays II and III. In Essay II, a netnographic approach has been employed to elucidate the experiences and well-being of individuals coping with chronic illnesses throughout their journeys. This methodology provides a valuable avenue for comprehending patient experiences and perceptions, which may pose challenges in traditional face-to-face interviews (Rhoades et al., 2001; Sanders et al., 2011). This approach facilitates the collection of insights into present experiences and reflections stemming from interactions with many peers, offering a more authentic portrayal of how individuals and their informal caregivers navigate and cope with chronic illnesses. (Kirk & Milnes, 2016).

Furthermore, the third Essay contributes methodologically in several ways. The use of multiple data sources, such as interviews, focus groups, and diaries, allows the study to comprehensively explore PXs, capturing nuanced insights and intricate details that may escape single-method approaches. These diverse data sources provide a spectrum of perspectives: interviews enable personalized exploration, focus groups foster interaction and group dynamics, and diaries offer longitudinal insights into patients' experiences over time. The integration of these methods enabled the capture of varied viewpoints and facilitated the identification of common themes or discrepancies among participants.

Moreover, the the credibility and validity of the findings was enhanced through triangulation. Triangulation involves comparing and contrasting data collected from different sources to validate

interpretations and corroborate findings (Creswell, 2014). For instance, themes identified in interviews are complemented and validated by data from text-based document analysis and non-participant observation, thereby bolstering the overall reliability of the study's findings.

5.2.4. Practical and policy contributions

First, this oresearch is likely to generate significant social impact by advocating for a practical approach to PX, which has the potential to yield valuable well-being outcomes for both patients and their families, as well as informal caregivers (Anderson et al., 2012;. Rosenbaum, 2015). Specifically, the social implications are extensive and profound for patients with T1D and ESRF and their ICs. Indeed, Esssay III particularly underscores the importance of fostering social interactions, meaningful connections, and shared experiences by emphasizing the significance of social-owned touchpoints, such as peer support networks. These avenues offer opportunities to enhance individuals' well-being despite the challenges posed by chronic illness.

Essay III identifies strategies for mitigating social isolation through initiatives like peer support networks, online communities, and group activities, thereby nurturing a sense of belonging and solidarity among individuals facing similar circumstances. Lastly, it illuminates the challenges faced by informal caregivers and underscores the necessity for additional support systems. The r acknowledgement of these challenges can leverage initiatives to provide respectful care, caregiver training, counselling services, and assistance to alleviate caregiver burden and enhance their well-being.

Secondly, Essay III proposes two "patient journey maps" depicting the experiences of chronically ill patients across various touchpoints throughout their journeys. These maps highlight the critical role of touchpoints within brand, hospital, patient, social, partner, and external spheres at different stages of the patient journey, emphasizing their significant impact on PX. Furthermore, the patient journey maps reveal critical points of convergence and divergence among patients and other participants, such as HCPs and informal caregivers (ICs). These models provided HCPs valuable insights for comprehensively understanding the holistic PX, guiding organizational strategies toward fostering robust PX and creating a strong PX response orientation. By offering insights into how organizations can shape their service strategies to prioritize PX and establish comprehensive measures to manage PX across various touchpoints and journey stages, this study facilitates a transition from conventional, episodic care approaches to a more integrated and continuous patient-centric continuum (Luxford & Sutton, 2014; Wolf et al., 2021).

5.3. Limitations and further research

This section delineates several limitations inherent in this study. These limitations facilitate the recognition of potential pathways for future research and underscore the iterative nature of academic inquiry. Through this process of reflection, a constructive outlook on scientific knowledge emerges, acknowledging its perpetual evolution and inherent imperfections (Sarmento, 2011).

Conceptually, despite the extensive scope of the current literature review, which encompasses scientific publications spanning from 1999 to 2024, it is imperative for forthcoming research to revisit and update the literature review. This will ensure alignment with the latest advancements and insights within the field, thereby upholding the scholarly integrity and currency of the investigation.

Firstly, this study examines two specific chronic conditions - T1D and ESRF. However, given the profound impact of long-term illnesses on patients, their families, and healthcare services, future research should broaden its scope to encompass other pertinent chronic illnesses, such as cancer, chronic heart disease, and epilepsy, among others. Indeed, forthcoming investigations should apply the proposed model of PX across various chronic conditions and discern specific nuances within each disease or journey, mainly focusing on critical touchpoints or dimensions that significantly influence patient experiences.

Secondly, our research was conducted in a Portuguese public hospital. Therefore, future studies must encompass a more comprehensive group of public hospitals across Portugal (National Health Service), enabling comparisons between different healthcare institutions. Additionally, exploring the domain of private hospitals could provide valuable insights, facilitating comparisons between these two contrasting HCPs within the national healthcare system.

Thirdly, the data collection techniques employed in this study must be refined and expanded. For instance, incorporating photovoice, a participatory research method, holds promise for enriching future research endeavours. Photovoice involves participants capturing photographs that serve as prompts for exploring community needs, strengths, and challenges, thereby fostering individual empowerment and critical dialogue (Wang & Burris, 1997). This method has been successfully used across diverse populations and contexts, offering a unique avenue for eliciting and understanding the experiences of chronically ill patients (Mysyuk & Huisman, 2019).

Moreover, netnography can also be developed by extending the OHCs to include social networking sites (SNSs), such as Instagram. As a visual-centric platform, Instagram offers visual data, including

images and videos, which can provide nuanced insights into patients' lifestyles, preferences, and patternss (Dutta, 2023).

Fourthly, while our study employed a longitudinal approach for patient interviews, data collection at the one-time point was the norm for other participants. However, longitudinal interviews with HCPs and informal caregivers must also be developed. The growing interest in employing longitudinal analysis reflects the dynamic nature of contemporary market environments (Linnhoff et al., 2015). Hence, longitudinal methods offer a convenient means of capturing the evolving dynamics of experiences over time (Jain et al., 2017; McColl-Kennedy, 2015; Ponsignon et al., 2018). Moreover, as PX is dynamic, it would be essential to track it longitudinally and across different touchpoints, observing how redesigning touchpoints leads to further enhancements in PX and whether specific redesigns only yield minor improvements in perceptions of the PX (McColl-Kennedy et al., 2018). In this sense, we recommend using longitudinal studies to understand long-term changes in patients' experiences better. Lastly, we recommend extending the interval between data collection points to capture more meaningful changes in participants' experiences and perceptions, particularly for patients (Schroots & Birren, 1993; Schroots, Fernandez- Ballesteros & Rudinger, 1999).

While the empirical component of this research initially adopted a qualitative approach, driven by the research questions and the nascent level of theoretical development, there is a pressing need to establish a more comprehensive system for evaluating and measuring the experiences of chronic patients. Therefore, the subsequent phase of this research should involve employing a quantitative approach to explore the impact of various touchpoints and dimensions throughout the patient journey on PX. Indeed, researchers must first understand the factors affecting and shaping PX before they develop valid and reliable tools to measure those experiences (Swallmeh et al., 2018; Wolf et al., 2014).

This new PX assessment system could involve administering a PX survey to measure interactions inside and outside hospital boundaries and after, during, and post-service encounters. Indeed, a comprehensive, short scale should be developed, and simple and quick measures per touchpoint may be needed (Lemon & Verhoef, 2016). In addition, this assessment instrument must include indicators for evaluating services and patient-reported outcomes, such as well-being before and after receiving care.

REFERENCES

A Handbook for Type 1 Diabetes Management in Schools, *Diabetes* (2008). https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/policies-politiques/e/704AH.pdf. Accessed 6 May 2024.

Abendroth, M., & Flannery, J. (2006). Predicting the Risk of Compassion Fatigue: A Study of Hospice Nurses. *Journal of Hospice & Palliative Nursing*, *8(6)*, 346–356. https://doi.org/10.1097/00129191-200611000-00007

Abhyankar, P., Uny, I., Semple, K., Wane, S., Hagen, S., Wilkinson, J., Guerrero, K., Tincello, D., Duncan, E., Calveley, E., Elders, A., McClurg, D., & Maxwell, M. (2019). Women's experiences of receiving care for pelvic organ prolapse: A qualitative study. *BMC Women's Health*, *19*(1), 1–12. https://doi.org/10.1186/s12905-019-0741-2

American Diabetes Association (ADA). (2024). *Your rights on the job*. https://diabetes.org/advocacy/know-your-rights/your-rights-on-the-job. Accessed 07 May 2024.

American Kidney Fund (2024). Stages of Kidney Disease. https://www.kidneyfund.org/all-about-kidneys/stages-kidney-disease. Accessed 07 May 2024.

Adams, R., Rush, K., Leddy, C., Cook, T., Leach, T., Bollinger, B., & & Hoyle, L. (2016). Increased consumer communication and knowledge leads to higher quality in health care. *Radiologic Technology, 88(1),* 80–83.

Addis, M. (2016). Understanding the Customer Journey to Create Excellent Customer Experiences in Bookshops. *International Journal of Marketing Studies*, *8*(4), 20. https://doi.org/10.5539/ijms.v8n4p20

Agwunobi, A., & Osborne, P. (2016). Dynamic Capabilities and Healthcare: A Framework for Enhancing The Competitive Advantage of Hospitals. *California Management Review*, *58*(4), 141–161. https://doi.org/10.1002/CJAS.117.

Ahmed, F., Burt, J., & Roland, M. (2014). Measuring patient experience: Concepts and methods. *The Patient*, *7*(3), 235–241. https://doi.org/10.1007/s40271-014-0060-5

AHRQ - Agency for Healthcare Research and Quality. (2016). *What Is Patient Experience?* https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html. Accessed 07 May 2024.

Akaka, M. & Vargo, S. (2015). Extending the context of service: from encounters to ecosystems. *Journal of Services Marketing*, *29*(6–7), 453–462. https://doi.org/10.1108/JSM-03-2015-0126

Al-Amin, M., Makarem, S., & Pradhan, R. (2011). Hospital ability to attract international patients: A conceptual framework. *International Journal of Pharmaceutical and Healthcare Marketing*, *5*(3), 205–221. https://doi.org/10.1108/17506121111172211

Anderl, E., Schumann, J., & Kunz, W. (2016). Helping Firms Reduce Complexity in Multichannel Online Data: A New Taxonomy-Based Approach for Customer Journeys. *Journal of Retailing*, *92*(2), 185–203. https://doi.org/https://doi.org/10.1016/j.jretai.2015.10.001

Anderson, E., Fornell, C., & Mazvancheryl, S. (2004). Customer Satisfaction and Shareholder Value. *Journal of Marketing, 68(4)*, 172–185. https://doi.org/10.1509/jmkg.68.4.172.42723

Anderson, L., Ostrom, A., Corus, C., Fisk, R., Gallan, A., Giraldo, M., Mende, M., Mulder, M., Rayburn, S., Rosenbaum, M., Shirahada, K., & Williams, J. (2012). Transformative service research: An agenda for the future. *Journal of Business Research*, *66*(8), 1203–1210. https://doi.org/10.1016/j.jbusres.2012.08.013

Anderson, L., & Ostrom, A.(2015). Transformative Service Research: Advancing Our Knowledge About Service and Well-Being. *Journal of Service Research*, *18*(3), 243–249. https://doi.org/10.1177/1094670515591316

Anderson, L., Ostrom, A., & Bitner, M. (2011). Surrounded by services: A new lens for examining the influence of services as social structures on well-being. *Working study, WP Carey School of Business, Arizona State University, Phoenix, AZ*.

Anderson, S., Nasr, L., & Rayburn, S. (2018). Transformative service research and service design: synergistic effects in healthcare. *Service Industries Journal*, *38*(1–2), 99–113. https://doi.org/10.1080/02642069.2017.1404579

Anhang Price, R., Elliott, M., Zaslavsky, A., Hays, R. D., Lehrman, W., Rybowski, L., Edgman-Levitan, S., & Cleary, P. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review : MCRR*, *71*(5), 522–554. https://doi.org/10.1177/1077558714541480

Antheunis, M., Tates, K., & Nieboer, T. (2013). Patients' and health professionals' use of social media in health care: motives, barriers and expectations. *Patient Education and Counseling*, *92*(3), 426–431. https://doi.org/10.1016/j.pec.2013.06.020

Armstrong, J. (2010). Naturalistic Inquiry. In N. J. Salk (Ed.), *Encyclopedia of research design* (1st ed., pp. 880–885). SAGE Publications.

Arora, N., Finney Rutten, L., Gustafson, D., Moser, R., & Hawkins, R. (2007). Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-Oncology*, *16*(5), 474–486. https://doi.org/10.1002/pon.1084

Ascensão, J. (2023). Portugal é o país europeu com maior incidência de doença renal crónicaa, mas não há "uma linha" sibre esta no Plano Nacional de Saúde. *Expresso*, 1–11. https://expresso.pt/sociedade/saude/2023-08-27-Portugal-e-o-pais-europeu-com-maior-incidencia-de-doenca-renal-cronica-mas-nao-ha-uma-linha-sobre-esta-no-Plano-Nacional-de-Saude-721c758d. Accessed 06 May 2024.

Aspinal, F., Gridley, K., Bernard, S., & Parker, G. (2012). Promoting continuity of care for people with long term neurological conditions: the role of the neurology nurse specialist. *Journal of Advanced Nursing*, *68(10)*, 2309–2319. https://doi.org/10.1111/j.1365-2648.2011.05928.x.

Audrain-Pontevia, A., & Menvielle, L., (2018). Effects of interpesonal trust among users of online health communities on patient trust in and satisfaction with their physician. *International Journal of Technology Assessment in Health Care*, *34*(1), 56–62. https://doi.org/10.1017/S0266462317004433

Avgar, A., Givan R., & Liu, M. (2011). Patient-centered, but employee delivered: Patient care innovation, turnover and organizational outcomes in hospitals. *Industrial and Labor Relations*

Review, *64(3)*, 423–440. https://doi.org/10.2307/41149473

Azimi, R., Mahmoudi, G., & Esmaeili, H. (2017). A Study of the Effect of Advertising on Attracting Medical Tourism. *International Journal of Travel Medicine and Global Health*, *5*(3), 89–93. https://doi.org/10.15171/ijtmgh.2017.19

Bagdoniene, L., Blazeviciene, A., & Valkauskiene, G. (2019). The Views of Professionals on Patients' Value Co-creation Activities in Public Healthcare. In *Human-Centered Digitalization and services* (pp. 119–138). https://doi.org/10.1007/978-981-13-7725-9_7

Bahl, S., & Milne, G. (2006). Mixed methods in interpretive research: an application to the study of self concept. In R. W. Belk (Ed.), *Handbook of Qualitative Research Methods in Marketing,* (pp. 198–218). Edward Elgar, Northampton, MA,.

Bailey, P. (1996). Assuring Quality in Narrative Analysis. *Western Journal of Nursing Research*, *18*(2), 186–194. https://doi.org/10.1177/019394599601800206

Baker, S., Gentry, J., & Rittenburg, T. (2005). Building Understanding of the Domain of Consumer Vulnerability. *Journal of Macromarketing*, *25*(2), 128–139. https://doi.org/10.1177/0276146705280622

Ball, M., & Smith, G. (1992). *Analyzing Visual Data*. SAGE Publications. https://doi.org/10.4135/9781412983402

Ballantyne, D., & Varey, R. (2006). Creating value-in-use through marketing interaction: the exchange logic of relating, communicating and knowing. *Marketing Theory*, *6*(3), 335–348. https://doi.org/10.1177/1470593106066795

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. In *Psychological Review* (Vol. 84, Issue 2, pp. 191–215). American Psychological Association. https://doi.org/10.1037/0033-295X.84.2.191

Bansal, H., & Voyer, P.(2000). Word-of-Mouth Processes within a Services Purchase Decision Context. *Journal of Service Research*, *3*(2), 166–177. https://doi.org/10.1177/109467050032005

Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups.

Computers in Human Behavior, *24*(5), 1867–1883. https://doi.org/https://doi.org/10.1016/j.chb.2008.02.004

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, *48*(2), 177–187. https://doi.org/10.1016/s0738-3991(02)00032-0

Baron, S., & Harris, K. (2010). Toward an understanding of consumer perspectives on experiences. *Journal of Services Marketing*, *24*(7), 518–531. https://doi.org/10.1108/08876041011081078

Barton, E., Freeman, T., Baum, F., Javanparast, S., & Lawless, A. (2019). The feasibility and potential use of case- tracked client journeys in primary healthcare : a pilot study. *BMJ Open*, *9*(e024419), 1–12. https://doi.org/10.1136/bmjopen-2018-024419

Batenburg, A., & Das, E. (2015). Virtual Support Communities and Psychological Well-Being: The Role of Optimistic and Pessimistic Social Comparison Strategies. *Journal of Computer-Mediated Communication*, *20*(6), 585–600. https://doi.org/10.1111/jcc4.12131

Bauer, G. (2018). Delivering Value-Based Care With E-Health Services. *Journal of Healthcare Management*, *63*(4), 251–260. https://doi.org/10.1097/JHM-D-18-00077

Baxendale, S., Macdonald, E.., & Wilson, H. 2015). The Impact of Different Touchpoints on Brand Consideration. *Journal of Retailing*, *91*(2), 235–253. https://doi.org/10.1016/j.jretai.2014.12.008

Bayliss, E., Steiner, J., & Main, D. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice*, *25*, 287–293. https://doi.org/10.1093/fampra/cmn040

Beattie, M., Murphy, D., Atherton, I., & Lauder, W. (2015). Instruments to measure patient experience of healthcare quality in hospitals: A systematic review. *Systematic Reviews*, *4(97),*, 1–21. https://doi.org/10.1186/s13643-015-0089-0

Bender, J., Katz, J., Ferris, L., & Jadad, A. (2013). What is the role of online support from the perspective of facilitators of face-to-face support groups? A multi-method study of the use of breast cancer online communities. *Patient Education and Counseling*, *93*(3), 472–479.

https://doi.org/10.1016/j.pec.2013.07.009

Benham-hutchins, M., Staggers, N., Mackert, M., & Johnson, A.(2017). "I want to know everything" : a qualitative study of perspectives from patients with chronic diseases on sharing health information during hospitalization. *BMC Health Services Research*, *17*(529), 1–11. https://doi.org/10.1186/s12913-017-2487-6

Berglund, B., & Westerlund, I. (2016). Patient organizations and primary care development: reflections by patients with chronic diseases. *Patient Experience Journal*, *3*(2), 31–36. https://doi.org/10.35680/2372-0247.1138

Berglund, B., Mattiasson, A., & Randers, I. (2010). Dignity not fully upheld when seeking health care: experiences by individuals suffering from Ehlers-Danlos syndrome. *Disability and rehabilitation,32*(1), 1–7. https://doi.org/10.3109/09638280903178407

Bernacki, K., Keister, A., Sapiro, N., Joo, J., & Mattle, L. (2021). Impact of COVID-19 on patient and healthcare professional attitudes, beliefs, and behaviors toward the healthcare system and on the dynamics of the healthcare pathway. *BMC Health Services Research*, *21*(1), 1309. https://doi.org/10.1186/s12913-021-07237-y

Bernard, H. (2002). *Research Methods in Anthropology: Qualitative and Quantitative Methods* (3rd Ed. (Ed.)). Walnut Creek, CA: Alta Mira Press.

Berry, L., Davis, S., & Wilmet, J. (2015). When the customer is stressed. *Harvard Business Review*, *93*, 86–94. https://hbr.org/2015/10/when-the-customer-is-stressed

Berry, L., Attai, D. Scammon, D., & Awdish, R. (2022). When the Aims and the Ends of Health Care Misalign. *Journal of Service Research*, *25*(1), 160–184. https://doi.org/10.1177/1094670520975150

Berry, L.., & Bendapudi, N. (2007). Health care: A fertile field for service research. *Journal of Service Research*, *10*(2), 111–122. https://doi.org/10.1177/1094670507306682

Berry, L., Carbone, L.., & Haeckel, S.(2002). Managing the total customer experience. *MIT Sloan Management Review*, 43(3), 1-6. https://sloanreview.mit.edu/article/managing-the-total-customer-experience/

Berry, L. & Seltman, K.(2007). Building a strong services brand: Lessons from Mayo Clinic. *Business Horizons*, *50*(3), 199–209. https://doi.org/10.1016/j.bushor.2007.01.005

Berry, L., Wall, E., & Carbone, L.(2006). Service clues and customer assessment of the service experience: Lessons from marketing. *Academy of Management Perspectives*, *20*(2), 43–57. https://doi.org/10.5465/AMP.2006.20591004

Bettoli, V., Pasquinucci, S., Caracciolo, S., Piccolo, D., Cazzaniga, S., Fantini, F., Binello, L., Pintori, G., & Naldi, L. (2016). The Hidradenitis suppurativa patient journey in Italy: current status, unmet needs and opportunities. *Journal of the European Academy of Dermatology and Venereology*, *30*(11), 1965–1970. https://doi.org/10.1111/jdv.13687

Bitner, M.(1990). Evaluating Service Encounters: The Effects of Physical Surroundings and Employee Responses. *Journal of Marketing*, *54*(2), 69–82. https://doi.org/10.1177/002224299005400206

Bitner, M. (1992). Servicescapes: The Impact of Physical Surroundings on Customers and Employees. *Journal of Marketing*, *56*(2), 57–71. https://doi.org/10.2307/1252042

Bitner, M.., Ostrom, A., & Morgan, F. (2008). Service blueprinting: A practical technique for service innovation. *California Management Review*, *50*(3), 66–94. https://doi.org/10.2307/41166446

Bitner, M., & Wang, H. (2014). Service encounters in service marketing research. In *Handbook of Service Marketing Research* . Cheltenham, UK: Edward Elgar Publishing. https://doi.org/10.4337/9780857938855.00019

Bitner, M., Zeithaml, V., & Gremler, D. (2010). *Technology's Impact on the Gaps Model of Service Quality* (pp. 197–218). https://doi.org/10.1007/978-1-4419-1628-0_10

Björk, P., & Kauppinen-Räisänen, H. (2012). A netnographic examination of travelers' online discussions of risks. *Tourism Management Perspectives*, *2–3 (Apr-Jul 2012),* 65–71. https://doi.org/https://doi.org/10.1016/j.tmp.2012.03.003

Black, H., & Gallan, A. (2015). Transformative Service Networks: Cocreated Value as Well-Being. *The Service Industries Journal*, *35*(15–16), 826–845.

https://doi.org/https://doi.org/10.1080/02642069.2015.1090978

Black, I., & Tagg, S. (2007). A grounded theory of doctors' information search behaviour. Implications for information provision, pharmaceutical market entry and development. *Journal of Marketing Management*, *23(2-4)*, 347–366. https://doi.org/10.1362/026725707X196413

Black, N., & Jenkinson, C. (2009). Measuring patients' experiences and outcomes. *BMJ (Clinical Research Ed.)*, *339*, b2495. https://doi.org/10.1136/bmj.b2495

Blazevic, V., & Lievens, A. (2008). Managing innovation through customer coproduced knowledge in electronic services: An exploratory study. *Journal of the Academy of Marketing Science*, *36*(1), 138–151. https://doi.org/10.1007/s11747-007-0064-y

Blocker, C., & Barrios, A. (2015). The Transformative Value of a Service Experience. *Journal of Service Research*, *18(3), 265-283*. https://doi.org/10.1177/1094670515583064

Bloom, B. (2002). Crossing the Quality Chasm: A New Health System for the 21st Century. *The Journal of the American Medical Association*, *287*(5), 646–647. https://doi.org/10.17226/10027

Bodine, K., & Hagen, P. (2013). *The Customer Experience Ecosystem*. Research Report, *Forrester Research Inc*. 1–27. https://www.forrester.com/report/the-customer-experience-ecosystem/RES59115

Bodke, H., Wagh, V., & Kakar, G. (2023). Diabetes Mellitus and Prevalence of Other Comorbid Conditions: A Systematic Review. *Cureus*, *15*(11), e49374. https://doi.org/10.7759/cureus.49374

Bolton, R., & Lemon, K. (1999). A Dynamic Model of Customers' Usage of Services: Usage as an Antecedent and Consequence of Satisfaction. *Journal of Marketing Research*, *36(2),*, 171–186. https://doi.org/10.1177/002224379903600203

Bolton, R., Gustafsson, A., McColl-Kennedy, J., Sirianni, N., & Tse, D. (2014). Small details that make big differences: A radical approach to consumption experience as a firm's differentiating strategy. *Journal of Service Management*, *25*(2), 253–274.

https://doi.org/10.1108/JOSM-01-2014-0034

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal*, *9*(2), 27–40. https://doi.org/10.3316/QRJ0902027

Bowling, A., Rowe, G., Lambert, N., Waddington, M., Mahtani, K., Kenten, C., Howe, A., & Francis, S. (2012). The measurement of patients' expectations for health care: A review and psychometric testing of a measure of patients' expectations. *Health Technology Assessment*, *16*(30), i–509. https://doi.org/10.3310/hta16300

Boyd, H., McKernon, S., Mullin, B., & Old, A. (2012). Improving healthcare through the use of co-design. *New Zealand Medical Journal*, *125*(1357), 76-87. https://pubmed.ncbi.nlm.nih.gov/22854362/

Bradburn, N. (1969). The structure of psychological well-being. In *The structure of psychological well-being.* Oxford: Aldine. https://www.norc.org/content/dam/norc-org/pdfs/BradburnN_Struc_Psych_Well_Being.pdf

Brakus, J., Schmitt, B., & Zarantonello, L. (2009). Brand Experience: What Is It? How Is It Measured? Does It Affect Loyalty? *Journal of Marketing*, *73*(3), 52–68. https://doi.org/10.1509/jmkg.73.3.52

Brand, S., & Pollock, K. (2018). How is continuity of care experienced by people living with chronic kidney disease? *Journal of Clinical Nursing*, *27*(1–2), 153–161. https://doi.org/10.1111/jocn.13860

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bray, J., Evans, S., Bruce, M., Carter, C., Brooker, D., Milosevic, S., Thompson, R., Longden, J., & Robinson, J. (2015). Improving the hospital environment for people with dementia. *Nursing Older People*, *27*(9), 16–20. https://doi.org/10.7748/nop.27.9.16.s17

Briggs, M., & Flemming, K. (2007). Living with leg ulceration: A synthesis of qualitative research. *Journal of Advanced Nursing*, *59*(4), 319–328. https://doi.org/10.1111/j.1365-2648.2007.04348.x

Brincat, A., Bonanno, P., Stewart, D., & Weidmann, A.(2020). Patients' lived experiences with antineoplastic medicines for the management of malignant solid tumours: A systematic review. *Research in Social & Administrative Pharmacy: RSAP*, *16*(4), 450–463. https://doi.org/10.1016/j.sapharm.2019.06.020

Brodie, R., Hollebeek, L., Jurić, B., & Ilić, A. (2011). Customer Engagement: Conceptual Domain, Fundamental Propositions, and Implications for Research. *Journal of Service Research*, *14*(3), 252–271. https://doi.org/10.1177/1094670511411703

Brook, O., Siewert, B., Weinstein, J., Ahmed, M., & Kruskal, J. (2017). Measuring and improving the patient experience in radiology. *Abdominal* Radiology, 42, 1259–1267 (2017). https://doi.org/10.1007/s00261-016-0960-z

Broughton, J., Harris, S., Beasant, L., Crawley, E., & Collin, S.(2017). Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): a qualitative study in England. *BMC Health Services Research*, *17*(1), 1–13. https://doi.org/10.1186/s12913-017-2337-6

Brown, J., & Duguid, P. (2001). Knowledge and Organization: A Social-Practice Perspective. *Organization Science*, *12*(2), 198–213. http://www.jstor.org/stable/3086055

Bryman, A. (2014). *Social Research Methods* (4th editio). Oxford University Press.

Bryman, A., & Bell, E. (2011). *Business Research Methods* 3rd Edition, Oxford University Press, Oxford.

Buljac, M., Clark, M., Exel, N., & Wijngaarden, J. (2021). Patients as team members: Factors affecting involvement in treatment decisions from the perspective of patients with a chronic condition. *Health Expectations*, *25(1), 138-148*. https://doi.org/10.1111/hex.13358

Bulto, L., Davies, E., Kelly, J., & Hendriks, J. (2024). Patient journey mapping: emerging methods for understanding and improving patient experiences of health systems and services. *European Journal of Cardiovascular Nursing*, 00, 1–5 https://doi.org/10.1093/eurjcn/zvae012

Burrill, S., Betts, D., Kroll, A., Wheeler, T., & Sowar, J. (2020). Implications of the COVID-19 crisis

for the health care ecosystem Gearing up for the next normal ecosystem and the consumers it serves face an unfamiliar. *Deloitte*. https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/implications-of-the-covid19-crisis.pdf. Accessed 10 May 2023.

CDC - Centers for Disease Control and Prevention. *How You Can Prevent Chronic Diseases*. (2021). https://www.cdc.gov/chronicdisease/about/prevent/index.htm#print. Accessed 5 May 2023.

Caldeira, S., Romeiro, J., & Martins, H. (2019). *The Role of the Nurse in Providing Spiritual Care: A Case Study Approach to Exploring Specific Care Provision by Healthcare Workers in the Context of an Interdisciplinary Healthcare Team.* In: Timmins, F., Caldeira, S. (eds) Spirituality in Healthcare: Perspectives for Innovative Practice. Springer, Cham. https://doi.org/10.1007/978-3-030-04420-6_8

Campbell-Crofts, & Stewart, G. (2018). How perceived feelings of 'wellness' influence the decision-making of people with pre- dialysis chronic kidney disease. *Journal of Clinical Nursing*, *27*(7-8), 1561–1571. https://doi.org/10.1111/jocn.14220

Campos, C., Mantovani, M. de F., Brum do Nascimento, M., & Cassi, C. (2015). Social representations among people with chronic kidney disease. *Revista Gaúcha de Enfermagem*, *36*(2), 106–112.

Carlzon, J. (1989). *Moments of Truth*. HarperCollins. https://books.google.pt/books?id=YjPA029I3IAC

Carù, A., & Cova, B. (2003). Revisiting Consumption Experience: A More Humble but Complete View of the Concept. *Marketing Theory*, *3*(2), 267–286. https://doi.org/10.1177/14705931030032004

Caruana, E. J., Roman, M., Hernández-sánchez, J., & Solli, P. (2015). Longitudinal studies. *Journal of Thoracic Disease.*, *7*(11), 537–540. https://doi.org/10.3978/j.issn.2072-1439.2015.10.63

Casti. (1994). *Complexification*. London: Abacus.

Centola, D., & van de Rijt, A. (2015). Choosing your network: Social preferences in an online health community. *Social Science & Medicine*, *125*, 19–31. https://doi.org/https://doi.org/10.1016/j.socscimed.2014.05.019

Chan, K., & Li, S.(2010). Understanding consumer-to-consumer interactions in virtual communities: The salience of reciprocity. *Journal of Business Research*, *63*(9), 1033–1040. https://doi.org/https://doi.org/10.1016/j.jbusres.2008.08.009

Chandler, J., & Lusch, R. (2015). Service Systems: A Broadened Framework and Research Agenda on Value Propositions, Engagement, and Service Experience. *Journal of Service Research*, *18*(1), 6–22. https://doi.org/10.1177/1094670514537709

Chandler, J., & Vargo, S. (2011). Contextualization and value-in-context: How context frames exchange. *Marketing Theory*, *11*(1), 35–49. https://doi.org/10.1177/1470593110393713

Charmel, PA and Frampton, S. (2008). Building the business case for patient-centered care. *Healthcare Financial Management*, *62*(3), 80–85.

Chase, R., & Dasu, S. (2014). Experience psychology - a proposed new subfield of service management. *Journal of Service Management*, *25*(5), 574–577. https://doi.org/10.1108/JOSM-03-2014-0094

Cheng, C., Wang, T., Lin, Y., Lin, H., Hu, W., Wung, S., & Liang, S. (2013). The illness experience of middle-aged men with oral cancer. *Journal of Clinical Nursing*, *22*(23–24), 3549–3556. https://doi.org/10.1111/jocn.12455

Cheng, S., Yang, M., & Cguang, T. (2003). Patient satisfaction with and recommendation of a hospital: effects of interpersonal and technical aspects of hospital care. *International Journal for Quality in Health Care*, *15*(4), 345–355. https://doi.org/10.1093/intqhc/mzg045

Cherif, E., Martin-Verdier, E., & Rochette, C. (2020). Investigating the healthcare pathway through patients' experience and profiles: implications for breast cancer healthcare providers. *BMC Health Services Research*, *20*(1), 735. https://doi.org/10.1186/s12913-020-05569-9

Chou, W., Prestin, A., Lyons, C., & Wen, K. (2013). Web 2.0 for health promotion: Reviewing the current evidence. *American Journal of Public Health*, *103*(1), 9–18.

https://doi.org/10.2105/AJPH.2012.301071

Christensen, C., Hall, T., Dillon, K., & Duncan, D. (2016). Know your customers "jobs to be done." *Harvard Business Review*, *94*(9), 54–60.

Clatworthy, S. (2011). Service Innovation Through Touch-points: Development of an Innovation Toolkit for the First Stages of New Service Development. *International Journal of Design*, *5*, 15–28.

Cognetta-Rieke, C., & Guney, S. (2016). Analytical insights from patient narratives: The next step for better patient experience. *Journal of Patient Experience*, *1(1): 20–22*. https://doi.org/10.1177/237437431400100105

Cohen, S., Tomas, B., & Mount, L. (1996). Existential well-being is an important determinant of quality of life: evidence from the McGill quality of life questionnaire. *Cancer*, *77*(3), 576–586.

Corley, K., & Gioia, D.(2004). Identity Ambiguity and Change in the Wake of a Corporate Spin-off. *Administrative Science Quarterly*, *49*(2), 173–208. https://doi.org/10.2307/4131471

Costa, P., Santos, N., Cunha, P., Cotter, J., & Sousa, N. (2013). The Use of Multiple Correspondence Analysis to Explore Associations between Categories of Qualitative Variables in Healthy Ageing. *Journal of Aging Research*, *2013*, 1-12 https://doi.org/10.1155/2013/302163

Costello, L., McDermott, M., & Wallace, R. (2017). Netnography: Range of Practices, Misperceptions, and Missed Opportunities. *International Journal of Qualitative Methods*, *16*(1), 1609406917700647. https://doi.org/10.1177/1609406917700647

Coulson, N. (2005). Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychology & Behavior : The Impact of the Internet, Multimedia and Virtual Reality on Behavior and Society*, *8*(6), 580–584. https://doi.org/10.1089/cpb.2005.8.580

Court, D., Elzinga, D., Mulder, S., & Jørgen V. (2009). The consumer decision journey. *The McKinsey Quarterly*, *3*, 3–11. https://www.mckinsey.com/capabilities/growth-marketing-and-sales/our-insights/the-consumer-decision-journey. Accessed 20 April 2022

Cowen, E. (2000). Psychological wellness: Some hopes for the future. In *The promotion of wellness in children and adolescents.* (pp. 477–503). Child Welfare League of America.

Coyle, J., & Williams, B. (1999). Seeing the wood for the trees: defining the forgotten concept of patient dissatisfaction in the light of patient satisfaction research. *International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services*, *12*(6–7), i–ix. https://doi.org/10.1108/13660759910298707

Crepeau, E. (2000). Reconstructing Gloria: A Narrative Analysis of Team Meetings. *Qualitative Health Research*, *10(6)*, 766–787. https://doi.org/10.1177/104973200129118813

Creswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J., & Clark, P. (2011). Choosing a mixed methods design. *Designing and Conducting Mixed Methods Research*, *2*, 53–106.

Creswell, J. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (4th editio). SAGE Publications.

Cronin. Jr, & Taylor, S. (1992). Measuring Service Quality - A Reexamination And Extension. *The Journal of Marketing*, *56(3)*, 55–68. https://doi.org/10.2307/1252296

Crosier, A., & Handford, A. (2012). Customer journey mapping as an advocacy tool for disabled people: A case study. *Social Marketing Quarterly*, *18*(1), 67–76. https://doi.org/10.1177/1524500411435483

Crow, R., Gage, H., Hampson, S., Hart, J., Kimber, A., Storey, L., & Thomas, H. (2002). The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. *Health Technology Assessment (Winchester, England)*, *6*(32), 1–244. https://doi.org/10.3310/hta6320

Curry, A., & Sinclair, E. (2002). Assessing the quality of physiotherapy services using SERVQUAL. *International Journal of Health Care Quality Assurance*, *15(5)*, 197–205. https://doi.org/10.1108/09526860210437412

Curry, A., & Stark, S. (2000). Quality of Service in Nursing Homes. *Health Services Management*

Research, *13*(4), 205–215. https://doi.org/10.1177/095148480001300401

Cyert, R., & March, J. (1963). *A Behavioral Theory of the Firm*. Englewood Cliffs, NJ: Prentice Hall.

Dagger, T., & Sweeney, J.(2007). Service quality attribute weights: How do novice and longer-term customers construct service quality perceptions? *Journal of Service Research*, *10*(1), 22–42. https://doi.org/10.1177/1094670507303010

Dalglish, S. L., Khalid, H., & McMahon, S. A. (2020). Document analysis in health policy research: the READ approach. *Health Policy and Planning*, *35*(10), 1424–1431. https://doi.org/10.1093/heapol/czaa064

Dalsted, R., Hølge-Hazelton, B., Kousgaard, M., & Andersen, J.(2012). Informal work and formal plans: Articulating the active role of patients in cancer trajectories. *International Journal of Integrated Care*, *12*(8). https://doi.org/10.5334/ijic.822

Danaher, T., & Gallan, A. (2016). Service Research in Health Care: Positively Impacting Lives. *Journal of Service Research*, *19*(4), 433–437. https://doi.org/10.1177/1094670516666346

Davies, E., Bulto, L, Walsh, A., Pollock, D., Langton, V., Laing, R., Graham, A., Arnold-Chamney, M., & Kelly, J. (2023). Reporting and conducting patient journey mapping research in healthcare: A scoping review. *Journal of Advanced Nursing*, *79*(1), 83–100. https://doi.org/10.1111/jan.15479

De Almeida, E., Raimundo, M., Coelho, A., & Sá, H. (2021). Incidence, prevalence and crude survival of patients starting dialysis in Portugal (2010–16): analysis of the National Health System individual registry. *Clinical Kidney Journal*, *14*(3), 869–875. https://doi.org/10.1093/ckj/sfaa023

De Cruppé, W., & Geraedts, M. (2011). How do patients choose a hospital for elective surgery? *Bundesgesundheitsblatt, Gesundheitsforschung. Gesundheitsschutz, 54*(8), 951–957.

De Haan, E., Kannan, P. K., Verhoef, P. C., & Wiesel, T. (2015). The Role of Mobile Devices in the Online Customer Journey. In *MSI Working Paper No. 15-24*.

De Keyser, A., Lemon, K., Klaus, P., & Keiningham, T. (2015). A Framework for Understanding

and Managing the Customer Experience. *Marketing Science Institute Working Paper Series 2015, Report No. 15-121, Forthcoming*, *Report No. 15-121*, 1–47.

Dellaert, B. (2018). The consumer production journey: marketing to consumers as co-producers in the sharing economy. *Journal of the Academy of Marketing Science*, *47 (2019) 238–254*. https://doi.org/10.1007/s11747-018-0607-4

Deloitte. (2022). *Transforming the patient experience*. https://www2.deloitte.com/content/dam/Deloitte/global/Documents/gx-lshc-dei-patient-experience.pdf. Accessed 20 May 2023

Demiris, G. (2006). The diffusion of virtual communities in health care: concepts and challenges. *Patient Education and Counseling*, *62*(2), 178–188. https://doi.org/10.1016/j.pec.2005.10.003

Demirkan, H. (2013). A Smart Healthcare Systems Framework. *IT Professional*, *15*(5), 38–45. https://doi.org/10.1109/MITP.2013.35

Dempsey, C., Wojciechowski, S., McConville, E., & Drain, M. (2014). Reducing patient suffering through compassionate connected care. *The Journal of Nursing Administration*, *44*(10), 517–524. https://doi.org/10.1097/NNA.0000000000000110

Denzin, N., Lincoln, Y., MacLure, M., Otterstad, A., Torrance, H., Cannella, G., Koro-Ljungberg, M., & McTier, T. (2017). Critical qualitative methodologies: Reconceptualizations and emergent construction. *International Review of Qualitative Research*, *10*(4), 482–498. https://doi.org/10.1525/irqr.2017.10.4.482.

Dhebar, A. (2013). Toward a compelling customer touchpoint architecture. *Business Horizons*, *56*(2), 199–205. https://econpapers.repec.org/RePEc:eee:bushor:v:56:y:2013:i:2:p:199-205

Dickerson, S., Reinhart, A., Boemhke, M., & Akhu-Zaheya, L. (2011). Cancer as a problem to be solved: Internet use and provider communication by men with cancer. *CIN - Computers Informatics Nursing*, *29*(7), 388–395. https://doi.org/10.1097/NCN.0b013e3181f9ddb1

Dickson-Swift, V., James, E., Kippen, S., & Liamputtong, P. (2009). Researching sensitive topics:

Qualitative research as emotion work. *Qualitative Research*, *9*(1), 61–79. https://doi.org/10.1177/1468794108098031

Diener, A., O'Brien, B., & Gafni, A. (1998). Health care contingent valuation studies: A review and classification of the literature. *Health Economics*, *7*(4), 313–326. https://doi.org/10.1002/(SICI)1099-1050(199806)7:4<313::AID-HEC350>3.0.CO;2-B

Diener, E. (1984). Subjective well-being. In *Psychological Bulletin* (Vol. 95, Issue 3, pp. 542–575). American Psychological Association. https://doi.org/10.1037/0033-2909.95.3.542

Diener, E. (2000). Subjective well-being. The science of happiness and a proposal for a national index. *The American Psychologist*, *55*(1), 34–43.

Diener, E., Pressman, S., Hunter, J., & Delgadillo-Chase, D. (2017). If, Why, and When Subjective Well-Being Influences Health, and Future Needed Research. *Applied Psychology: Health and Well-Being*, *9*(2), 133–167. https://doi.org/https://doi.org/10.1111/aphw.12090

Diener, E., Suh, E., Lucas, R., & Smith, H. (1999). Subjective Well-Being: Three Decades of Progress. *Psychological Bulletin*, *125(2)*, 276–302. https://doi.org/10.1037/0033-2909.125.2.276

Dimkovic, N., Majster, Z., Davidovic, Z., & Dimkovic, S. (2009). CAPD Assisted by Family Member — a Single-Center Experience. *Peritoneal Dialysis International*, *29*(2), 238–239. https://doi.org/10.1177/089686080902900224

Dobele, A., & Lindgreen, A. (2011). Exploring the nature of value in the word-of-mouth referral equation for health care. *Journal of Marketing Management*, *27(3-4)*, 269–290. https://doi.org/10.1080/0267257X.2011.545677

Dodds, S., Bulmer, S., & Murphy, A. (2018). Incorporating visual methods in longitudinal transformative service research. *Journal of Service Theory and Practice*, *28*(4), 434–457. https://doi.org/10.1108/JSTP-02-2017-0022

Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, *2*(3), 222–235. https://doi.org/10.5502/ijw.v2i3.4

Doey, L., & Kurta, J. (2011). Correspondence Analysis applied to psychological research. *Tutor.*

Quantitative Methods for Psycholgy., *Vol. 7(1), p. 5-14.* https://doi.org/10.20982/tqmp.07.1.p005

Doherty, D., Benbow, S., & Craig, J. (2009). Patients ´ and carers ´ journeys through older people ´ s mental health services: Powerful tools for learning. *Dementia*, *8(4)*, 501–513. https://doi.org/10.1177/1471301209350286

Donald, M., Kahlon, B., Beanlands, H., Straus, S., Ronksley, P., Herrington, G., Tong, A., Grill, A., Waldvogel, B., Large, C., Large, C. L., Harwood, L., Novak, M., James, M., Elliott, M., Fernandez, N., Brimble, S., Samuel, S., & Hemmelgarn, B.(2018). Self-management interventions for adults with chronic kidney disease: A scoping review. *BMJ Open*, *8*(3), 1–21. https://doi.org/10.1136/bmjopen-2017-019814

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*, *3:e001570*, 1–19. https://doi.org/10.1136/bmjopen-2012-001570

Drentea, P., & Moren-Cross, J.(2005). Social capital and social support on the web: the case of an internet mother site. *Sociology of Health & Illness*, *27*(7), 920–943. https://doi.org/https://doi.org/10.1111/j.1467-9566.2005.00464.x

Drevs, F., & Hinz, V. (2014). Who chooses, who uses, who rates: the impact of agency on electronic word-of-mouth about hospitals stays. *Health Care Management Review*, *39*(3), 223—233. https://doi.org/10.1097/hmr.0b013e3182993b6a

Drewniak, D., Glässel, A., Hodel, M., & Biller-Andorno, N. (2020). Risks and Benefits of Web-Based Patient Narratives: Systematic Review. *Journal of Medical Internet Research*, *22*(3), e15772. https://doi.org/10.2196/15772

Dubberly, H., & Evenson, S. (2008). On modeling: The experience cycle. *Interactions*, *15*(3), 11–15. https://doi.org/10.1145/1353782.1353786

Duncan, T., & Moriarty, S. (2006). How integrated marketing communication's "touchpoints" can operationalize the service-dominant logic. *The Service-Dominant Logic of Marketing: Dialog, Debate and Directions*, 236–249.

Dutta, A. (2023). Netnography and instagram community : An empirical study Netnography and instagram community : An empirical study. *Business Information Review*, *40(*1), 33-37 https://doi.org/10.1177/02663821231157501

Egan, R., Llewellyn, R., Wood, S., Doherty, J., Albert, T., Walsh, C., Atkinson, K., & Kerslake, P. (2016). The Cancer Stories Project: Narratives of encounters with cancer in Aotearoa, New Zealand. *Psycho-Oncology*, *25*(3), 300–307. https://doi.org/10.1002/pon.3914

Egede, L., & Zheng, D. (2003). Independent factors associated with major depressive disorder in a national sample of individuals with diabetes. *Diabetes Care*, *26*(1), 104–111. https://doi.org/10.2337/diacare.26.1.104

Eisner, E. (1992). The enlightened eye. In *Evaluation Practice*, 13(3), 205-206 https://doi.org/10.1016/0886-1633(92)90008-y

Elrod, J., & Fortenberry, J. (2018). Am i seeing things through the eyes of patients? An exercise in bolstering patient attentiveness and empathy. *BMC Health Services Research*, *18*(Suppl 3), 1–4. https://doi.org/10.1186/s12913-018-3681-x

Entman, S., Glass, C., Hickson, G., Githens, P., Whetten-Goldstein, K., & Sloan, F. (1994). The Relationship Between Malpractice Claims History and Subsequent Obstetric Care. *JAMA : The Journal of the American Medical Association*, *272*, 1588–1591. https://doi.org/10.1001/jama.272.20.1588

Epping-Jordan, J., Pruitt, S., & Wagner, E. (2004). Improving the quality of health care for chronic conditions. *Qual Saf Health Care*, *13*(4), 299–305. https://doi.org/https://dx.doi.org/10.1136%2Fqshc.2004.010744

Eriksson, P., Henttonen, E., & Meriläinen, S. (2012). *Ethnographic Field Notes and Reflexivity*. https://doi.org/10.5772/36039

Etkin, J., & Sela, A. (2016). How experience variety shapes postpurchase product evaluation. *Journal of Marketing Research*, *53*(February), 77–90.

Evers, K, Prochaska, J., Castle, P., Johnson, J., Prochaska, J., Harrison, P., Rula, E., Coberley, C., & Pope, J. (2012). Development of an individual well-being scores assessment. *Psychology*

of Well-Being: Theory, Research and Practice, *2*(1), 2. https://doi.org/10.1186/2211-1522-2-2

Eysenbach, G., & Diepgen, T. (1999). Patients looking for information on the Internet and seeking teleadvice: motivation, expectations, and misconceptions as expressed in e-mails sent to physicians. *Archives of Dermatology*, *135*(2), 151–156. https://doi.org/10.1001/archderm.135.2.151

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ (Clinical Research Ed.)*, *328*(7449), 1166. https://doi.org/10.1136/bmj.328.7449.1166

Fader, P. (2012). *Customer Centricity : Focus on the Right Customers for Strategic Advantage.*

Farin, E., & Nagl, M. (2013). The patient-physician relationship in patients with breast cancer: Influence on changes in quality of life after rehabilitation. *Quality of Life Research*, *22*(2), 283–294. https://doi.org/10.1007/s11136-012-0151-5

Farley, H. (2020). Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *Nursing Open*, *7*(1), 30–41. https://doi.org/10.1002/nop2.382

Farr, M., & Cressey, P. (2015). Understanding staff perspectives of quality in practice in healthcare. *BMC Health Services Research*, *15*(1), 1–11. https://doi.org/10.1186/s12913-015-0788-1

Ferguson, R., Paulin, M., & Bergeron, J. (2010). Customer sociability and the total service experience: Antecedents of positive word-of-mouth intentions. *Journal of Service Management*, *21*(1), 25–44. https://doi.org/10.1108/09564231011025100

Fisk, R. (2009). A Customer Liberation Manifesto. *Service Science*, *1*(3), 135–141. https://doi.org/10.1287/serv.1.3.135

Fleming, N. (2016). *The customer loyalty loop*. Wayne, NJ: Carrer Press.

Flick, U. (2009). *An Introduction To Qualitative Fourth Edition*. SAGE Publications, fourth edition.

Fliess, S., & Kleinaltenkamp, M. (2004). Blueprinting the service company: Managing service processes efficiently. *Journal of Business Research*, *57*, 392–404.

Følstad, A., & Kvale, K. (2018). Customer Journeys: A Systematic Literature Review. *Journal of Service Theory and Practice*. http://brage.bibsys.no/sintef

Folstad, A., Kvale, K., & Halvorsrud, R. (2013). *Customer journey measures - State of the art research and best practice*.

Fottler, M. D., Ford, R. C., Roberts, V., & Ford, E. W. (2000). Creating a healing environment: The importance of the service setting in the new consumer-oriented healthcare system. *Journal of Healthcare Management*, *45*(2), 91–107. https://doi.org/10.1097/00115514-200003000-00007

Fox, N., Ward, K., & O'Rourke, A. (2005). The "expert patient": empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science & Medicine*, *60*(6), 1299–1309. https://doi.org/10.1016/j.socscimed.2004.07.005

Fox, S. (2014). The social life of health information. *Pew Research Center Report*. https://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/ Accessed 20 February 2023.

Fox, S., & Duggan, M. (2013). Health Online 2013. *Pew Research Internet Project Report*. https://www.pewresearch.org/internet/2013/01/15/health-online-2013/.Accessed March 2023.

Frampton, S. (2012). Healthcare and the patient experience: Harmonizing care and environment. *Health Environments Research & Design Journal*, *5*(2), 3–6. https://doi.org/https://doi.org/10.1177%2F193758671200500201

Franck, L., McNulty, A., & Alderdice, F. (2017). The Perinatal-Neonatal Care Journey for Parents of Preterm Infants What Is Working and What Can Be Improved. *Journal of Perinatal & Neonatal Nursing*, *31*(3), 244–255. https://doi.org/10.1097/JPN.0000000000000273

Freeborn, D., Dyches, T., Roper, S., & Mandleco, B. (2013). Identifying challenges of living with type 1 diabetes: child and youth perspectives. *Journal of Clinical Nursing*, *22*(13–14), 1890–

1898. https://doi.org/https://doi.org/10.1111/jocn.12046

Friedman, L. & Kovner, A. (2018). *101 careers in Healthcare Management.* Second edition. Springer Publishing Company

Friedman, D., Hooker, S., Wilcox, S., Burroughts, E., & Rheaume, C. (2012). African American Men´s Perspectives on promoting physical activity: "we´re not that difficult to figure out." *Journal of Health Communication: International Perspectives*, *17*(10), 1151–1170.

Friedman, D., Parrish, R. G., & Ross, D. (2013). Electronic health records and US public health: current realities and future promise. *American Journal of Public Health*, *103*(9), 1560–1567. https://doi.org/10.2105/AJPH.2013.301220

Frost, J., & Massagli, M. (2009). PatientsLikeMe the case for a data-centered patient community and how ALS patients use the community to inform treatment decisions and manage pulmonary health. *Chronic Respiratory Disease*, *6*(4), 225–229. https://doi.org/10.1177/1479972309348655

Frow, P., McColl-Kennedy, J., & Payne, A. (2016). Co-creation practices: their role in shaping a health care ecosystem. *Industrial Marketing Management*, *56(2016)*, 24–39.

Furrer, O., Liu, B.., & Sudharshan, D. (2000). The Relationships between Culture and Service Quality Perceptions: Basis for Cross-Cultural Market Segmentation and Resource Allocation. *Journal of Service Research*, *2*(4), 355–371. https://doi.org/10.1177/109467050024004

Galarza-Winton, M., Dicky, T., O'Leary, L., Lee, & O'Brien, K. (2013). Implementing family-integrated care in the NICU: educating nurses. *Advances in Neonatal Care : Official Journal of the National Association of Neonatal Nurses*, *13*(5), 335–340. https://doi.org/10.1097/ANC.0b013e3182a14cde

Gallant, M., & Coutts, L. (2003). Evaluation of an oncology outpatient orientation program: patient satisfaction and outcomes. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *11*(12), 800–805. https://doi.org/10.1007/s00520-003-0543-8

Geana, M., Kimminau, K., & Greiner, K. (2011). Sources of health information in a multiethnic,

underserved, urban community: does ethnicity matter? *Journal of Health Communication: International Perspectives*, *16*(6), 583–594.

Gentry, S., & Badrinath, P. (2017). Defining Health in the Era of Value-based Care: Lessons from England of Relevance to Other Health Systems. *Cureus*, *9*(3). https://doi.org/10.7759/cureus.1079

Gheorghe, I.., & Liao, M. (2012). Investigating Romanian Healthcare Consumer Behaviour in Online Communities: Qualitative Research on Negative eWOM. *Procedia - Social and Behavioral Sciences*, *62*(24), 268–274. https://doi.org/10.1016/j.sbspro.2012.09.043

Gibbons, E., Graham, C., King, J., Flott, K., & Jenkinson, C. (2016). Developing approaches to the collection and use of evidence of patient experience below the level of national surveys. *Patient Experience Journal*, *3*(1), 92–100. https://doi.org/10.35680/2372-0247.1118

Giffi, A. (1996). *Non-Linear Multivariate Analysis.* John Willey & Sons, Chichester, UK.

Gijsenberg, M. J., Van Heerde, H. J., & Verhoef, P. C. (2015). Losses Loom Longer than Gains: Modeling the Impact of Service Crises on Perceived Service Quality over Time. *Journal of Marketing Research*, *52*(5), 642–656. https://doi.org/10.1509/jmr.14.0140

Gilbert, K., Dodson, S., Gill, M., & McKenzie, R. (2012). Online communities are valued by people with type 1 diabetes for peer support: How well do health professionals understand this? *Diabetes Spectrum*, *25*(3), 180–191. https://doi.org/10.2337/diaspect.25.3.180

Gill, J., & Liamputtong, P. (2009). 'Walk a mile in my shoes': Researching the lived experience of mothers of children with autism. *Journal of Family Studies*, *15*(3), 309–319. https://doi.org/10.5172/jfs.15.3.309

Gillespie, K. (2006). Type 1 diabetes: Pathogenesis and prevention. *CMAJ. Canadian Medical Association Journal*, *175*(2), 165–170. https://doi.org/10.1503/cmaj.060244

Gioia, D., Corley, K., & Hamilton, A. (2013). Seeking Qualitative Rigor in Inductive Research: Notes on the Gioia Methodology. *Organizational Research Methods*, *16*(1), 15–31. https://doi.org/10.1177/1094428112452151

Gioia, D., & Pitre, E. (1990). Multiparadigm Perspectives on Theory Building. *Academy of*

Management Review, *15*, 584–602. https://api.semanticscholar.org/CorpusID:168141651

Gittell, J.(2002). Relationships between Service Providers and Their Impact on Customers. *Journal of Service Research*, *4*(4), 299–311. https://doi.org/10.1177/1094670502004004007

Gittell, J, Fairfield, K., Bierbaum, B., Head, W., Jackson, R., Kelly, M., Laskin, R., Lipson, S., Siliski, J., Thornhill, T., & Zuckerman, J. (2000). Impact of relational coordination on quality of care, postoperative pain and functioning, and length of stay: a nine-hospital study of surgical patients. *Medical Care*, *38*(8), 807–819. https://doi.org/10.1097/00005650-200008000-00005

Gittell, J., Seidner, R., & Wimbush, J. (2010). A Relational Model of How High-Performance Work Systems Work. *Organization Science*, *21*(2), 490–506. https://doi.org/10.1287/orsc.1090.0446

Goldstein, S., Eftekhari, S., Mitchell, L., Winders, T., Kaufman, L., Dudas, D., Paknis, B., Kavati, A., Delwart, V., & Sofen, H. (2019). Perspectives on Living with Chronic Spontaneous Urticaria: From Onset through Diagnosis and Disease Management in the US*. *Acta Dermato-Venereologica*, *99*(12), 1091–1098. https://doi.org/10.2340/00015555-3282

Golics, C., Basra, M., Finlay, A., & Salek, S. (2013). The impact of disease on family members: a critical aspect of medical care. *Journal of the Royal Society of Medicine*, *106*(10), 399–407. https://doi.org/10.1177/0141076812472616

Gonzalez-Dolginko, B. (2016). Picture of health: An artist's journey through disease as told in his photographs. *Journal of Applied Arts & Health*, *7*(3), 369–389. https://doi.org/10.1386/jaah.7.3.369_1

Goodman, R., Posner, S., Huang, E., Parekh, A, & Koh, H. (2013). Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Preventing Chronic Disease*, *10* , 1-16. https://doi.org/10.5888/pcd10.120239

Goudy, E., Jackson, M., Den Otter, R., & Bater, M. (2015). The journey to include patient and family voices. *Healthcare Management Forum*, *28*(2), 61–64. https://doi.org/10.1177/0840470414562641

Gove, P. (2002). *Webster's third new international dictionary of the English language, unabridged*. Springfield: Merriam-Webster.

Goyette, I., Ricard, I., Bergeron, J., & Marticotte, F. (2010). e-Wom Sclale: word-of-mouth measurement scale for e-services context. *Canadian Journal of Administrative Sciences*, *27*(1), 5–23.

Graffigna, G., Cecchini, I., Breccia, M., Capochiani, E., Della Seta, R., Galimberti, S., Melosi, A., Simonetti, F., Pizzuti, M., Capalbo, S., Falzetti, F., Mazza, P., Di Renzo, N., Mastrullo, L., Rapezzi, D., Orlandi, E., Intermesoli, T., Iurlo, A., Pungolino, E., & Pacilli, M. (2017). Recovering from chronic myeloid leukemia: the patients' perspective seen through the lens of narrative medicine. *Quality of Life Research*, *26*(10), 2739–2754. https://doi.org/10.1007/s11136-017-1611-8

Graffigna, G., & Vegni, E. (2017). Editorial: Consumer engagement in health and well-being: Theoretical and empirical perspectives in patient centered medicine. *Frontiers in Psychology*, *8*, 1–3. https://doi.org/10.3389/fpsyg.2017.01811

Graham-Wisener, L., & Dempster, M. (2017). Peer advice giving from posttreatment to newly diagnosed esophageal cancer patients. *Diseases of the Esophagus*, *30*(10), 1–7. https://doi.org/10.1093/dote/dox089

Granero-Molina, J., Fernández Medina, I. M., Fernández-Sola, C., Hernández-Padilla, J. M., Jiménez Lasserrotte, M. del M., & López Rodríguez, M. del M. (2019). Experiences of Mothers of Extremely Preterm Infants after Hospital Discharge. *Journal of Pediatric Nursing*, *45*(e2–e8). https://doi.org/10.1016/j.pedn.2018.12.003

Greaves, C., Bailey, E., Storey, L., & Nicholson, A. (2009). Implementing end of life care for patients with renal failure. *Nursing Standard (Royal College of Nursing (Great Britain): 23*(52), 35–41. https://doi.org/10.7748/ns2009.09.23.52.35.c7236

Grewal, D., Levy, M., & Kumar, V. (2009). Customer Experience Management in Retailing: An Organizing Framework. *Journal of Retailing*, *85*(1), 1–14. https://doi.org/10.1016/j.jretai.2009.01.001

Grocott, M. (2019). Pathway redesign: Putting patients ahead of professionals. *Clinical Medicine,*

Journal of the Royal College of Physicians of London, *19*(6), 468–472. https://doi.org/10.7861/clinmed.2019-0292

Groene, O., Arah, O. A., Klazinga, N. S., Wagner, C., Bartels, P. D., Kristensen, S., Saillour, F., Thompson, A., Thompson, C. A., Pfaff, H., DerSarkissian, M., & Sunol, R. (2015b). Patient Experience Shows Little Relationship with Hospital Quality Management Strategies. *PloS One*, *10*(7), 1–15. https://doi.org/10.1371/journal.pone.0131805

Gronroos, C. (1993). *Towards a third phase in service quality research: challenges and future directions.* College of Business, Department of Marketing, Arizona State Univ.

Gulati, R., & Oldroyd, J. B. (2005). The quest for customer focus. *Harvard Business Review*, *83*(4), 92-101,133. https://hbr.org/2005/04/the-quest-for-customer-focus. Accessed 21 February 2023.

Guler, P. (2017). Patient Experience: A Critical Indicator of Healthcare Performance. *Frontiers of Health Services Management*, *33*(3), 17–29. https://doi.org/10.1097/HAP.0000000000000003

Gurrieri, L., & Drenten, J. (2019). Visual storytelling and vulnerable health care consumers: normalising practices and social support through Instagram. *Journal of Services Marketing*, *33*(6), 702–720. https://doi.org/10.1108/JSM-09-2018-0262

Gustafsson, A., Aksoy, L., Brady, M, McColl-Kennedy, J. R., Sirianni, N., Witell, L., & Wuenderlich, N. (2015). Conducting service research that matters. *Journal of Services Marketing*, *29*(6–7), 425–429. https://doi.org/10.1108/JSM-02-2015-0103

Haase, I., Lehnert-Batar, A., Schupp, W., Gerling, J., & Kladny, B. (2006). Factors contributing to patient satisfaction with medical rehabilitation in German hospitals. *International Journal of Rehabilitation Research,* *29*(4), 289–294. https://doi.org/10.1097/MRR.0b013e328010b9cc

Hajli, M. (2014). A study of the impact of social media on consumers. *International Journal of Market Research*, *56*(3), 387–404. https://doi.org/10.2501/IJMR-2014-025

Hall, A., Towers, N., & Shaw, D. (2017). Understanding how Millennial shoppers decide what to

buy. *International Journal of Retail & Distribution Management*, *45*(5), 498–517. https://doi.org/10.1108/IJRDM-11-2016-0206

Hall, W., Chapman, M. V, Lee, K., Merino, Y. M., Thomas, T., Payne, B., Eng, E., Day, S., & Coyne-Beasley, T. (2015). Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review. *American Journal of Public Health*, *105*(12), e60-76. https://doi.org/10.2105/AJPH.2015.302903

Halm, M., Sabo, J., & Rudiger, M. (2006). The Patient-Family Advisory Council Keeping a Pulse on Our Customers. *Critical Care Nurse*, *26*(5), 58–67. https://doi.org/10.4037/ccn2006.26.5.58

Hamdan, A.., Alshammary, S., Tamani, J., Peethambaran, S., Hussein, M., & Alharbi, M. (2016). The impact of creating a child-friendly hospital environment in pediatric cancer patients and their families in comprehensive cancer center at King Fahad Medical City. *Current Pediatric Research*, *20*(1–2), 47–54.

Hamilton, R., Ratner, R., & Thompson, D. (2011). Outpacing others: When consumers value products based on relative usage frequency. *Journal of Consumer Research*, *37*(6), 1079–1094.

Hammersley, M., Chapman, P., Atkinson, P., & Sciences, S. (2007). Ethnography. In *Ethnography - principles in practice*.

Harrison, R., & Reilly, T. (2011). Mixed methods designs in marketing research. *Qualitative Market Research: An International Journal*, *14*(1), 7–26. https://doi.org/10.1108/13522751111099300

Hatch, J. (2002). *Doing qualitative research in educational settings*. Albany: State University of New York Press.

Healy, M., & Beverland, M. (2013). Unleashing the animal within: Exploring consumers' zoomorphic identity motives. *Journal of Marketing Management*, *29*(1–2), 225–248. https://doi.org/10.1080/0267257X.2013.766233

Heinonen, K., & Medberg, G. (2018). Netnography as a tool for understanding customers:

implications for service research and practice. *Journal of Services Marketing*, *32*(6), 657–679. https://doi.org/10.1108/JSM-08-2017-0294

Heinonen, K., Strandvik, T., Mickelsson, J., Edvardsson, B., Sundström, E., & Andersson, P. (2010). A Customer-Dominant Logic of Service. *Journal of Service Management*, *21*, 531–548. https://doi.org/10.1108/09564231011066088

Hekman, D., Aquino, K., Owens, B., Mitchell, T., Schilpzand, P., & Leavitt, K. (2010). An Examination of Whether and How Racial and Gender Biases Influence Customer Satisfaction. *Academy of Management Journal*, *53*(2), 238–264. https://doi.org/10.5465/AMJ.2010.49388763

Hendriks, M., Spreeuwenberg, P., & Delnoij, D. (2009). Dutch Healthcare reform: did it result in performance improvement of health plans? A comparison of consumer experiences over time. *BMC Health Services Research*, *9*(1), 167–175.

Hewitson, P., Skew, A., Graham, C., Jenkinson, C., & Coulter, A. (2014). People with limiting long-term conditions report poorer experiences and more problems with hospital care. *BMC Health Services Research*, *14*(1), 1–10. https://doi.org/10.1186/1472-6963-14-33

Hibard, J., & Green, J. (2013). What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*, *32*(2), 207–214. https://doi.org/https://doi.org/

Hillary, W., Justin, G., Bharat, M., & Jitendra, M. (2016). Value Based Healthcare | Better Value HealthCare. *Advances in Management*, *9*(1), 1–9.

Hinz, V., Drevs, F., & Wehner, J. (2012). *Electronic Word of Mouth about medical devices*. hche (Hamburg Center for Health Economics), Research Paper No. 2012/05 https://www.hche.uni-hamburg.de/dokumente/research-papers/rp5-world-of-mouth.pdf

Hoffman, D. L., & Franke, G. R. (1986). Correspondence Analysis: Graphical Representation of Categorical Data in Marketing Research. *Journal of Marketing Research*, *23*(3), 213–227. https://doi.org/10.2307/3151480

Hogg, J., Chu, F., Utokaparch, S., Woods, R., Elliott, W., Buzatu, L., Cherniack, R., Rogers, R. M.,

Sciurba, F., Coxson, H., & Paré, P.(2004). The nature of small-airway obstruction in chronic obstructive pulmonary disease. *The New England Journal of Medicine*, *350*(26), 2645–2653. https://doi.org/10.1056/NEJMoa032158

Holbrook, M., & Hirschman, E. (1982). The experiential aspects of consumption: Consumer fantasies, feelings, and fun. *Journal of Consumer Research*, *9*(2), 132–140. https://doi.org/10.1086/208906

Holopainen, R., Piirainen, A., Heinonen, A., Karppinen, J., & O'Sullivan, P. (2018). From "Non-encounters" to autonomic agency. Conceptions of patients with low back pain about their encounters in the health care system. *Musculoskeletal Care*, *16*(2), 269–277. https://doi.org/10.1002/msc.1230

Homburg, C., Danjiel, J., & Christina, K. (2015). Customer Experience Management: Toward Implementing an Evolving Marketing Concept. *Journal of Academy of Marketing Science*, *45*(3), 377–401. https://doi.org/https://doi.org/10.1007/s11747-015-0460-7

Hostetter, T. H. (2001). Prevention of end-stage renal disease due to type 2 diabetes. *The New England Journal of Medicine 345* (12), 910–912. https://doi.org/10.1056/NEJM200109203451209

Howard, J., & Sheth, J. (1969). The Theory of Buyer Behavior. *Journal of the American Statistical Association, 65* (331), 1406-1407. https://doi.org/10.2307/2284311

Hoyer, W. (1984). An Examination of Consumer Decision Making for a Common Repeat Purchase Product. *Journal of Consumer Research*, *11*(3), 822–829. https://doi.org/10.1086/209017

Hsu, C., Vittinghoff, E., Lin, F., & Shlipak, M. (2004). The incidence of end-stage renal disease is increasing faster than the prevalence of chronic renal insufficiency. *Annals of Internal Medicine*, *141*(2), 95–101. https://doi.org/10.7326/0003-4819-141-2-200407200-00007

Hunneman, A., Verhoef, P., & Sloot, L. (2015). The Impact of Consumer Confidence on Store Satisfaction and Share of Wallet Formation. *Journal of Retailing*, *91*(3), 516–532. https://doi.org/https://doi.org/10.1016/j.jretai.2015.02.004

Hutchins, J., & Rodriguez, D. (2017). The soft side of branding: leveraging emotional intelligence. *Journal of Business & Industrial Marketing*, *33* (1), 117-125 https://doi.org/10.1108/JBIM-02-2017-0053

Hyers, L. (2018). *Diary Methods*. Oxford University PressISBN: ISBN-13: 978-0190256692

Institute of Medicine (US) Committee on Quality of Health Care in America. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century.* National Academies Press (US). https://pubmed.ncbi.nlm.nih.gov/25057539/

Isaac, T., Zaslavsky, A., Cleary, P., & Landon, B. (2010). The relationship between patients' perception of care and measures of hospital quality and safety. *Health Services Research*, *45*(4), 1024–1040. https://doi.org/10.1111/j.1475-6773.2010.01122.x

Jackson, K., Oelke, N., Besner, J., & Harrison, A. (2012). Patient journey: Implications for improving and integrating care for older adults with chronic obstructive pulmonary disease. *Canadian Journal on Aging*, *31*(2), 223–233. https://doi.org/10.1017/S0714980812000086

Jain, R., Aagja, J., & Bagdare, S. (2017). Customer experience – a review and research agenda. *Journal of Service Theory and Practice*, *27*(3), 642–662. https://doi.org/10.1108/JSTP-03-2015-0064

Jenkinson, C., Coulter, A., Bruster, S., & Chandola, T. (2002). Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Qual Saf Health Care*, *11*, 335–339. https://doi.org/https://doi.org/10.1136/qhc.11.4.335

Jha, A., Orav, E., Zheng, J., & Epstein, A. (2008). Patients' Perception of Hospital Care in the United States. *New England Journal of Medicine*, *359*(18), 1921–1931. https://doi.org/10.1056/NEJMsa0804116

Johnson, D., & Lowe, B. (2015). Emotional Support, Perceived Corporate Ownership and Skepticism toward Out-groups in Virtual Communities. *Journal of Interactive Marketing*, *29*(1), 1–10. https://doi.org/10.1016/j.intmar.2014.07.002

Johnson, G., & Ambrose, P. (2006). Neo-tribes: the power and potential of online communities in

health care. *Commun. ACM*, *49*(1), 107–113.

Johnson, R., & Wichern, D. (2007). *Applied Multivariate Statistical Analysis.* Sixth Edition, Pearson Prentice Hall.

Johnston, A., Worrell, J., Gangi, P.., & Wasko, M. (2013). Online health communities: An assessment of the influence of participation on patient empowerment outcomes. *Information Technology and People*, *26*(2), 213–235. https://doi.org/10.1108/ITP-02-2013-0040

Johnston, R., & Kong, X. (2011). The customer experience: a road-map for improvement. *Managing Service Quality*, *21*(1), 5–24.

Joinson, A. (2001). Self-disclosure in computer-mediated communication: The role of self-awareness and visual anonymity. *European Journal of Social Psychology*, *31*(2), 177-192 https://doi.org/10.1002/ejsp.36

Kadry, B., Chu, L. Kadry, B., Gammas, D., & Macario, A. (2011). Analysis of 4999 online physician ratings indicates that most patients give physicians a favorable rating. *Journal of Medical Internet Research*, *13*(4), e95. https://doi.org/10.2196/jmir.1960

Kahanovitz, L., Sluss, P., & Russell, S. (2017). Type 1 Diabetes - A Clinical Perspective. *Point of Care*, *16*(1), 37–40. https://doi.org/10.1097/POC.0000000000000125

Kahn, W. (1990). Psychological conditions of personal engagement and disengagement at work. *Academy of Management Journal*, *33*(4), 692–724. https://doi.org/10.2307/256287

Kahneman, D., & Krueger, A. (2006). Developments in the Measurement of Subjective Well-Being. *Journal of Economic Perspectives*, *20*(1), 3–24. https://doi.org/10.1257/089533006776526030

Kahneman, D., & Riis, J. (2005). Living, and thinking about it: two perspectives on life. In F. A. Huppert, N. Baylis, & B. Keverne (Eds.), *The Science of Well-Being*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198567523.003.0011

Kahneman, D., Wakker, P., & Sarin, R. (1997). Back to Bentham? Explorations of experienced utility. *Quarterly Journal of Economics*, *112*(2), 375–405. https://doi.org/10.1162/003355397555235

Kaitelidou, D., Kalogeropoulou, M., Katostaras, T., Konstantakopoulou, O., Minogiannis, P., Skitsou, A., Siskou, O., Charalampous, G., Ardavanis, A., & Liaropoulos, L. (2015). Living with breast cancer: Patients' journey within the Greek National Health system. *Forum of Clinical Oncology*, *6*(4), 1–6. https://doi.org/10.1515/fco-2015-0016

Kamalpour, M., Rezaei Aghdam, A., Watson, J., Tariq, A., Buys, L., Eden, R., & Rehan, S. (2021). Online health communities, contributions to caregivers and resilience of older adults. *Health & Social Care in the Community*, *29*(2), 328–343. https://doi.org/10.1111/hsc.13247

Kang, E., Gillespie, B. M., Tobiano, G., & Chaboyer, W. (2020). General surgical patients' experience of hospital discharge education: A qualitative study. *Journal of Clinical Nursing*, *29*(1–2), 1–10. https://doi.org/https://doi.org/10.1111/jocn.15057

Karassavidou, E., Glaveli, N., & Papadopoulos, C. (2009). Quality in NHS hospitals: No one knows better than patients. *Measuring Business Excellence*, *13*, 34–46. https://doi.org/10.1108/13683040910943036

Kash, B., McKahan, M., Tomaszewski, L., & McMaughan, D. (2018). The four Ps of patient experience: A new strategic framework informed by theory and practice. *Health Marketing Quarterly*, *35*(4), 313–325. https://doi.org/10.1080/07359683.2018.1524598

Kedzior, R. (2014). *How Digital Worlds Become Material: An Ethnographic and Netnographic Investigation.* Hanken School of Economics. http://hdl.handle.net/10138/135859

Keeling, D., Khan, A., & Newholm, T. (2013). Internet forums and negotiation of healthcare knowledge cultures. *Journal of Services Marketing*, *27*(1), 59–75. https://doi.org/10.1108/08876041311296383

Keim-Malpass, J., & Steeves, R. (2012). Talking with death at a diner: young women's online narratives of cancer. *Oncology Nursing Forum*, *39*(4), 373-378,406. https://doi.org/10.1188/12.ONF.373-378

Keim-Malpass, J., Steeves, R., & Kennedy, C. (2014). Internet ethnography: A review of methodological considerations for studying online illness blogs. *International Journal of Nursing Studies*, *51*(12), 1686–1692. https://doi.org/https://doi.org/10.1016/j.ijnurstu.2014.06.003

Keller, K. (1993). Conceptualizing, Measuring, and Managing Customer-Based Brand Equity. *Journal of Marketing*, *57*(1), 1–22. https://doi.org/10.1177/002224299305700101

Kelley, S., & Davis, M. (1994). Antecedents to customer expectations for service recovery. *Journal of the Academy of Marketing Science*, *22*(1), 52–61. https://doi.org/10.1177/0092070394221005

Kemp, E., Jillapalli, R., & Becerra, E. (2014). Healthcare branding: Developing emotionally based consumer brand relationships. *Journal of Services Marketing*, *28*(2), 126–137. https://doi.org/10.1108/JSM-08-2012-0157

Kennedy, D. (2017). Creating an Excelent Patient Experience Through Service Education. *Journal of Patient Experience*, *4*(4), 4156–4161. https://doi.org/https://dx.doi.org/10.1177%2F2374373517718351

Kennedy, D., Fasolino, J., & Gullen, D. (2014). Improving the patient experience through provider communication skills building. *Patient Experience Journal*, *1*(1), 56–60. https://doi.org/10.35680/2372-0247.1009

Kerin, L., Lynch, D., & McNicholas, F. (2020). Participatory development of a patient–clinician communication tool to enhance healthcare transitions for young people with 22q11.2. *Irish Journal of Medical Science*, *189*(3), 761–769. https://doi.org/10.1007/s11845-019-02104-6

Keyes, C. (1998). Social Well-Being. *Social Psychology Quarterly*, *61*(2), 121–140.

Khanna, M., Jacob, I., & Yadav, N. (2014). Identifying and analyzing touchpoints for building a higher education brand. *Journal of Marketing for Higher Education*, *24*(1), 122–143. https://doi.org/10.1080/08841241.2014.920460

Kim, J. (2018). The effect of patient participation through physician's resources on experience and wellbeing. *Sustainability*, *10*(6), 2102. https://doi.org/10.3390/su10062102

Kim, S., & Yoon, J. (2012). The use of an online forum for health information by married Korean women in the United States. *Information Research*, *17*(2).

Kirk, S., & Milnes, L. (2016). An exploration of how young people and parents use online support

in the context of living with cystic fibrosis. *Health Expectations*, *19*(2), 309–321. https://doi.org/10.1111/hex.12352

Kitchin, R., & Lauriault, T. (2015). Small data in the era of big data. *GeoJournal*, *80*(4), 463–475. http://www.jstor.org/stable/44076310

Klaus, P. (2018). Luxury patient experience (LPX): review, conceptualization, and future research directions. *Service Industries Journal*, *38*(1–2), 87–98. https://doi.org/10.1080/02642069.2017.1377190

Klinkenberg, W., Boslaugh, S., Waterman, B., Otani, K., Inguanzo, J., & Gnida, J. (2011). Inpatients´willingness to recommend: a multilevel analysis. *Health Care Management Review*, *36*(4), 349–358.

Klose, K., Kreimeier, S., Tangermann, U., Aumann, I., & Damm, K. (2016). Patient- and person-reports on healthcare: preferences, outcomes, experiences, and satisfaction – an essay. *Health Economics Review*, *6*(1), 1–11. https://doi.org/10.1186/s13561-016-0094-6

Knibb, R., Huissoon, A, Baretto, R., Ekbote, A., Onyango-Odera, S., Screti, C., Newman, K, & Krishna, M. (2019). "It's not an illness, it's just bad luck": The impact of anaphylaxis on quality of life in adults. *Clinical and Experimental Allergy*, *49*(7), 1040–1046. https://doi.org/10.1111/cea.13410

Kohler, G., Sampalli, T., Ryer, A., Porter, J., Wood, L., Bedford, L., Higgins-Bowser, I., Edwards, L., Christian, E., Dunn, S., Gibson, R., Carson, S., Vallis, M., Zed, J., Tugwell, B., Van Zoost, C., Canfield, C., & Rivoire, E. (2017). Bringing value-based perspectives to care: Including patient and family members in decision-making processes. *International Journal of Health Policy and Management*, *6*(11), 661–668. https://doi.org/10.15171/ijhpm.2017.27

Kooli, K., Cai, H., Tang, X., Beer, C., & Wright, L. (2016). Better together? A hospitality case for umbrella branding. *Journal of Business & Industrial Marketing*, *31*(8), 1004–1016. https://doi.org/10.1108/JBIM-10-2016-273

Kotler, P., & Keller, K. (2015). *Marketing Management*. Pearson Education, Limited. https://books.google.pt/books?id=PDUOrgEACAAJ

Kozinets, R. (2002). The Field Behind the Screen: Using Netnography for Marketing Research in Online Communities. *Journal of Marketing Research*, *39*(1), 61–72. https://doi.org/10.1509/jmkr.39.1.61.18935

Kozinets, R. (2010). *Netnography: Doing Ethnographic Research Online*. SAGE Publications. https://books.google.pt/books?id=QNDaeutR9v4C

Kranzbuhler, A., Kleijnen, M., Morgan, R., & Teerling, M. (2018). The Multilevel Nature of Customer Experience Research : An Integrative Review and Research Agenda. *International Journal of Management Reviews*, *20*(2), 433–456. https://doi.org/10.1111/ijmr.12140

Kreps, G. (2008). Strategic use of communication to market cancer prevention and control to vulnerable populations. *Health Marketing Quarterly*, *25*(1–2), 204–216. https://doi.org/10.1080/07359680802126327

Kumar, R., Dash, S., & Malhotra, N. (2018). The impact of marketing activities on service brand equity: The mediating role of evoked experience. *European Journal of Marketing*, *52*(3–4), 596–618. https://doi.org/10.1108/EJM-05-2016-0262

Laestadius, L., & Wahl, M.(2017). Mobilizing social media users to become advertisers: Corporate hashtag campaigns as a public health concern. *Digital Health, 3*, 1-12. 2055207617710802. https://doi.org/10.1177/2055207617710802

Lagu, T., Hannon, N., Rothberg, M., & Lindenauer, P. (2010). Patients' evaluations of health care providers in the era of social networking: an analysis of physician-rating websites. *Journal of General Internal Medicine*, *25*(9), 942–946. https://doi.org/10.1007/s11606-010-1383-0

Laing, S, Jones, M., Swerdlow, A., Burden, A., & Gatling, W. (2005). Psychosocial and socioeconomic risk factors for premature death in young people with type 1 diabetes. *Diabetes Care*, *28*(7), 1618–1623. https://doi.org/10.2337/diacare.28.7.1618

Lally, J., Byrne, F., McGuire, E., & McDonald, C. (2013). Patient satisfaction with psychiatric outpatient care in a university hospital setting. *Irish Journal of Psychological Medicine*, *30*(4), 271–277. https://doi.org/10.1017/ipm.2013.54

Lamprell, K., & Braithwaite, J. (2016). Patients as story-tellers of healthcare journeys. *Medical*

Humanities, *42*(3), 207–209. https://doi.org/10.1136/medhum-2016-010885

Langer, R., & Beckman, S. C. (2005). Sensitive research topics: netnography revisited. *Qualitative Market Research: An International Journal*, *8*(2), 189–203. https://doi.org/10.1108/13522750510592454

Lapsley, P., & Groves, T. (2004). The patient´s journey: travelling through life with a chronic illness. BMJ: *British Medical Journal*, *329*(7466), 582–583.

LaVela, S., & Gallan, A. (2014). Evaluation and Measurement of Patient Experience. *Patient Experience Journal*, *1*(1), 28–36. https://doi.org/10.35680/2372-0247.1003

Lee, H., Vlaev, I., King, D., Mayer, E., Darzi, A., & Dolan, P. (2013). Subjective well-being and the measurement of quality in healthcare. *Social Science and Medicine*, *99*, 27–34. https://doi.org/10.1016/j.socscimed.2013.09.027

Lee, S. (2011). Evaluating serviceability of healthcare servicescapes: Service design perspective. *International Journal of Design*, *5*(2), 61–71. https://www.ijdesign.org/index.php/IJDesign/article/view/919

Leeflang, P., Spring, P., Van Doorn, J., & Wansbeek, T. (2013). Identifying the direct mail-prone consumer. *Journal of Global Scholars of Marketing Science*, *23*(2), 175–195. https://doi.org/10.1080/21639159.2012.760923

Lemke, F., Clark, M., & Wilson, H. (2011). Customer experience quality: An exploration in business and consumer contexts using repertory grid technique. *Journal of the Academy of Marketing Science*, *39*(6), 846–869. https://doi.org/10.1007/s11747-010-0219-0

Lemon, K., & Verhoef, P. (2016). Understanding customer experience throughout the customer journey. *Journal of Marketing*, *80*(6), 69–96. https://doi.org/10.1509/jm.15.0420

Lervik-Olsen, L., Oest, R., & Verhoef, P. (2015). *When is customer satisfaction "locked"? A longitudinal analysis of satisfaction stickness*. BI Norwegian Business School

Leva, M., & Ziliani, C. (2018). The role of customer experience touchpoints in driving loyalty intentions in services. *The TQM Journal*, *30*(5), 444–457. https://doi.org/10.1108/TQM-11-2017-0141

Lexa, F. (2006). 300,000,000 customers: patient perspectives on service and quality. *Journal of the American College of Radiology : JACR*, *3*(5), 346–350. https://doi.org/10.1016/j.jacr.2005.11.014

Leydon, G., Bynoe-Sutherland, J., & Coleman, M. (2003). The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of Cancer Care*, *12*(4), 317–326. https://doi.org/10.1046/j.1365-2354.2003.00418.x

Li, N., Orrange, S., Kravitz, R., & Bell, R. (2014). Reasons for and predictors of patients' online health information seeking following a medical appointment. *Family Practice*, *31*(5), 550–556. https://doi.org/10.1093/fampra/cmu034

Libai, B., Bolton, R., Bügel, M., de ruyter, ko, Götz, O., Risselada, H., & Stephen, A. (2010). Customer-to-Customer Interactions: Broadening the Scope of Word of Mouth Research. *Journal of Service Research.* *13*(3), 267–282. https://doi.org/10.1177/1094670510375600

Lillrank, P. (2009). Service processes. In *Introduction to Service Engineering* (pp. 338–364). Wiley.

Lin, M., & Chu, K.(2022). The experience of urgent dialysis patients with end-stage renal disease: A qualitative study. *PloS One*, *17*(1), e0261941. https://doi.org/10.1371/journal.pone.0261941

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Liu, F., & Maitilis, S. (2010). Non participant observation. In E. W. Durepos, Mills; G. (Eds.) *Encyclopedia of Case Study Research* (pp. 610–612). Thousand Oaks, CA: SAGE Publications.

Liu, N., Brown, A., Younge, M., Guzman, S., Close, K., & Wood, R. (2017). Stigma in people with type 1 or type 2 diabetes. *Clinical Diabetes*, *35*(1), 27–34. https://doi.org/10.2337/cd16-0020

Liu, Y., Dickerson, T., Waddingham, P., & Clarkson, P. J. (2019). Improving people's access to community-based back pain treatment through an inclusive design approach. *Applied Ergonomics*, *81*(April), 102876. https://doi.org/10.1016/j.apergo.2019.102876

Lombarts, A. (2018). The hospitality model revisited: Developing a hospitality model for today and tomorrow. *Hospitality and Society*, *8*(3), 297–311. https://doi.org/10.1386/hosp.8.3.297_7

López, A., Detz, A., Ratanawongsa, N., & Sarkar, U. (2012). What patients say about their doctors online: a qualitative content analysis. *Journal of General Internal Medicine*, *27*(6), 685–692. https://doi.org/10.1007/s11606-011-1958-4

Lotz, S., Raabe, J., & Roggenhofer, S. (2018). The role of customer care in a customer experience transformation. *McKinsey & Company*, 1–6. https://www.mckinsey.com/~/media/mckinsey/business functions/operations/our insights/the role of customer care in a customer experience transformation/the-role-of-customer-care-in-a-customer-experience-transformation-vf.pdf

Lown, B., Rosen, J., & Marttila, J. (2011). An agenda for improving compassionate care: a survey shows about half of patients say such care is missing. *Health Affairs*, *30*(9), 1772—1778. https://doi.org/10.1377/hlthaff.2011.0539

Lugosi, P. (2006). Between overt and covert research: Concealment and disclosure in an ethnographic study of commercial hospitality. *Qualitative Inquiry*, *12*(3), 541-561. https://doi.org/10.1177/1077800405282801

Luhmann, N. (1995). *Social Systems*. Stanford University Press.

Luxford, K., & Sutton, S. (2014). How does patient experience fit into the overall healthcare picture? *Patient Experience Journal*, *1*(1), 20–27. https://doi.org/10.35680/2372-0247.1002

Lyng, H.., Macrae, C., Guise, V., Haraldseid-Driftland, C., Fagerdal, B., Schibevaag, L., Alsvik, J. G., & Wiig, S. (2021). Balancing adaptation and innovation for resilience in healthcare – a metasynthesis of narratives. *BMC Health Services Research*, *21*(1), 759. https://doi.org/10.1186/s12913-021-06592-0

Maas, V., Dibbets, F., Peters, V. (2023). The never-ending patient journey of chronically ill patients : A qualitative case study on touchpoints in relation to patient-centered care. . *PLoS ONE 18*(5): e0285872. https://doi.org/10.1371/journal.pone.0285872

MacInnis, D. (2011). A Framework for Conceptual Contributions in Marketing. *Journal of Marketing*, *75*(4), 136–154. https://doi.org/10.1509/jmkg.75.4.136

Maddalena, V., O'Shea, F., & Barrett, B. (2018). An Exploration of Palliative Care Needs of People With End-Stage Renal Disease on Dialysis: Family Caregiver's Perspectives. *Journal of Palliative Care*, *33*(1), 19–25. https://doi.org/10.1177/0825859717747340

Makarem, S., & Al-Amin, M. (2014). Beyond the Service Process : The Effects of Organizational and Market Factors on Customer Perceptions of Health Care Services. *Journal of Service Research, 17*(4), 399-414. https://doi.org/10.1177/1094670514541965

Malone, R. (2003). Distal nursing. *Social Science & Medicine (1982)*, *56*(11), 2317–2326. https://doi.org/10.1016/s0277-9536(02)00230-7

Manary, M., Boulding, W., Staelin, R., & Glickman, S. (2013). The Patient Experience and Health Outcomes. *New England Journal of Medicine*, *368*(3), 201–203. https://doi.org/10.1056/NEJMp1211775

Manchaiah, V., & Stephens, D. (2012). The "patient journey" of adults with sudden-onset acquired hearing impairment: A pilot study. *Journal of Laryngology and Otology*, *126*(5), 475–481. https://doi.org/10.1017/S0022215111003197

Mandal, S. (2017). The influence of organizational culture on healthcare supply chain resilience: moderating role of technology orientation. *Journal of Business & Industrial Marketing*, *32* (8), 1021-1037. https://doi.org/10.1108/JBIM-08-2016-0187

Mansfield, P. M., & Pinto, M. (2008). Consumer Vulnerability and Credit Card Knowledge Among Developmentally Disabled Citizens. *Journal of Consumer Affairs*, *42*(3), 425–438. https://doi.org/https://doi.org/10.1111/j.1745-6606.2008.00115.x

Marshall, C., & Rossman, G. (2011). *Designing qualitative research* (5th ed.). Thousand Oaks, CA: Sage.

Martin, S. (2017). Word-of-mouth in the health care sector : a literature analysis of the current state of research and future perspectives. *International Review Public Nonprofit Marketing*, *14*, 35–56. https://doi.org/10.1007/s12208-016-0154-y

Mathwick, C., Wiertz, C., & de Ruyter, K. (2008). Social Capital Production in a Virtual P3 Community. *Journal of Consumer Research*, *34*(6), 832–849. https://econpapers.repec.org/RePEc:oup:jconrs:v:34:y:2008:i:6:p:832-849

Mayring, P. (2014). Qualitative Content Analysis: Theoretical Background and Procedures. In: Bikner-Ahsbahs, A., Knipping, C., Presmeg, N. (eds) *Approaches to Qualitative Research in Mathematics Education. Advances in Mathematics Education*. Springer, Dordrecht. https://doi.org/10.1007/978-94-017-9181-6_13

Mazzarol, T., Sweeney, J., & Soutar, G. (2007). Conceptualizing word-of-mouth activity, triggers and conditions: an exploratory study. *European Journal of Marketing*, *41*(11/12), 1475–1494. https://doi.org/10.1108/03090560710821260

McAlister, L., & Pessemier, E. (1982). Variety Seeking Behavior: An Interdisciplinary Review. *Journal of Consumer Research*, *9*(3), 311–322. https://doi.org/10.1086/208926

McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y., Kenny, L., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems*, *25*(1), 354–368. https://doi.org/10.1080/12460125.2016.1187394

McClelland, L., & Vogus, T. (2014). Compassion practices and HCAHPS: does rewarding and supporting workplace compassion influence patient perceptions? *Health Services Research*, *49*(5), 1670–1683. https://doi.org/10.1111/1475-6773.12186

McColl-Kennedy, J. (2015). Fresh perspectives on customer experience. *Journal of Services Marketing*, *29*(6–7), 430–435. https://doi.org/https://doi.org/10.1108/JSM-01-2015-0054

McColl-Kennedy, J. Danaher, T., Gallan, A., Orsingher, C., Lervik-Olsen, L., & Verma, R. (2017a). How do you feel today? Managing patient emotions during health care experiences to enhance well-being. *Journal of Business Research*, *79*, 247–259. https://doi.org/10.1016/j.jbusres.2017.03.022

McColl-Kennedy, J., Hogan, S., Witell, L., & Snyder, H. (2017b). Cocreative customer practices: Effects of health care customer value cocreation practices on well-being. *Journal of Business*

Research, *70*, 55–66. https://doi.org/10.1016/j.jbusres.2016.07.006

McColl-Kennedy, J., Snyder, H., Elg, M., Witell, L., Helkkula, A., Hogan, S., & Anderson, L. (2017c). The changing role of the health care customer: review, synthesis and research agenda. *Journal of Service Management*, *28*(1), 2–33. https://doi.org/10.1108/JOSM-01-2016-0018

McColl-Kennedy, J., Vargo, S., Dagger, T., Sweeney, J., & van Kasteren, Y. (2012). Health Care Customer Value Cocreation Practice Styles. *Journal of Service Research*, *15*(4), 370–389. https://doi.org/10.1177/1094670512442806

McColl-Kennedy, J., Zaki, M., Lemon, K., Urmetzer, F., & Neely, A. (2018). Gaining Customer Experience Insights That Matter. *Journal of Service Research*, *22*(1), 8–26. https://doi.org/10.1177/1094670518812182

McCosker, A., & Darcy, R. (2013). Living with cancer. *Information, Communication & Society*, *16*(8), 1266–1285. https://doi.org/10.1080/1369118X.2012.758303

McGlynn, E., Asch, S., Adams, J., Keesey, J., Hicks, J., De Cristofaro, A., & Al, E. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine*, *348*, 2635–2645. https://doi.org/10.1056/NEJMsa022615

McLaughlin, J., Anderson, R., Ferketich, A., Seiber, E., Balkrishnan, R., & Paskett, E. (2012). Effect on survival of longer intervals between confirmed diagnosis and treatment initiation among low-income women with breast cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, *30*(36), 4493–4500. https://doi.org/10.1200/JCO.2012.39.7695

McMahon, S., & Winch, P. (2018). Systematic debriefing after qualitative encounters: an essential analysis step in applied qualitative research. *BMJ Global Health*, *3*(5), e000837. https://doi.org/10.1136/bmjgh-2018-000837

Mechen, C., & Andrews, M. (2019). Looking after himself now: A leg ulcer patient's journey back to health. *Wounds UK*, *15*(2), 34–38.

Mehrabian, A., & Russel, J. (1974). *An approach to environmental Psychology*. Cambridge, MA:

MIT Press.

Mele, C., Pels, J., & Storbacka, K. (2014). A holistic market conceptualization. *Journal of the Academy of Marketing Science*, *43*, 100–114. https://doi.org/10.1007/s11747-014-0383-8

Meyer, & Schwager. (2007). Understanding Customer Experience. *Harvard Business Review*. https://doi.org/10.1057/9780230291775

Miles, M. & Huberman, A. (1994). *Qualitative data analysis: A sourcebook of new methods*. Thounsand Oaks, CA: Sage.

Ministério da Saúde. Direção-Geral da Saúde. (2019). *Crianças e Jovens Com Diabetes Diabetes Mellitus tipo: Manual de formação para apoio aos profissionais de saúde e de educação*. https://www.spedp.pt/news/criancas-e-jovens-com-diabetes-mellitus-tipo-1. Accessed 15 March 2023.

Misra, R., Mukherjee, A., & Peterson, R. (2008). Value creation in virtual communities: The case of a healthcare web site. *International Journal of Pharmaceutical and Healthcare Marketing*, *2*(4), 321–337. https://doi.org/10.1108/17506120810922358

Mitchell, G., Porter, S., & Manias, E. (2019). From telling to sharing to silence: A longitudinal ethnography of professional-patient communication about oral chemotherapy for colorectal cancer. *Psycho-Oncology*, *28*(2), 336–342. https://doi.org/10.1002/pon.4945

Mitchell, J., Boettcher-Sheard, N., Duque, C., & Lashewicz, B. (2018). Who Do We Think We Are? Disrupting Notions of Quality in Qualitative Research. *Qualitative Health Research*, *28*(4), 673–680. https://doi.org/10.1177/1049732317748896

Mitchell, S., Gardiner, P., Sadikova, E., Martin, J., Jack, B., Hibbard, J., & Paasche-Orlow, M. K. (2014). Patient activation and 30-day post-discharge hospital utilization. *Journal of General Internal Medicine*, *29*(2), 349–355. https://doi.org/10.1007/s11606-013-2647-2

Mitra, S. (2016). Can Healthcare Servicescape Affect Customer´s Attitude? A Study of the Mediating Role of Image Congruence and Moderating Role of Customer´s Prior Experience. *Management Research Review*, *8*(2), 1–22.

https://doi.org/10.1108/mrr.2010.02133jaa.002

Mittal, V., Kumar, P., & Tsiros, M. (1999). Attribute-level performance, satisfaction, and behavioral intentions over time: A consumption-system approach. *Journal of Marketing*, *63*(2), 88–101.

Mittal, V., Ross, W. T., & Baldasare, P. M. (1998). The Asymmetric Impact of Negative and Positive Attribute-Level Performance on Overall Satisfaction and Repurchase Intentions. *Journal of Marketing*, *62*(1), 33–47. https://doi.org/10.2307/1251801

Mogilner, C., & Bhattacharjee, A. (2014). Happiness from Ordinary and Extraordinary Experiences. *Journal of Consumer Research*, *41*(1), 1–17. https://doi.org/10.1086/674724

Molm, L., Takahashi, N., & Peterson, G. (2000). Risk and Trust in Social Exchange: An Experimental Test of a Classical Proposition. *American Journal of Sociology*, *105*(5), 1396–1427. https://doi.org/10.1086/210434

Mosadeghrad, A. (2014). Patient choice of a hospital: Implications for health policy and management. *International Journal of Health Care Quality Assurance*, *27*(2), 152–164. https://doi.org/10.1108/IJHCQA-11-2012-0119

Muehrer, R., Schatell, D., Witten, B., Gangnon, R., Becker, B., & Hofmann, R. (2011). Factors Affecting Employment at Initiation of Dialysis. *Clinical Journal of the American Society of Nephrology*, *6*(3), 489-496 https://doi.org/10.2215/CJN.02550310

Mullins, L. (1995). *Hospitality Management: A Human Resources Approach*. Trans-Atlantic Pubns. https://books.google.pt/books?id=jZFkQgAACAAJ

Muniz Jr., & O'Guinn, T. (2001). Brand Community. *Journal of Consumer Research*, *27*(4), 412–432. https://doi.org/10.1086/319618

Musella, F., Guglielmetti Mugion, R., Raharjo, H., & Di Pietro, L. (2017). Reconciling internal and external satisfaction through probabilistic graphical models: An empirical study. *International Journal of Quality and Service Sciences*, *9*(3–4), 347–370. https://doi.org/10.1108/IJQSS-02-2017-0007

Myburgh, C., Boyle, E., Larsen, J., & Christensen, H. (2016). Health care encounters in Danish chiropractic practice from a consumer perspectives - a mixed methods investigation.

Chiropractic and Manual Therapies, *24*(1), 1–8. https://doi.org/10.1186/s12998-016-0103-1

Nakata, C., Izberk-Bilgin, E., Sharp, L., Spanjol, J., Cui, A., Crawford, S., & Xiao, Y. (2019). Chronic illness medication compliance: a liminal and contextual consumer journey. *Journal of the Academy of Marketing Science*, *47*(2), 192–215. https://doi.org/10.1007/s11747-018-0618-1

Nambisan, P. (2011). Evaluating patient experience in online health communities: Implications for health care organizations. *Health Care Management Review*, *36*(2), 124–133. https://doi.org/10.1097/HMR.0b013e3182099f82

Nambisan, P., & Nambisan, S. (2009). Models of consumer value cocreation in health care. *Health Care Management Review*, *34*(4), 344–354. https://doi.org/10.1097/HMR.0b013e3181abd528

Nambisan, P., & Watt, J. (2011). Managing customer experiences in online product communities. *Journal of Business Research*, *64*(8), 889–895. https://doi.org/https://doi.org/10.1016/j.jbusres.2010.09.006

Nambisan, S., & Sawhney, M. (2009). Making the most of the global brain for innovation. *International Commerce Review.*, *8*, 128–135. https://doi.org/10.1007/s12146-010-0042-z

Namukwaya, E., Grant, L., Downing, J., Leng, M., & Murray, S. (2017). Improving care for people with heart failure in Uganda: Serial in-depth interviews with patients' and their health care professionals. *BMC Research Notes*, *10*(1), 1–13. https://doi.org/10.1186/s13104-017-2505-0

Narang, R., Polsa, P., Soneye, A., & Fuxiang, W. (2015). Impact of hospital atmosphere on perceived health care outcome. *International Journal of Health Care Quality Assurance*, *28*(2), 129–140. https://doi.org/10.1108/IJHCQA-12-2013-0142

Nazarov, S., Manuwald, U., Leonardi, M., Silvaggi, F., Foucaud, J., Lamore, K., Guastafierro, E., Scaratti, C., Lindström, J., & Rothe, U. (2019). Chronic Diseases and Employment: Which Interventions Support the Maintenance of Work and Return to Work among Workers with

Chronic Illnesses? A Systematic Review. *International Journal of Environmental Research and Public Health*, *16*(10), 1864. https://doi.org/10.3390/ijerph16101864

Needham, B. (2012). The truth about patient experience: What we can learn from other industries, and how three Ps can improve health outcomes, strengthen brands, and delight customers. *Journal of Healthcare Management*, *57*(4), 255–263. https://doi.org/10.1097/00115514-201207000-00006

Nelson, G., & Prilleltensky, I. (2005). *Community Psychology: In Pursuit of Liberation and Well-being*. Palgrave Macmillan

Nembhard, I., Alexander, J. A., Hoff, T., & Ramanujam, R. (2009). Why Does the Quality of Health Care Continue to Lag? Insights from Management Research. *Academy of Management Perspectives*, *23*(1), 24–42. http://www.jstor.org/stable/27747492

Nemec, M., Kolar, T., & Rusjan, B. (2018). Online communities as a new source of exploring patient dissatisfaction. *Journal of Health Organization and Management*, *32*(8), 962–979. https://doi.org/10.1108/JHOM-03-2018-0104

Nenonen, S., Kärnä, S., Rasila, H., & Junnonen, J. (2008). *Customer journey – a method to investigate user experiences*.

Ng, E., & Fisher, A. (2013). Understanding Well-Being in Multi-Levels: A review. *Health, Culture and Society*, *5*(1), 308–323. https://doi.org/10.5195/hcs.2013.142

Niehues, S., Emmert, M., Haas, M., Schoffski, O., & Hamm, B. (2012). The impact of the emergence of internet hospital rating sites on patient´s choice: a quality evaluation and examination of the patterns of approach. *International Journal of Technology Marketing*, *7*(1), 4–19.

Norton, D., & Pine, B. (2013). Using the customer journey to road test and refine the business model. *Strategy & Leadership*, *41*(2), 12–17.

Nottingham, Q., Johnson, D. M., & Russell, R. (2018). A multi-year SEM model predicting the impact of behavior attributes on overall patient satisfaction. *International Journal of Quality & Reliability Management*, *35*(9), 2006–2034. https://doi.org/10.1108/IJQRM-02-2018-

0031

O'Callaghan, A. M., McAllister, L., & Wilson, L. (2011). Experiences of care: perspectives of carers of adults with traumatic brain injury. *International Journal of Speech-Language Pathology*, *13*(3), 218–226. https://doi.org/10.3109/17549507.2011.549240

O'Gara, G., Tuddenham, S., & Pattison, N. (2018). Haemato-oncology patients' perceptions of health-related quality of life after critical illness: A qualitative phenomenological study. *Intensive and Critical Care Nursing*, *44*, 76–84. https://doi.org/https://doi.org/10.1016/j.iccn.2017.09.011

O'Loughlin, D., Gummerus, J., & Kelleher, C. (2023). It Never Ends: Vulnerable Consumers' Experiences of Persistent Liminality and Resource (Mis)Integration. *Journal of Service Research*, *0*(0). https://doi.org/10.1177/10946705231184610

Ojiako, U., Maguire, S., Koh, L., Grainger, T., & Wainwright, D. (2010). Softer perspectives on enhancing the patient experience using IS/IT. *International Journal of Health Care Quality Assurance*, *23*(2), 187–208. https://doi.org/10.1108/09526861011017102

Oliver, R. (1997). *Satisfaction: A Behavioral Perspective on the Consumer*. McGraw Hill. https://books.google.pt/books?id=iCeQQgAACAAJ

Olsson, K., Näslund, U., Nilsson, J., & Hörnsten, Å. (2018). Patients' experiences of the transcatheter aortic valve implantation trajectory: A grounded theory study. *Nursing Open*, *5*(2), 149–157. https://doi.org/10.1002/nop2.124

Orszag, P. (2011). How Health Care Can Save or Sink America: The Case for Reform and Fiscal Sustainability. *Foreign Affairs*, *90*(4), 42–56.

Osei-Frimpong, K., & Owusu-Frimpong, N. (2017). Value Co-Creation in Health Care: A Phenomenological Examination of the Doctor-Patient Encounter. *Journal of Nonprofit and Public Sector Marketing*, *29*(4), 365–384. https://doi.org/10.1080/10495142.2017.1326356

Osei-Frimpong, K., Wilson, A., & Owusu-Frimpong, N. (2015). Service experiences and dyadic value co-creation in healthcare service delivery: A CIT approach. *Journal of Service Theory and*

Practice, *25*(4), 443–462. https://doi.org/10.1108/JSTP-03-2014-0062

Ostrom, A, Bitner, M. J., Brown, S., Burkhard, K., Goul, M., Smith-Daniels, V., Demirkan, H., & Rabinovich, E. (2010). Moving forward and making a difference: Research priorities for the science of service. *Journal of Service Research*, *13*(1), 4–36. https://doi.org/10.1177/1094670509357611

Ostrom, A., Parasuraman, A., Bowen, D., Patrício, L., & Voss, C. (2015). Service Research Priorities in a Rapidly Changing Context. *Journal of Service Research*, *18*(2), 127–159. https://doi.org/10.1177/1094670515576315

Otani, K., Waterman, B., Faulkner, K., Boslaugh, S., Burroughs, T., & Dunagan, W. (2009). Patient satisfaction: focusing on "excellent". *Journal of Healthcare Management / American College of Healthcare Executives*, *54*(2), 93.

Ou, Y., de Vries, L., Wiesel, T., & Verhoef, P. (2013). The Role of Consumer Confidence in Creating Customer Loyalty. *Journal of Service Research*, *17*(3), 339–354. https://doi.org/10.1177/1094670513513925

Oujidi, W., Sekhsoukh, R., Harrar, Y., & Mehdi, M. (2022). Study of variation glycated haemoglobin in diabetic patients using PCA method. Case study: Moroccan eastern region. *Annals of Medicine and Surgery (2012)*, *81*, 104459. https://doi.org/10.1016/j.amsu.2022.104459

Ouschan, R., Sweeney, J., & Johnson, L. (2000). Dimensions of patient empowerment: implications for professional services marketing. *Health Marketing Quarterly*, *18*(1–2), 99–114. https://doi.org/10.1300/J026v18n01_08

Padilla, T. (2017). Kindness: At the Center of Patient Experience Strategies. *Journal of Healthcare Management*, *62*(4), 229–233. https://doi.org/10.1097/JHM-D-17-00083

Padma, R., & Sai, P. (2009). A conceptual framework of service quality in healthcare: Perspectives of Indian patients and their attendants. *Benchmarking: An International Journal*, *16*(2), 157-191. https://doi.org/10.1108/14635770910948213

Palmer, M. (1993). Putting Things in Even Better Order: The Advantages of Canonical Correspondence Analysis. *Ecology*, *74*(8), 2215–2230.

https://doi.org/https://doi.org/10.2307/1939575

Palumbo, R., Cosimato, S., & Tommasetti, A. (2017a). Dream or reality ? A recipe for sustainable and innovative health care ecosystems. *The TQM Journal*, *29*(6), 847–862. https://doi.org/10.1108/TQM-02-2017-0023

Palumbo, R., Annarumma, C., & Musella, M. (2017b). Exploring the meaningfulness of healthcare organizations: a multiple case study. *International Journal of Public Sector Management*, *30*(5), 503–518. https://doi.org/10.1108/IJPSM-10-2016-0174

Panella, M., Marchisio, S., & Di Stanislao, F. (2003). Reducing clinical variations with clinical pathways: Do pathways work? *International Journal for Quality in Health Care*, *15*(6), 509–521. https://doi.org/10.1093/intqhc/mzg057

Pansari, A., & Kumar, V. (2017). Customer engagement: the construct, antecedents, and consequences. *Journal of the Academy of Marketing Science*, *45*(3), 294–311. https://doi.org/10.1007/s11747-016-0485-6

Parasuraman, A., Zeithaml, V., & Berry, L. (1988). Servqual: A Multiple-Item Scale For Measuring Consumer Perc. In *Journal of Retailing, 64*(1), 12-40

Parasuraman, A., Zeithaml, V., & Berry, L. (1985). A Conceptual Model of Service Quality and Its Implications for Future Research. *Journal of Marketing*, *49*(4), 41–50. https://doi.org/10.2307/1251430

Park, M., Cho, H., Johnson, K., & Yurchisin, J. (2017). Use of behavioral reasoning theory to examine the role of social responsibility in attitudes toward apparel donation. *International Journal of Consumer Studies*, *41*, 333–339. https://doi.org/10.1111/ijcs.12347

Park, Y. R., Lee, Y., Lee, G., Lee, J. H., & Shin, S. Y. (2015). Smartphone applications with sensors used in a tertiary hospital—current status and future challenges. *Sensors, 15*(5), 9854–9869. https://doi.org/10.3390/s150509854

Parker, S., & Heapy, J. (2006). *The journey to the interface: How public service design can connect users to reform*. London, UK: Demos.

Parkinson, J., Schuster, L., Mulcahy, R., & Taiminen, H. (2017). Online support for vulnerable

consumers: a safe place? *Journal of Services Marketing*, *31*(4–5), 412–422. https://doi.org/10.1108/JSM-05-2016-0197

Patrício, L., De Pinho, N, Teixeira, J., & Fisk, R. (2018). Service Design for Value Networks: Enabling Value Cocreation Interactions in Healthcare. *Service Science*, *10*(1), 76–87. https://doi.org/10.1287/serv.2017.0201

Patrício, L., Fisk, R., e Cunha, J., & Constantine, L. (2011). Multilevel service design: From customer value constellation to service experience blueprinting. *Journal of Service Research*, *14*(2), 180–200. https://doi.org/10.1177/1094670511401901

Patrício, L., Fisk, R.., & Falcão E Cunha, J. (2008). Designing multi-interface service experiences: The service experience blueprint. *Journal of Service Research*, *10*(4), 318–334. https://doi.org/10.1177/1094670508314264

Patrick,D; Guyatt, G and Acquadro, C. (2011). Patient-reported outcomes. In S. Higgins, J; Green (Ed.), *Cochrane Hanbook for Systematic Reviews*. Cochrane Collaboration. https://doi.org/https://doi.org/10.1002/9780470712184.ch17

Patton, M. (2002). Two Decades of Developments in Qualitative Inquiry: A Personal, Experiential Perspective. *Qualitative Social Work*, *1*(3), 261–283. https://doi.org/10.1177/1473325002001003636

Payne, A., & Frow, P. (2005). A strategic framework for customer relationship management. *Journal of Marketing*, *69*, 167–176.

Pemberton, S., & Richards, H. (2013). A vision of the future for patient experience. *Nursing Times*, *109*(33–34), 19–21.

Perren, R., & Kozinets, R. (2017). Lateral Exchange Markets: How Social Platforms Operate in a Networked Economy. *Journal of Marketing*, *82(1), 20-36*. https://doi.org/10.1509/jm.14.0250

Pham, T., Sweeney, J., & Soutar, G. (2019). Customer value cocreation activities: An exploration of psychological drivers and quality of life outcomes. *Journal of Service Theory and Practice*, *29*(3), 282–308. https://doi.org/10.1108/JSTP-07-2018-0163

Pieters, R., Baumgartner, H., & Allen, D. (1995). A means-end chain approach to consumer goal structures. *International Journal of Research in Marketing*, *12*(3), 227–244. https://doi.org/https://doi.org/10.1016/0167-8116(95)00023-U

Pine, B. & Gilmore, J. (1998). Welcome to the Experience Economy. *Harvard Business Review*, *76*(4), 97–105. https://hbr.org/1998/07/welcome-to-the-experience-economy

Platonova, E. Kennedy, K. & Shewchuk, R. (2008). Understanding patient satisfaction, trust, and loyalty to primary care physicians. *Medical Care Research and Review : MCRR*, *65*(6), 696–712. https://doi.org/10.1177/1077558708322863

Pöllänen, S., & Weissmann-Hanski, M.(2020). Hand-made well-being: Textile crafts as a source of eudaimonic well-being. *Journal of Leisure Research*, *51*(3), 348–365. https://doi.org/10.1080/00222216.2019.1688738

Pollard, E., & Lee, P. (2003). Child well-being: A systematic review of the literature. *Social Indicators Research*. https://doi.org/10.1023/A:1021284215801

Polsa, P., Fuxiang, W., S Ksj Rvi, M., & Shuyuan, P. (2013). Cultural values and health service quality in China. *International Journal of Health Care Quality Assurance*, *26*(1), 55–73.

Ponsignon, F., Smart, A., & Phillips, L. (2018). A customer journey perspective on service delivery system design: insights from healthcare. *International Journal of Quality & Reliability Management*, *35*(10), 2328–2347. https://doi.org/https://doi.org/10.1108/IJQRM-03-2018-0073

Ponsignon, F., Smart, A., Williams, M., & Hall, J. (2015). Healthcare experience quality: An empirical exploration using content analysis techniques. *Journal of Service Management*, *26*(3), 460–485. https://doi.org/10.1108/JOSM-10-2014-0265

Poppleton, S., Briner, R., & Kiefer, T. (2008). The roles of context and everyday experience in understanding work-non-work relationships: A qualitative diary study of white- and blue-collar workers. *Journal of Occupational and Organizational Psychology*, *81*, 481–502. https://doi.org/10.1348/096317908X295182

Porter, M. (2014). Value-Based Health Care Delivery. *Value Based Health Care Seminar*, *Januray*

15. https://www.isc.hbs.edu/health-care/health-care-courses/Pages/vbhcd-intensive-seminars.aspx

Porter, M., & Lee, T. (2013). The Strategy That Will Fix Health Care. *Harvard Business Review*, *91*(10), 50–70.

Porter, M., & Teisberg, E. (2006). Redefining Health Care: Creating Value-Based Competition on Results. *Harvard Business School Press*.

Prahalad, C., & Ramaswamy, V. (2004). Co-creating unique value with customers. *Strategy & Leadership*, *32*(3), 4–9. https://doi.org/10.1108/10878570410699249

Preece, J., & Ghozati, K. (2001). Observations and explorations of empathy online. *The Internet and Health Communication: Experience and Expectations*. Thousand Oaks: Sage Publications Inc, 2001:237–60 https://doi.org/10.4135/9781452233277.n11

Pressman, S., Kraft, D., & Bowlin, S. (2013). Well-being: Physical, psychological, social. In *Encyclopedia of behavioral medicine* (pp. 2047–2052).

Prilleltensky, I., & Prilleltensky, O. (2006). Promoting well-being : linking personal, organizational, and community change. John Wiley & Sons Inc.. https://doi.org/LK - https://worldcat.org/title/65063814

Proudfoot, K. (2022). Inductive/Deductive Hybrid Thematic Analysis in Mixed Methods Research. *Journal of Mixed Methods Research*, *17*(3), 308–326. https://doi.org/10.1177/15586898221126816

Provan, K., & Kenis, P. (2008). Modes of Network Governance: Structure, Management, and Effectiveness. *Journal of Public Administration Research and Theory*, *18*(2), 229–252 https://doi.org/10.1093/jopart/mum015

Purcărea, T. (2016). Creating the ideal patient experience. *Journal of Medicine and Life*, *9*(4), 380–385. https://doi.org/10.22336/jml.2016.0411

Purcarea, V. (2019). The impact of marketing strategies in healthcare systems. *Journal of Medicine and Life*, *12*(2), 93–96. https://doi.org/10.25122/jml-2019-1003

Purcărea, V., Rațiu, M., Purcărea, T., & Davila, C. (2008). Offering memorable patient experience through creative, dynamic marketing strategy. *Journal of Medicine and Life*, *1*(2), 198–205. http://www.scopus.com/inward/record.url?eid=2-s2.0-73049114932&partnerID=40&md5=9d5234b1e056918f7615b359cfe7e8a6

Pusic, A., Klassen, A., Snell, L., Cano, S., McCarthy, C., Scott, A., Cemal, Y., Rubin, L., & Cordeiro, P. (2012). Measuring and managing patient expectations for breast reconstruction: impact on quality of life and patient satisfaction. *Expert Review of Pharmacoeconomics & Outcomes Research*, *12*(2), 149–158. https://doi.org/10.1586/erp.11.105

RACGP - Royal Australian College of General Practice -Diabetes Australia. (2020). *Management of type 2 diabetes: a handbook for general practice*. https://www.racgp.org.au/FSDEDEV/media/documents/Clinical Resources/Guidelines/Diabetes/General-practice-management-of-type-2-diabetes_1.pdf

Radu, G., Solomon, M., Gheorghe, C., Hostiuc, M., Bulescu, I., & Purcarea, V. (2017). The adaptation of health care marketing to the digital era. *Journal of Medicine and Life*, *10*(1), 44–46.

Raharjo, H., Guglielmetti, R., Di Pietro, L., & Toni, M. (2016). Do satisfied employees lead to satisfied patients? An empirical study in an Italian hospital. *Total Quality Management & Business Excellence*, *27*, 1–22. https://doi.org/10.1080/14783363.2016.1190641

Ramsey, L., Sheard, L., Lawton, R., & O'Hara, J. (2019). How do healthcare staff respond to patient experience feedback online? A typology of responses published on Care Opinion. *Patient Experience Journal*, *6*(2), 42–50. https://doi.org/10.35680/2372-0247.1363

Rashid, W., & Jusoff, H. (2009). Service quality in health care setting. *International Journal of Health Care Quality Assurance*, *22*(5), 471–482. https://doi.org/10.1108/09526860910975580

Rathert, C., Wyrwich, M., & Boren, S. (2013). Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review: MCRR*, *70*(4), 351–379. https://doi.org/10.1177/1077558712465774

Rawson, A., Duncan, E., & Jones, C. (2013). The truth about customer experience. *Harvard*

Business Review, *September 2013*, 91–98.

Revenson, T. & Felton, B. (1989). Disability and coping as predictors of psychological adjustment to rheumatoid arthritis. *Journal of Consulting and Clinical Psychology* , 57(3), 344–348. https://doi.org/10.1037/0022-006X.57.3.344

Rhoades, D., McFarland, K., Finch, W., & Johnson, A. (2001). Speaking and interruptions during primary care office visits. *Family Medicine*, *33*(7), 528–532.

Rich, N., & Piercy, N. (2013). Losing patients: a systems view on healthcare improvement. *Production Planning & Control*, *24*(10–11), 962–975.

Richardson, A. (2015). *Using Customer Journey Maps to Improve Customer Experience*. https://api.semanticscholar.org/CorpusID:168296849

Richardson, S., Casey, M., & Hider, P. (2007). Following the patient journey: Older persons' experiences of emergency departments and discharge. *Accident and Emergency Nursing*, *15*(3), 134–140. https://doi.org/10.1016/j.aaen.2007.05.004

Richter, J., & Muhlestein, D. (2017). Patient experience and hospital profitability: Is there a link? *Health Care Management Review*, *42*(3), 247–257. https://doi.org/10.1097/HMR.0000000000000105

Ritchie, C., Ehrlich, C., & Sterling, M. (2017). Living with ongoing whiplash associated disorders: A qualitative study of individual perceptions and experiences. *BMC Musculoskeletal Disorders*, *18*(1), 1–9. https://doi.org/10.1186/s12891-017-1882-9

Robinson, O. (2023). Probing in qualitative research interviews: Theory and practice. *Qualitative Research in Psychology.* 20. 1-16. https://doi.org /10.1080/14780887.2023.2238625.

Robson, K., Plangger, K., Kietzmann, J., McCarthy, I., & Pitt, L. (2014). Understanding Gamification of Consumer Experiences. *Advances in consumer research. Association for Consumer Research.* https://api.semanticscholar.org/CorpusID:39963972

Rodriguez, A., & King, N. (2014). Sharing the care: The key-working experiences of professionals and the parents of life-limited children. *International Journal of Palliative Nursing*, *20*(4), 165–171. https://doi.org/10.12968/ijpn.2014.20.4.165

Rose, G. (2016). *Visual Methodologies: An Introduction to the Interpretation of Visual Materials*, 4(1). SAGE Publications.

Rosenbaum, M. (2015). Transformative service research: research that matters. *Service Industries Journal*, *35*(15–16), 801–805. https://doi.org/10.1080/02642069.2015.11096388

Rosenbaum, M., & Smallwood, J. (2013). Cancer resource centers as third places. *Journal of Services Marketing*, *27*. https://doi.org/10.1108/JSM-10-2011-0147

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social Learning Theory and the Health Belief Model. *Health Education Quarterly*, *15*(2), 175–183. https://doi.org/10.1177/109019818801500203

Rozenes, S., & Cohen, Y. (2017). *Handbook of Research on Strategic Alliances and Value Co-Creation in the Service Industry*. IGI Global, Hershey, PA.

Rupert, D. J., Moultrie, R., Read, J., Amoozegar, J., Bornkessel, A., O'Donoghue, A., & Sullivan, H. (2014). Perceived healthcare provider reactions to patient and caregiver use of online health communities. *Patient Education and Counseling*, *96*(3), 320–326. https://doi.org/10.1016/j.pec.2014.05.015

Rush, K. L., Oelke, N. D., Shay, M., & Pedersen, C. (2017). Seeing the rural healthcare journeys of older adults with atrial fibrillation through a photographic lens. *Chronic Illness*, *13*(3), 204–216. https://doi.org/10.1177/1742395316670462

Russel, R., Johnson, D., & White, S. (2015). Patient perceptions of quality: analyzing patient satisfaction surveys. *International Journal of Operations and Production Management*, *35*(8), 1158–1181.

Russel, S. (2013). *Patients´experiences: Top heavy with research Literature Review*. Fitzroy North, Australia: Research Matters.

Russell-Bennett, R., Glavas, C., Previte, J., Härtel, C., & Smith, G. (2017). Designing a medicalized wellness service: balancing hospitality and hospital features. *The Service Industries Journal*, *37*(9–10), 657–680. https://doi.org/10.1080/02642069.2017.1354988.

Russell, R., Johnson, D., & White, S.(2015). Patient perceptions of quality: analyzing patient

satisfaction surveys. *International Journal of Operations & Production Management*, *35*(8), 1158–1181. https://doi.org/10.1108/IJOPM-02-2014-0074

Rust, R., & Oliver, R. (1994). Service Quality: Insights and Managerial Implications from the Frontier. In *Service Quality: New Directions in Theory and Practice,* (pp. 1–19). Sage Publications, Thousand Oaks.

Rust, R. & Oliver, R. (2000). Should we delight the customer? *Journal of the Academy of Marketing Science*, *28*(1), 86–94. https://doi.org/10.1177/0092070300281008

Ryan, M., Kinghorn, P., Entwistle, V. & Francis, J. (2014). Valuing patients' experiences of healthcare processes: Towards broader applications of existing methods. *Social Science and Medicine*, *106*, 194–203. https://doi.org/10.1016/j.socscimed.2014.01.013

Ryan, R., & Deci, E. (2008). Self-determination theory and the role of basic psychological needs in personality and the organization of behavior. In *Handbook of personality: Theory and research, 3rd ed.* (pp. 654–678). The Guilford Press.

Ryff, C., & Keyes, C. (1995). The Structure of Psychological Well-Being Revisited. *Journal of Personality and Social Psychology*, *69*, 719–727. https://doi.org/10.1037/0022-3514.69.4.719

Salisbury, C., Wallace, M., & Montgomery, A. (2010). Patients' experience and satisfaction in primary care: Secondary analysis using multilevel modelling. *BMJ (Online)*, *341:c5004*, 1–8. https://doi.org/10.1136/bmj.c5004

Samal, A., Misra, L. & Pradhan, B. (2017). Nexus between hospitality and healthcare for enhancing patient's experiences: Lessons to learn from the hotel industry. *International Journal of Economic Research*, *14*(17), 503–520.

Sanders, D., Kydd, R., Morunga, E., & Broadbent, E. (2011). Differences in patients' perceptions of Schizophrenia between Māori and New Zealand Europeans. *The Australian and New Zealand Journal of Psychiatry*, *45*(6), 483–488. https://doi.org/10.3109/00048674.2011.561479

Sandy Kuo, M.; Karen E. Huang; Scott A. Davis, M; Steven R. Feldman, M. (2015). Rosacea Patient

Journey. *Cutis*, *95*(January), 37–43. https://www.mdedge.com/sites/default/files/issues/articles/CT095010037.pdf

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Schildmeijer, K., Frykholm, O., & Ekstedt, M. (2018). Not a Straight Line V Patient ' s Experiences of Prostate Cancer and Their Journey Through the Healthcare System. *Cancer Nursing*, *00*(0), 1–8. https://doi.org/10.1097/NCC.0000000000000559

Schmitt, B. (2003). *Customer Experience Management: A Revolucionary Approach to Connecting with Your Customers*. The Free Press.

Schneider, B., & Bowen, D. (1999). Understanding customer delight and outrage. *Sloan Management Review*, *41*, 35-45. https://sloanreview.mit.edu/article/understanding-customer-delight-and-outrage. Accessed 25 April 2023.

Schneider, K., O´Donnell, B., & Dean, D. (2009). Prevalence of multiple chronic conditions in the United States' Medicare population. *Health Qual Life Outcomes*, *7*(82), 1-11.

Schrijvers, G., van Hoorn, A., & Huiskes, N. (2012). The care pathway: concepts and theories: an introduction. *International Journal of Integrated Care*, *12*(Spec Ed Integrated Care Pathways), e192. https://doi.org/10.1056/NEJMp1011024

Shah, D., Rust, R., Parasuraman, A., Staelin, R., & Day, G. (2006). The Path to Customer Centricity. *Journal of Service Research, 9(2)*, 113–124. https://doi.org/10.1177/1094670506294666

Shale, S. (2013). Patient experience as an indicator of clinical quality in emergency care. *Clinical Governance: An International Journal*, *18*(4), 285–292. https://doi.org/10.1108/CGIJ-03-2012-0008

Shaw, W., Zaia, A., Pransky, G., Winters, T., & Patterson, W. (2005). Perceptions of provider communication and patient satisfaction for treatment of acute low back pain. *Journal of*

Occupational and Environmental Medicine, *47*(10), 1036–1043. https://doi.org/10.1097/01.jom.0000172863.26222.14

Sheridan, J., & Chamberlain, K. (2011). The power of things. *Qualitative Research in Psychology*, *8*, 315–332. https://doi.org/10.1080/14780880903490821

Sheridan, N., Kenealy, T., Kuluski, K., Mckillop, A., Parsons, J., & Wong-cornall, C. (2016). *Are Patient and Carer Experiences Mirrored in the Practice Reviews of Self-management Support (PRISMS) Provider Taxonomy ? 17*(2), 1–8.

Sheth, J., Sisodia, R., & Sharma, A. (2000). The antecedents and consequences of customer-centric marketing. *Journal of the Academy of Marketing Science*, *28*(1), 55–66. https://doi.org/10.1177/0092070300281006

Siebert, A., Gopaldas, A., Lindridge, A., & Simões, C. (2020). Customer Experience Journeys: Loyalty Loops Versus Involvement Spirals. *Journal of Marketing*, *84*(4), 45–66. https://doi.org/10.1177/0022242920920262

Silvera, G., Haun, C., & Wolf, J. (2017). Patient Experience: The field and future. *Patient Experience Journal*, *4*(1), 7–22. https://doi.org/10.35680/2372-0247.1220

Simon, A. (1996). *The sciences of the artificial* (3rd ed.). Cambridge: MIT Press.

Simon, M., Driest, F., & Wilms, T. (2016). Driving Customer-Centric Growth: A Practical Roadmap: The Pivotal Role of Insights and Analytics In the Customer-Centric Organization. *Journal of Advertising Research*, *56*, 159–168. https://doi.org/10.2501/JAR-2016-029.

Sińska, B., Kucharska, A., Panczyk, M., Matejko, B., Traczyk, I., Harton, A., & Jaworski, M. (2023). Identification of Sociodemographic and Clinical Factors Influencing the Feeling of Stigmatization in People with Type 1 Diabetes. *Healthcare*, *11*(15). https://doi.org/10.3390/healthcare11152185.

Smailhodzic, E., Hooijsma, W., Boonstra, A., & Langley, D. (2016). Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals. *BMC Health Services Research*, *16*(1), 442. https://doi.org/10.1186/s12913-016-1691-0

Smedley, R., & Coulson, N. (2017). A thematic analysis of messages posted by moderators within health-related asynchronous online support forums. *Patient Education and Counseling*, *100*(9), 1688–1693. https://doi.org/10.1016/j.pec.2017.04.008

Smith, J., & Osborn, M. (2004). Interpretative Phenomenological Analysis. In *Doing Social Psychology Research* (pp. 229–254). https://doi.org/https://doi.org/10.1002/9780470776278.ch10

Smith, S., & Weldring, T. (2013). Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Health Services Insights*, 61. https://doi.org/10.4137/HSI.S11093

Sofaer, S., Crofton, C., Goldstein, E., Hoy, E., & Crabb, J. (2005). What do consumers want to know about the quality of care in hospitals? *Health Services Research*, *40*, 2018–2036. https://doi.org/10.1111/j.1475-6773.2005.00473.x.

Sorra, J., Khanna, K., Dyer, N., Mardon, R., & Famolaro, T. (2012). *and Patients ' Assessments of Hospital Care*. *8*(3), 131–139. https://doi.org/10.1097/PTS.0b013e31825ca46

Spanjol, J., Cui, A., Nakata, C., Sharp, L., Crawford, S., Xiao, Y., Watson-Manheim, M. (2015). Co-Production of Prolonged, Complex, and Negative Services: An Examination of Medication Adherence in Chronically Ill individuals. *Journal of Service Research*, *18*(3), 284–302. https://doi.org/https://doi.org/10.1177/1094670515583824

Spat, S., Höll, B., Beck, P., Chiarurgi, F., Kontogiannis, V., Spanakis, M., Manousos, D., & Pieber, T. (2012). A Mobile Android-Based Application for In-hospital Glucose Management in Compliance with the Medical Device Directive for Software BT - Wireless Mobile Communication and Healthcare. In K. S. Nikita, J. C. Lin, D. I. Fotiadis, & M.-T. Arredondo Waldmeyer (Eds.), *International Conference on Wireless Mobile Communication and Healthcare* (pp. 211–216). Springer Berlin Heidelberg.

Spicker, P. (2011). Ethical Covert Research. *Sociology*, *45*(1), 118–133. https://doi.org/10.1177/0038038510387195

Serviço Português de Nefrologia (SPN). (2019). Portuguese Registry of Dialysis and Transplantation 2019. In *SPN* (Volume 4, Issue 1).

https://www.spnefro.pt/assets/relatorios/tratamento_doenca_terminal/er2020_registo.pdf. Accessed 26 March 2024.

Srivastava, R., & Thomas, G. (2010). Managing brand performance: Aligning positioning, execution and experience. *Journal of Brand Management*, *17*(7), 465–471. https://doi.org/10.1057/bm.2010.11

Srivastava, R., & Shervani, T. (1999). Marketing, Business Processes, and Shareholder Value: An Organizationally Embedded View of Marketing Activities and the Discipline of Marketing. *Journal of Marketing*, *63*(4), 168–179.

Stang, A., & Wong, B. (2014). Patients teaching patient safety: The challenge of turning negative patient experiences into positive learning opportunities. *BMJ Quality & Safety*, *24,* 4-6. https://doi.org/10.1136/bmjqs-2014-003655

Staniszewska, S., Boardman, F., Gunn, L.., & Seers K., Roberts, J., Clay, D., Bullocck, I., O' Flyn, N. (2014). The Warwick Patient Experiences Framework: patient-based evidence in clinical guidelines. *The International Journal for Quality in Health Care*, *26*(2), 151–157. https://doi.org/10.1093/intqhc/mzu003

Staniszewska, S., & Bullock, I. (2012). Can we help patients have a better experience? Implementing NICE guidance on patient experience. *Evidence Based Nursing*, *15*(4), 99. https://doi.org/http://dx.doi.org/10.1136/eb-2012-10098

Stauss, B., & Weinlich, B. (1997). Process-oriented measurement of service quality. *European Journal of Marketing*, *31*(1), 33–55. https://doi.org/10.1108/03090569710157025

Stavros, C., & Westberg, K. (2009). Using triangulation and multiple case studies to advance relationship marketing theory. *Qualitative Market Research*, *12*(3), 307–320. https://doi.org/10.1108/13522750910963827

Stellefson M, Chaney B, Barry A, Chavarria E, Ten- nant B, Walsh-Childers K, Sriram PS, Z. (2013). Web 2.0 chronic disease self-management for older adults: a systematic review. *Journal of medical Internet research, 15*(2), e35. https://doi.org/10.2196/jmir.2439

Stempel, G. (1952). Research in Brief. *Journalism Quarterly*, *29*(3), 333–334.

https://doi.org/10.1177/107769905202900312

Stempniak, M. (2013). The Patient Experience: Taking it to the next level. *Hospitals Health Networks*, *87*(4), 41–47.

Stewart, D., Shamdasani, P., & Rook, D. (2007). Focus groups: Theory and practice, 2nd ed. In *Focus groups: Theory and practice, 2nd ed.* Sage Publications, Inc. https://doi.org/10.4135/9781412991841

Stewart Loane, S., Webster, C., & D'Alessandro, S. (2014). Identifying Consumer Value Co-created through Social Support within Online Health Communities. *Journal of Macromarketing*, *35*(3), 353–367. https://doi.org/10.1177/0276146714538055

Stone, D., & Devine, J. (2013). *From Moments to Journeys: A Paradigm Shift in Customer Experience Excellence*. https://www.mckinsey.com/capabilities/growth-marketing-and-sales/our-insights/from-moments-to-journeys-a-paradigm-shift-in-customer-experience-excellence

Stone, R. (2018). Code Lavender: A tool for staff support. *Nursing2024*, *48*(4). https://doi.org/10.1097/01.NURSE.0000531022.93707.08

Storbacka, K., Brodie, R., Böhmann, T., Maglio, P., & Nenonen, S. (2016). Actor engagement as a microfoundation for value co-creation. *Journal of Business Research*, *69*(8), 3008–3017. https://doi.org/https://doi.org/10.1016/j.jbusres.2016.02.034

Strandvik, T., & Heinonen, K. (2015). Essentials of Customer Dominant Logic. In C. von K. Johanna Gummerus (Ed.), *The Nordic School: Service Marketing and Management for the Future* (pp. 111–127). CERS, Hanken School of Economics, Helsinki, Finland.

Suess, C., & Mody, M. (2017). Hospitality healthscapes: A conjoint analysis approach to understanding patient responses to hotel-like hospital rooms. *International Journal of Hospitality Management*, *61*, 59–72. https://doi.org/10.1016/j.ijhm.2016.11.004

Sun, B., Adams, J., Orav, E., Rucker, D., Brennan, T., & Burstin, H. (2000). Determinants of patient satisfaction and willingness to return with emergency care. *Annals of Emergency Medicine*, *35*(5), 426–434.

Surprenant, C., & Solomon, M. (1987). Predictability and Personalization in the Service Encounter. *Journal of Marketing*, *51(2)*, 86–96. https://doi.org/10.1177/002224298705100207

Swallmeh, E., Byers, V., & Arisha, A. (2018). Informing quality in emergency care: understanding patient experiences. *International Journal of Health Care Quality Assurance*, *31*(7), 704–717. https://doi.org/10.1108/IJHCQA-03-2017-0052

Swan, J., & Oliver, R. (1989). Postpurchase communications by consumers. *Journal of Retailing*, *65*(4), 516–533.

Sweeney, J., Danaher, T., & McColl-Kennedy, J. (2015). Customer Effort in Value Cocreation Activities: Improving Quality of Life and Behavioral Intentions of Health Care Customers. *Journal of Service Research*, *18*(3), 318–335. https://doi.org/10.1177/1094670515572128

Tabachnick, B., & Fidell, S. (1996). *Using multivariate statistics* (3rd ed). HarperCollins College Publishers. https://doi.org/LK - https://worldcat.org/title/318463745

Tallandini, M., & Scalembra, C. (2006). Kangaroo mother care and mother-premature infant dyadic interaction. *Infant Mental Health Journal*, *27*(3), 251–275. https://doi.org/10.1002/imhj.20091

Tax, S., McCutcheon, D., & Wilkinson, I. (2013). The Service Delivery Network (SDN): A Customer-Centric Perspective of the Customer Journey. *Journal of Service Research*, *16*(4), 454–470. https://doi.org/10.1177/1094670513481108

Tax, S., Smith, A., & Murali, C. (2011). Tangled web or a tidy knot? Assessing failure and recovery in a service network. *Naples Forum on Service*.

Tenderich, A., Tenderich, B., Barton, T., & Richards, S. (2018). What Are PWDs (People With Diabetes) Doing Online? A Netnographic Analysis. *Journal of Diabetes Science and Technology*, *13*(2), 187–197. https://doi.org/10.1177/1932296818813192

Thackeray, R., Neiger, B., Hanson, C., & McKenzie, J. (2008). Enhancing promotional strategies within social marketing programs: use of Web 2.0 social media. *Health Promotion Practice*, *9*(4), 338–343. https://doi.org/10.1177/1524839908325335

Theodoratou, M., Vassilopoulou, C., Giotsidi, V., Tsitsas, G., Flora, K., & Kougioumtzis, G. (2023). Psychological Distress and coping strategies of patients with Chronic Diseases. In *European Psychiatry* (Vol. 66, Issue Suppl 1, pp. S989-90). https://doi.org/10.1192/j.eurpsy.2023.2104

Thomas, D. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, *27*(2), 237–246. https://doi.org/10.1177/1098214005283748

Thorpe, K. (2005). The rise in health care spending and what to do about it: Disease prevention/health promotion approaches are key to slowing the rise in health care spending. *Health Affairs*, *24*(6), 1436–1445. https://doi.org/10.1377/hlthaff.24.6.1436

Tian, K., Sautter, P., Fisher, D., Fischbach, S., Luna-Nevarez, C., Boberg, K., Kroger, J., & Vann, R. (2014). Transforming Health Care: Empowering Therapeutic Communities through Technology-Enhanced Narratives. *Journal of Consumer Research*, *41*, 237–260. https://doi.org/10.1086/676311

Timko, C., & Janoff-Bulman, R. (1985). Attributions, vulnerability, and psychological adjustment: The case of breast cancer. *Health Psychology*, *4*(6), 521–544. https://doi.org/10.1037/0278-6133.4.6.521.

Tometich, D., Mosher, C., Hirsh, A., Rand, K., Johns, S., Matthias, M., Outcalt, S. Schneider, B. P., Mina, L., Storniolo, A., Newton, E., & Miller, K. (2018). Metastatic breast cancer patients' expectations and priorities for symptom improvement. *Supportive Care in Cancer*, *26*(11), 3781–3788. https://doi.org/10.1007/s00520-018-4244-8

Tonsaker, T., Bartlett, G., & Trpkov, C. (2014). Health information on the Internet Gold mine or minefield? Tag the good and bad. *Canadian Family Physician, 60*, 407–408. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4020634/pdf/0600407.pdf

Topaloglu, O., & Erkaya, Y. (2018). Nobody understands me! The need for empathy: Exploring the mind-set of consumers with medical problems. *International Journal of Pharmaceutical and Healthcare Marketing*, *12*(2), 146–157. https://doi.org/10.1108/IJPHM-05-2017-0022

Travlos, V., Bulsara, C., Patman, S., & Downs, J. (2016). A fine balance and a shared learning

journey: Exploring healthcare engagement through the experiences of youth with Neuromuscular Disorders. *NeuroRehabilitation*, *39*(4), 519–534. https://doi.org/10.3233/NRE-161383

Trenchard, K., Semlies, L., & Gierlinger, S. (2019). The digital revolution will see you now: transforming patient experience in the digital era. *Patient Experience Journal*, *6*(2), 12–15. https://doi.org/10.35680/2372-0247.1367

Trueblood, A., & Bonk, A. (2019). A Journey to Mission Experience: Measuring Mission Through the Eyes of the Patient. *Nurse Leader*, *17*(4), 315–320. https://doi.org/10.1016/j.mnl.2019.05.007

Tsai, L., Wang, K., Liang, S., Tsai, J., & Tsay, S. (2017). The lived experience of gynecologic cancer survivors in Taiwan. *Journal of Nursing Research*, *25*(6), 447–454. https://doi.org/10.1097/JNR.0000000000000229

Tsiotsou, R. (2016). A service ecosystem experience-based framework for sport marketing. *The Service Industries Journal*, *36*(11–12), 478–509. https://doi.org/10.1080/02642069.2016.1255731

Tustin, N. (2010). The role of patient satisfaction in online health information seeking. *Journal of Health Communication*, *15*(1), 3–17. https://doi.org/10.1080/10810730903465491

Ugalde, A., Blaschke, S., Boltong, A., Schofield, P., Aranda, S., Phipps-Nelson, J., Chambers, S. K., Krishnasamy, M., & Livingston, P. (2019). Understanding rural caregivers' experiences of cancer care when accessing metropolitan cancer services: A qualitative study. *BMJ Open*, *9*(7), 1–10. https://doi.org/10.1136/bmjopen-2018-028315

Urry, J. (2005). The Complexity Turn. *Theory, Culture & Society*, *22*(5), 1-14. https://doi.org/10.1177/0263276405057188

Vachon, B., Sherbrooke, U. De, Quesnel, L., & Camirand, M. (2017). Patients ' expectations and solutions for improving primary diabetes care. *International Journal of Health Care Quality Assurance*, *30*(6), 554–567. https://doi.org/10.1108/IJHCQA-07-2016-0106

Van Doorn, J., Lemon, K., Mittal, V., Nass, S., Pick, D., Pirner, P., & Verhoef, P. (2010). Customer

Engagement Behavior: Theoretical Foundations and Research Directions. *Journal of Service Research - J SERV RES*, *13*, 253–266. https://doi.org/10.1177/1094670510375599

Van Fleet, D. & Peterson, T. (2016). Improving healthcare practice behaviors: An exploratory study identifying effective and ineffective behaviors in healthcare. *International Journal of Health Care Quality Assurance*, *29*(2), 141–161. https://doi.org/10.1108/IJHCQA-07-2015-0089

Van Maanen, J. (2011). Ethnography as Work: Some Rules of Engagement. *Journal of Management Studies*, *48*(1), 218–234. https://doi.org/https://doi.org/10.1111/j.1467-6486.2010.00980.x

Van Oerle, S., Lievens, A., & Mahr, D. (2018). Value co-creation in online healthcare communities: The impact of patients' reference frames on cure and care. *Psychology and Marketing*, *35*(9), 629–639. https://doi.org/10.1002/mar.21111

Van Oostrom, S., Gijsen, R., Stirbu, I., Korevaar, J., Schellevis, F., Picavet, H.., & Hoeymans, N. (2016). Time Trends in Prevalence of Chronic Diseases and Multimorbidity Not Only due to Aging: Data from General Practices and Health Surveys. *PloS One*, *11*(8), e0160264. https://doi.org/10.1371/journal.pone.0160264

Vargo, S., Akaka, M., & Vaughan, C. (2017). Conceptualizing Value: A Service-ecosystem View. *Journal of Creating Value*, *3*(2), 117–124. https://doi.org/10.1177/2394964317732861

Vargo, S., & Lusch, R.(2004). Evolving to a New Dominant Logic for Marketing. *Journal of Marketing*, *68*(1), 1–17. https://doi.org/10.1509/jmkg.68.1.1.24036

Vargo, S., & Lusch, R. (2008). Service-dominant logic: contiuing the evolution. *Journal of Academy of Marketing Science*, *36*, 1–10. https://doi.org/10.1007/s11747-007-0069-6

Varnali, K. (2018). Understanding customer journey from the lenses of complexity theory. *Service Industries Journal*, *0*(0), 1–16. https://doi.org/10.1080/02642069.2018.1445725

Verhoef, P., Lemon, K., Parasuraman, A., Roggeveen, A., Tsiros, M., & Schlesinger, L. (2009). Customer Experience Creation: Determinants, Dynamics and Management Strategies. *Journal of Retailing*, *85*, 31–41. https://doi.org/10.1016/j.jretai.2008.11.001

Vogus, T., & Mcclelland, L. (2016). Human Resource Management Review When the customer is

the patient : Lessons from healthcare research on patient satisfaction and service quality ratings☆. *Human Resource Management Review*, *26*(1), 37–49. https://doi.org/10.1016/j.hrmr.2015.09.005

Voorhees, C., Fombelle, P., Gregoire, Y., Bone, S., Gustafsson, A., Sousa, R., & Walkowiak, T. (2017). Service encounters, experiences and the customer journey: Defining the field and a call to expand our lens. *Journal of Business Research*, *79*, 269–280. https://doi.org/10.1016/j.jbusres.2017.04.014

Voss, C., & Zomerdijk, L. (2007). Innovation in Experiential Services - An Empirical View. In *Innovation in services* (pp. 97–134). London, UK:DTI.

Vu, M., White, A., Kelley, V., Hopper, J., & Liu, C. (2016). Hospital and health plan partnerships: The affordable care act's impact on promoting health and wellness. *American Health and Drug Benefits*, *9*(5), 269–277.

Wahyuni, D. (2012). The Research Design Maze : Understanding Paradigms , Cases , Methods and Methodologies. *Journal of Applied Management Accounting Research (JAMAR)*, *10*(1), 69–80.

Waldner, M., & Olson, J.(2007). Taking the patient to the classroom: applying theoretical frameworks to simulation in nursing education. *International Journal of Nursing Education Scholarship*, *4*(1). https://doi.org/10.2202/1548-923X.1317

Walker, S., Andrew, S., Hodson, M., & Roberts, C. (2017). Stage 1 development of a patient-reported experience measure (PREM) for chronic obstructive pulmonary disease (COPD). *Npj Primary Care Respiratory Medicine*, *27*(1), 1–9. https://doi.org/10.1038/s41533-017-0047-5

Walther, J. (2007). Selective self-presentation in computer-mediated communication: Hyperpersonal dimensions of technology, language, and cognition. *Computers in Human Behavior*, *23*(5), 2538–2557. https://doi.org/10.1016/j.chb.2006.05.002

Ward, K., Rolland, E., & Patterson, R. (2005). Improving outpatient health care quality: understanding the quality dimensions. *Health Care Management Review*, *30*(4), 361–371. https://doi.org/10.1097/00004010-200510000-00010

Wasko, M., & Faraj, S. (2005). Why Should I Share? Examining Social Capital and Knowledge Contribution in Electronic Networks of Practice. *MIS Quarterly*, *29*(1), 35–57. https://doi.org/10.2307/25148667

Webb, S., Kristensen, J., Nordenström, A., Vitali, D., Amodru, V., Wiehe, L., & Bolz-Johnson, M. (2022). Patient journey experiences may contribute to improve healthcare for patients with rare endocrine diseases. *Endocrine Connections*, *11*(12), e220385. https://doi.org/10.1530/EC-22-0385

Webster, C., Jowsey, T., Lu, L. M., Henning, M, Verstappen, A., Wearn, A., Reid, P. M., Merry, A. F., & Weller, J. (2019). Capturing the experience of the hospital-stay journey from admission to discharge using diaries completed by patients in their own words: A qualitative study. *BMJ Open*, *9*(3), 1-10. https://doi.org/10.1136/bmjopen-2018-027258

Wechsler, J. (2012). Reflections on Service Design, Frameworks, and the Service Organization. *Design Management Review*, *23*(2), 58–64. https://doi.org/10.1111/j.1948-7169.2012.00186.x

Weech-Maldonado, Elliot, M. Pradhan, R., Schiller, C., Hall, A., Hays, R. (2012). Can hospital cultural competency reduce disparities in patient experiences with care? *Medical Care*, *50*(Suppl.), s48–s55. https://doi.org/10.1097/MLR.0b013e3182610ad1

Weiss, M., & Tyink, S. (2009). Creating sustainable ideal patient experience cultures. *Medsurg nursing: official journal of the Academy of Medical-Surgical Nurs*es, *18*(4), 249–252

Welbourne, J., Blanchard, A., & Wadsworth, M. (2013). Motivations in virtual health communities and their relationship to community, connectedness and stress. *Computers in Human Behavior*, *29*(1), 129–139. https://doi.org/https://doi.org/10.1016/j.chb.2012.07.024

Wennberg, J., Bronner, K., Skinner, J., Fisher, E., & Goodman, D. (2009). Inpatient care intensity and patients' ratings of their hospital experiences. *Health Affairs*, *28*(1), 103–112. https://doi.org/10.1377/hlthaff.28.1.103

Werder, M. (2015). Health information technology: A key ingredient of the patient experience. *Patient Experience Journal*, *2*(1), 143–147. http://pxjournal.org/journal/vol2/iss1/19

Wessel, M., Lynoe, N., & Juth, N. et al. (2012). The tip of an iceberg? A cross sectional study of the general public´s experiences of reporting healthcare complaints in Stockholm, Sweden. *BMJ Open*, *2:e000489*.

Westbrook, R., & Oliver, R. (1991). The Dimensionality of Consumption Emotion Patterns and Consumer Satisfaction. *Journal of Consumer Research*, *18*(1), 84–91. https://doi.org/10.1086/209243

Whaley-Connell, A., Nistala, R., & Chaudhary, K. (2011). The importance of early identification of chronic kidney disease. *Missouri Medicine*, *108*(1), 25–28.

Wheelock, A., Miraldo, M., Parand, A., Vincent, C., & Sevdalis, N. (2014). Journey to vaccination: A protocol for a multinational qualitative study. *BMJ Open*, *4*(1). https://doi.org/10.1136/bmjopen-2013-004279

WHO - World Health Organization. (2016). Patient engagement. In *Side Effects of Drugs Annual*, first edition, volume 45, Elsevier, https://doi.org/10.1016/S0378-6080(10)32050-2

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., Bradley, R., & Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research*, *12*(2), e19. https://doi.org/10.2196/jmir.1549

Wilde-Larsson, B., & Larsson, G. (2009a). Patients' views on quality of care and attitudes towards re-visiting providers. *International Journal of Health Care Quality Assurance*, *22*(6), 600–611. https://doi.org/10.1108/09526860910986867

Wiley, J., Westbrook, M., Long, J., Greenfield, J., Day, R, & Braithwaite, J. (2014). Diabetes education: the experiences of young adults with type 1 diabetes. *Diabetes Therapy : Research, Treatment and Education of Diabetes and Related Disorders*, *5*(1), 299–321. https://doi.org/10.1007/s13300-014-0056-0

Willis, C., Saul, J., Bitz, J., Pompu, K., Best, A., & Jackson, B. (2014). Improving organizational capacity to address health literacy in public health: a rapid realist review. *Public Health*, *128*(6), 515–524. https://doi.org/10.1016/j.puhe.2014.01.014

Willis, E., & Royne, M. B. (2017). Online Health Communities and Chronic Disease Self-

Management. *Health Communication*, *32*(3), 269–278. https://doi.org/10.1080/10410236.2016.1138278

Willis, K., Collyer, F., Lewis, S., Gabe, J., Flaherty, I., & Calnan, M. (2016). Knowledge matters: producing and using knowledge to navigate healthcare systems. *Health Sociology Review*, *25*(2), 202–216. https://doi.org/10.1080/14461242.2016.1170624

Winkelman, W. J., & Choo, C. W. (2003). Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, *6*(4), 352–358. https://doi.org/10.1046/j.1369-7625.2003.00237.x

Withers, K., Puntoni, S., O'Connell, S., Palmer, R., & Carolan-Rees, G. (2018). Standardising the collection of patient-reported experience measures to facilitate benchmarking and drive service improvement. *Patient Experience Journal*, *5*(3), 16–24. https://doi.org/10.35680/2372-0247.1268

Wohn, D., & Lampe, C. (2018). Psychological wellbeing as an explanation of user engagement in the lifecycle of online community participation. *Proceedings of the International ACM SIGGROUP Conference on Supporting Group Work*, 184–195. https://doi.org/10.1145/3148330.3148351

Wolf, J. (2018a). *Consumer Perspectives on Patient Experience 2018 - The Beryl Institute*. https://www.patientlibrary.net/tempgen/179481.pdf

Wolf, J. (2018b). The consumer has spoken: Patient experience is now healthcare's core differentiator. *Patient Experience Journal*, *5*(1), 1–4. https://doi.org/10.35680/2372-0247.1304

Wolf, J. (2019). Reframing innovation and technology for healthcare: A commitment to the human experience. *Patient Experience Journal*, *6*(2), 1–4. https://doi.org/10.35680/2372-0247.1392

Wolf, J., Niederhauser, V., Marshburn, D.-, & LaVela, S. (2014). Defining Patient Experience. *Patient Experience Journal*, *1*(1), 7–19. https://doi.org/10.35680/2372-0247.1004

Wolf, J., Niederhauser, V., Marshburn, D., & LaVela, S. (2021). Reexamining "Defining Patient Experience": The human experience in healthcare. *Patient Experience Journal*, *8*(1), 16–29. https://doi.org/10.35680/2372-0247.1594

Wong, P., Liamputtong, P., Koch, S., & Rawson, H. (2015). Families' experiences of their interactions with staff in an Australian intensive care unit (ICU): A qualitative study. *Intensive and Critical Care Nursing*, *31*(1), 51–63. https://doi.org/https://doi.org/10.1016/j.iccn.2014.06.005

Wood, S. (2001). Remote Purchase Environments: The Influence of Return Policy Leniency on Two-Stage Decision Processes. *Journal of Marketing Research*, *38*(2), 157–169. https://doi.org/10.1509/jmkr.38.2.157.18847

World Health Organisation (WHO). (2023). *Diabetes*. https://www.who.int/news-room/fact-sheets/detail/diabetes.. Accessed 05 May 2024.

World Health Organization. (2016). Framework on integrated people-centred health services. Report by the Secretariat. World Health Organization. Sixty-ninth World Health Assembly.WHA69.39. In *Sixty-Ninth World Health Assembly: Vol. Provisiona* (Issue April). https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf

Worlu, R., Kehinde, O., & Borishade, T. (2016). Effective customer experience management in health-care sector of Nigeria: A conceptual model. *International Journal of Pharmaceutical and Healthcare Marketing*, *10*(4), 449–466. https://doi.org/10.1108/IJPHM-12-2015-0059

Wright, K.(2000). Computer-Mediated Social Support, Older Adults, and Coping. *Journal of Communication*, *50*, 100–118. https://doi.org/10.1111/j.1460-2466.2000.tb02855.x

Wright, K., & Bell, S. (2003). Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated communication theory. *Journal of Health Psychology*, *8*(1), 39–54.. https://doi.org/10.1177/1359105303008001429

Wu, P., & Bernardi, R. (2021). Community attachment and emotional well-being: an empirical study of an online community for people with diabetes. *Information Technology and People*, *34*(7), 1949–1975. https://doi.org/10.1108/ITP-06-2019-0293

Wu, W., & Tsai, C. (2007). The empirical study of CRM. *International Journal of Commerce and Management*, *17*(3), 194–210. https://doi.org/10.1108/10569210710833617

Xie, B., & Youash, S. (2011). The effects of publishing emergency department wait time on patient utilization patterns in a community with two emergency department sites: a retrospective, quasi-experiment design. *International Journal of Emergency Medicine*, *4*(1), 29. https://doi.org/10.1186/1865-1380-4-29

Xie, J., Hu, Y., Lu, C., Fu, Q., Carbone, J., Wang, L., & Deng, L. (2019). What Are the Risk Factors of Negative Patient Experience? A Cross-Sectional Study in Chinese Public Hospitals. *Inquiry : A Journal of Medical Care Organization, Provision and Financing*, *56*, 46958019847865. https://doi.org/10.1177/0046958019847865

Yan, L., & Tan, Y. (2014). Feeling blue? Go online: An empirical study of social support among patients. *Information Systems Research*, *25*(4), 690–709. https://doi.org/10.1287/isre.2014.0538

Yu, L., Huang, X., Gale, R., Wang, H., & Jiang, Q. (2019). Variables associated with patient-reported symptoms in persons with chronic phase chronic myeloid leukemia receiving tyrosine kinase inhibitor therapy. *Medicine*, *98*(48), e18079. https://doi.org/10.1097/MD.0000000000018079

Zadeh, A., Zolfagharian, M., & Hofacker, C. (2019). Customer–customer value co-creation in social media: conceptualization and antecedents. *Journal of Strategic Marketing*, *27*(4), 283–302. https://doi.org/10.1080/0965254X.2017.1344289

Zaltman, G., & Coulter, R. (1995). Seeing the voice of the customer: Metaphor-based advertising research. *Journal of Advertising Research*, *35*(4), 35–51.

Zhang, H., Xiao, L., & Ren, G. (2018). Experiences of social support among chinese women with breast cancer: A qualitative analysis using a framework approach. *Medical Science Monitor*, *24*, 574–581. https://doi.org/10.12659/MSM.908458

Zhang, Y., & Wildemuth, B. (2009). Qualitative Analysis of Content. *Applications of Social Research Methods to Questions in Information and Library Science*, 421. https://doi.org/10.1002/hbm.20661

Zhao, J., Wang, T., & Fan, X. (2015). Patient value co-creation in online health communities: Social identity effects on customer knowledge contributions and membership continuance intentions in online health communities. *Journal of Service Management*, *26*(1), 72–96. https://doi.org/10.1108/JOSM-12-2013-0344

Zheng, Q., Yao, T., & Fan, X. (2016). Improving customer well-being through two-way online social support. *Journal of Service Theory and Practice*, *26*(2), 179–202. https://doi.org/10.1108/JSTP-09-2014-0188

Zomerdijk, L., & Voss, C. (2010). Service design for experience-centric services. In *Journal of Service Research*, 13(1), 67-82. https://doi.org/10.1177/1094670509351960

Zomerdijk, L., & Voss, C. (2011). NSD processes and practices in experiential services. *Journal of Product Innovation Management*, *28*(1), 63–80. https://doi.org/10.1111/j.1540-5885.2010.00781.x

Zomerdijk, L., & Voss, C. (2010). Service Design for Experience-Centric Services. *Journal of Service Research*, *13*(1), 67–82. https://doi.org/10.1177/1094670509351960

APPENDICES

APPENDIX I - SEARCH STRATEGY

Main keywords (Scopus, Web of Science, Google Scholar, Proquest, JSTOR)
Customer experience AND healthcare services
Customer experience AND healthcare
Customer journey AND healthcare
Customer experience AND customer journey AND healthcare
Customer experience AND customer journey AND healthcare services
Customer experience AND healthcare services AND well-being
Customer experience AND customer journey AND touchpoints
Customer experience AND customer journey AND touchpoints AND healthcare
Patient experience AND patient journey AND healthcare
Holistic patient experience AND patient journey AND healthcare
Patient experience AND patient journey AND touchpoints
Patient experience AND healthcare services AND well-being
Patient experience AND well-being AND health outcomes
Patient experience AND patient journey AND chronic diseases/illnesses
Patient experience AND patient journey AND chronic diseases/illnesses AND well-being

APPENDIX II - SUPPLEMENTARY INFORMATION ABOUT CUSTOMER EXPERIENCE AND CUSTOMER JOURNEY CONCEPTUALIZATION

Customer experience
Accordingly, Customer Experience (CX) is defined as a multidimensional construct that centres on a customer's cognitive, emotional, behavioural, sensorial, and social responses to a firm's offering throughout a journey of touchpoints across pre-purchase, purchase, and post-purchase situations (Homburg et al., 2017; Lemon & Verhoef, 2016). In other words, the customer experience journey, also known as the customer journey, is commonly defined as the continuous Customer Experience (CX) throughout the phases of a service cycle (Folstad et al., 2013). These phases are variously demarcated in the CX literature as "pre-purchase, purchase, and post-purchase situations" (Homburg et al., 2017, p. 384); "pre-core, core, and post-core service encounters" (Voorhees et al., 2017, p.270); and "search, purchase, experience, and reflect [phases]" (Dellaert, 2018, p.243). Indeed, the customer journey represents the customer's interactions with the organisation over time during the purchase cycle. In each stage, customers experience touchpoints, only some of which are under the firm's control. Touchpoints include and go beyond channels and media, as they encompass any encounter in the customer journey that could be related to a firm (Baxendale et al., 2015). Therefore, some organisation/firm-controlled marketing factors that drive experience may include promotion, price, delivery process, service employee, atmosphere and supply chain location (Grewal et al., 2009; Lemon & Verhoef, 2016; Verhoef et al., 2009; Zomerdijk & Voss, 2010). A vast number of additional touchpoints have also been identified in the literature, including in-store, telephone, salesforce, catalogues, payments, returns, loyalty programs, digital, e-mail, paid and organic search, display ads, online platforms, customer service, personal interactions, word-of-mouth and so forth (Baxendale et al., 2015; Voorhees et al., 2017). Although existing studies suggest that different touchpoints can be identified (e.g. Baxendale et al., 2015; De Haan et al., 2015), today, it seems necessary to consider touchpoints even in a broader view (Leva & Ziliani, 2018). This goes in line with the idea that customers often perceive each contact as having a holistic nature, which is influenced by several experiential elements, some of which are beyond a company's control (Bitner & Wang, 2014). Customers co-create value with a firm through CXs during the journey, specifically by integrating resources at multiple contextual touchpoints through activities and interactions. In this sense, CX consists of value co-creation elements, customer discrete emotions, and customer cognitive responses at distinct touchpoints (McColl-Kennedy et al., 2012). Similarly, Lemke et al. (2011, p. 848) define CX as the "customer's subjective response to the holistic direct and indirect encounter with the firm, including but not necessarily limited to the communication encounter, the service encounter and the consumption encounter." De Keyser et al. (2015) suggest CX as the result of the customer's direct or indirect service exchange with (an)other actor(s). Embedded in this definition are three fundamental principles that form the foundation of every CX. The first fundamental principle of CX is its interactional nature, indicating that a CX always arises from an interaction between a customer and one or more market actors through various interfaces, including both human (e.g., employees) and non-human (e.g., technologies) interfaces De Keyser et al. (2015). The second basic

tenet holds that a specific level of uniqueness marks every CX. Specifically, experiences vary on a continuum ranging from ordinary to extraordinary (Mogilner & Bhattacharjee, 2014). Ordinary experiences correspond to routine activities that are common, frequent and occur in everyday life (Carù & Cova, 2003). Extraordinary experiences, instead, are uncommon and infrequent and extend beyond everyday life (Mogilner & Bhattacharjee, 2014). The third basic tenet of CX relates to its multidimensional nature, which goes beyond a purely rational, cognitive consideration of CX (Holbrook & Hirschman, 1982).

Acknowledging the richness of an experience, the literature proposes that cognitive, emotional, physical, sensorial, and social elements most readily encompass the broad spectrum of essential human experiences (Brakus et al., 2009). These experience elements are interrelated, forming a unitary CX. However, the specific expressions of each of the five experience elements might vary across contexts and situations. More specifically, specific elements of the CX might be more or less present depending on the context and situation in which the customer finds him/herself (De Keyser et al., 2015).

Customer journey

As previously mentioned, literature has emphasized the importance of the customer journey as a unit of analysis in pursuit of customer experience (CX). The customer journey (CJ) approach has generated significant interest in the design and management of services (Folstad et al., 2013). The journey is a simple and powerful tool to put the CX into action by mapping sequentially the steps customers go through when interacting with a company (Addis, 2016). Hence, the customer journey can adopt the customers' perspective and signify a necessary paradigm shift in how we comprehend a customer's experience of a service (Addis, 2016; D. Stone & Devine, 2013). A deep understanding of the customers' world is a needed step toward customer centricity (Norton & Pine, 2013). Customer journeys are seen as a prevalent approach for structuring early phase user research in service design projects (Følstad & Kvale, 2018). However, the literature on customer journey is still emerging, although some influential works such as Parker & Heapy (2006); Voss & Zomerdijk (2007) have left a significant impact on the field. Stable definitions and uses of customer journey terminology, as well as more empirical applications of customer journey, are still in the process of being established (Folstad et al., 2013; Lemon & Verhoef, 2016). The customer journey is the process that a customer undergoes to accomplish a specific goal involving one or more service providers. Customer journeys are typically depicted as a series of touchpoints or interactions between the customer and the service providers.(e.g., Clatworthy, 2011).

Varnali (2018) adopts a pragmatic and holistic view by proposing to understand the customer journey from the lenses of the complexity theory, wherein the central idea is that reality takes the form of emergent, dynamic, and self-organizing complex systems (Urry, 2005). Complex systems are characterized as:

(1) Autopoietic: what happens at each touchpoint in a customer journey participates in the production or transformation of what happens at another touchpoint in the same journey (Luhmann, 1995);

(2) Path-dependent: ordering events through time (i.e., direct or indirect contacts with touchpoints) influences the overall CX. Building on this notion, Verhoef et al. (2009) emphasized the significance of past experiences in shaping current and future ones;

(3) Non-linear: CX is emergent, sensitive to the surrounding world, and influenced by small fluctuations (Casti, 1994). For example, Bolton et al. (2014) suggested that small details in service design have multiplier effects on the CX when defined strategically across every customer touchpoint;

(4) Nested hierarchies: Each "journey" represents an aggregate entity of other complex systems. Each touchpoint may entail a deeper-level journey with many touchpoints within itself (Simon, 1996). Overall, the significance of adopting a customer journey perspective becomes more pronounced as the complexity of service provisioning increases. This is particularly evident in services that involve multiple touchpoints, each managed by different organisational units (Wechsler, 2012). Therefore, one could argue that healthcare is an example of such a complex service context (Patrício et al., 2011; Vogus & Mcclelland, 2016).

The customer journey is conceptualized in three generic high-level stages: pre-service encounter (consumption), during-service encounter (consumption) and post-service encounter (consumption). The consumer is theorized to move precisely from pre-purchase to purchase and finally post-purchase phases. Implicitly, this process presupposes that touchpoints can stimulate buyer actions in favour of a firm's offerings (Lemon & Verhoef (2016). According to this view, CX flows throughout an iterative and dynamic process, which starts even prior to the purchase when, for instance, consumers are exposed to advertising, proceed with the buying act, go on with the actual consumption, and end only when the memory of the experience disappears (Tax et al., 2013; Verhoef et al., 2009). Indeed, customer journey expands its focus beyond the production/consumption moment (Nenonen et al., 2008) and incorporates past experiences and external factors Lemon & Verhoef (2016). Customer journey aims to identify the fundamental interactions and their meanings from the customers' perspective, not restricting the analysis only to the behavioural customers' reactions.

The first stage, known as pre-service encounter or consumption stage, encompasses all aspects of the customer's interaction with the brand, category, and environment prior to a purchase transaction. Marketing literature has characterized pre-purchase as behaviours such as need recognition, search, goal, or impulse to the consideration of satisfying that need, goal, or impulse through a purchase or consumption (e.g., Hoyer, 1984; Pieters et al., 1995). The second stage, known as during service encounters or consumption, encompasses all customer interactions with the brand and its environment during the purchase or consumption event. It is characterized by behaviours such as choice, ordering, and payment (Lemon & Verhoef, 2016). Although this stage is typically the most temporally compressed of the three stages, it has received a significant amount of attention in the marketing literature, which has focused on how marketing activities (e.g., the marketing mix [(Kotler & Keller, 2015]) and the environment and atmospherics (e.g., the servicescape [(Bitner, 1990)], the service environment clues (Berry et al., 2002) influence the purchase/consumption decision. The third stage - post-service encounter (consumption) - encompasses customer interactions with the brand and its environment following the purchase/consumption. It extends "temporally from the purchase to the end of the customer's life" (Lemon & Verhoef, 2016, p.76) and constitutes the most

significant portion of the journey. Individuals in this phase of the journey interact with the product, service, or brand most extensively, and they often make repeat purchase and loyalty decisions based on these experiences (Etkin & Sela, 2016; Hamilton et al., 2011). Research on this third stage has focused on the consumption experience (e.g., Holbrook & Hirschman, 1982), service recovery (e.g., Kelley & Davis, 1994), and decisions to return products (e.g., Wood, 2001), repurchase (e.g., (Bolton, 1998), or seek variety (e.g., McAlister & Pessemier, 1982), as well as other nonpurchase behaviours such as word of mouth (WOM) and other forms of customer engagement (e.g., Van Doorn et al., 2010).

Customer experience – insights from the literature

Source	Holistic and multidimensional perspectives of CX from the customer standpoint: a customer journey approach
Prahalad & Ramaswamy (2004)	CX extends beyond the customer–firm exchange process to include many-sided interactions, wherein value derives from resource integration behaviors which may occur at the point of service or spatially or temporally distant from the service organisation.
Verhoef et al. (2009)	The CX construct is more holistic in nature and includes a customer's cognitive, social and physical responses. It encompasses the customer's total experience at different stages of consumption.
Johnston & Kong (2011)	CXs represents personal interpretation of the service process, interaction and involvement with it during customer journey through a series of touchpoints, and how those things make the customers feel.
Lemke et al (2011)	CX as the customer's subjective response to the holistic direct and indirect encounter with the firm, including but not necessarily limited to the communication encounter, the service encounter and the consumption encounter.
Gustafsson et al. (2015)	CX is holistic, dynamic in nature and occurs across all touchpoints and over time, which therefore evokes a service research stream that makes a transformational impact on individuals, organisations and society.
De Keyser et al. (2015)	CX is comprised of the cognitive, emotional, physical, sensorial, and social elements that mark the customer's direct or indirect interaction with a (set of) market actor(s).CX is 'comprised of cognitive, emotional, physical, sensorial, spiritual and social elements that mark the customer's direct or indirect interaction with (an)other actor(s) and is said to be the result of the customer's direct or indirect service exchange with (an)other actor(s).

Lemon & Verhoef (2016)	CX is a multidimensional construct focusing on a customer's cognitive, emotional, behavioral, sensorial, and social responses to a firm's offerings during the customer's entire purchase journey. Customer journey represents the customer´s interactions with a firm over time during the purchase cycle across multiple touchpoints. In each stage, customers experience touchpoints, only some of which are under the firm's control. Overall, eperience is the outcome of direct or indirect interaction with the firm's touchpoints.
Homburg et al. (2017)	CX is the involvement of a person's sensorial, affective, cognitive, relational, and behavioural responses to a firm or brand by living through a journey of touchpoints along pre-purchase, purchase, and post-purchase situations. They also emphasise that firms should build the capability to design the customer journey across multiple stages.
Jain et al. (2017)	CX is regarded as a holistic interactive process, facilitated through cognitive and emotional clues, moderated by customer and contextual characteristics, resulting into unique and pleasurable/un-pleasurable memories. CX needs to be considered and managed as a holistic strategic process for creating customer value, differentiation, customer satisfaction, loyalty and competitive advantage.
McColl-Kennedy et al (2018)	The CX can be conceptualized as holistic, comprised of multiple touchpoints in an end to end journey, involving the customer's cognitive, affective, emotional, social, and sensory elements. CX is a process, comprised of interactions and activities across multiple touchpoints. Touchpoints can also occur across several repetitions of a service, especially where customers repeatedly deal with the same organisation. Prior experiences shape expectations about future interactions.

APPENDIX III - SUPPLEMENTARY INFORMATION – ROOTS AND DISTINCTIVENESS OF THE HOLISTIC PATIENT EXPERIENCE (PX) AS A CONSTRUCT

Delimitating PX: major contributions from established research areas	
Consumer decision making process	Consumer decision-making process models applied in healthcare provide the foundation for holistic thinking about PX as a patient's experience. Ppatients also often describe their experiences as a journey (Danaher & Gallan, 2016), which begins the first time they consider where they will get their care (Luxford & Sutton, 2014).
Service quality	The service quality literature stream brings to CX the focus on the context in which experiences arise and the measurement/assessment aspects of CX. Service quality (and its constituent elements) would be considered an antecedent of CX (Lemon & Verhoef, 2016). For example, the SERVQUAL model and measurement scales were developed to measure customers' perceptions of service quality dimensions (Parasuraman et al.,1988). The SERVQUAL scale typically contains 22 sets of parameters divided into five dimensions Tangibles (e.g., the physical facilities, entities, equipment, personnel, their uniforms, and languages.); Reliability (the firm can carry on the services as promised); Responsibility (it is the readiness of the company to provide the services); Assurance (this includes the knowledge and courtesy of the firm to carry out the service delivery process); and Empathy (the caring nature and ability to understand the suffering of others). The SERVQUAL model is a marketing theory that has significantly influenced practice (Staniszewska et al., 2014). Since the development of SERVQUAL, numerous studies have aimed to validate and enhance the scale (i.e., SERVPERF by Cronin & Taylor, 1992), with many applications in specific contexts (e.g., e-service quality) being proosed. In healthcare, quality refers to the extent to which services achieve the desired health outcomes for individuals and populations (Institute of Medicine, 2001). Since increasing attention is given to patients' healthcare service quality perceptions, SERVQUAL has also been used successfully in healthcare (Curry & Sinclair, 2002; Curry & Stark, 2000) Overall, service quality links marketing and operations—focus on quality; Identifies the specific context and elements of the experience (e.g., atmospherics and environment)
Patient expectations and satifaction	Satisfaction has primarily been conceptualised as comparing the delivered performance with customer expectations. This disconfirmation (positive or negative) has been empirically shown to create customer satisfaction (Lemon & Verhoef, 2016). Indeed, one of the main purposes of the

	SERVQUAL is to measure customer´s perceptions of service quality dimensions (Parasuraman et al., 1985). Researchers have discussed several ways to measure satisfaction, including rather focused measurement (e.e. "How satisfied are you about XXX?"; (Bolton, 1998), with more extensive measurements using multiple items that also include emotions (e.g., happiness) (Westbrook & Oliver, 1991). Nonlinear effects of satisfaction and the importance of customer delight have also received attention (e.g., Oliver, 1997; Rust & Oliver, 2000; Schneider & Bowen, 1999). Studies have focused on empirical linkage models to identify key drivers and consequences of satisfaction (e.g., Anderson, Fornell and Mazvancherly, 2004). In healthcare, patient satisfaction is a complex, multidimensional construct (Russel, 2013) and an essential aspect of service quality (Lally et al., 2013). Patient satisfaction is an emotion or attitude related to the healthcare experience or a judgment about meeting expectations (Bloom, 2002). Varying standards, expectations, quality perceptions, disposition, time since care and previous experience influence patient satisfaction. However, research finds that patient satisfaction measures may be systematically biased (Hekman et al., 2010). Patient satisfaction responses in surveys may not be reliable, as high satisfaction rates can indicate either high-quality care or low expectations (Jenkinson et al., 2002). Scholars advise that it is best to ask patients to report their experience (e.g., "How often did your nurses listen carefully to you?") rather than use satisfaction ratings gathered through the HCAHPS survey (Salisbury et al., 2010). Contrary to patient satisfaction, PX questions relate to actual hospital experiences, which avoid value judgments and expectation effects. Therefore, creating an exceptional experience is far more than just satisfying patients; it goes well beyond the amenities that may be provided (Guler, 2017). Studies have shown that the variable 'experience' is the most relevant internal factor for improving overall patient satisfaction. Indeed, the patient-reported experience measures (PREMs) that capture the overall PX with care reveal positive associations with satisfaction (Musella et al., 2017; Smith & Weldring, 2013).
Patient engagement	In marketing literature, customer engagement (CE) has been discussed from a multidimensional perspective (Pansari & Kumar, 2017). Focusing on an attitudinal perspective, Brodie et al. (2011, p.260) define CE as a "psychological state that occurs through interactive, co-creative customer experiences with a focal agent/object (e.g., a brand) in focal service relationships". From a behavioural standpoint, Van Doorn et al. (2010, p.253) assume CE as the "the customer's behavioural manifestation towards a brand or firm, beyond purchase, resulting from motivational drivers." Such "beyond purchase" behavioural dimension of CE includes

	manifestations, such as co-creation, social influence through WOM, and customer referrals (e.g., Libai et al., 2010). In this respect, the digital and social media revolution has strengthened the importance of CE behaviour, as customers become active co-producers of value or destroyers of value for firms (Leeflang et al., 2013; van Doorn et al., 2010). Overall, Lemon & Verhoef (2016) define CE as the degree to which the customer reaches out to and initiates contact with the firm, whether attitudinally or behaviorally. Thus, engagement encompasses touchpoints along the customer journey and elicits the customer's cognitive, emotional, behavioural, sensorial, and social responses. Consequently, CE is integrated into the overall CX and, in its specific forms, represents distinct touchpoints along the customer journey Lemon & Verhoef (2016). In the healthcare field, the term "engagement" acknowledges that patients have an essential role to play in their health and well-being throughout their journey (Graffigna & Vegni, 2017) and calls for a renewed partnership among the actors (e.g., patients, HCPs, ICs). Patient engagement emerges as a component of PX through specific interactional touchpoints, such as social communities (e.g., (Johnson & Lowe, 2015) and interactions with healthcare service employees or other patients (e.g., Osei-Frimpong & Owusu-Frimpong, 2017). In summary, it recognizes the patient's role in the experience. The overall goal should be to support and strengthen patients' determination of their healthcare needs and self-care efforts throughout their journey to impact patient safety positively, patient's trust in clinicians, adherence to treatment, and their overall experience (Goudy et al., 2015).

APPENDIX IV - INTERVIEW (BASIS FOR CONCEPTUALIZATION)

Examples of main questions (patient´s interview guide)	Related concepts and basis for conceptualization
— Describe how you realised something was not right with your health.	Pre consumption. Noticing the first symptoms and searching for care. Ritchie et al (2017), Goldstein et al (2019), Manchaiah and Stephens (2012).
— Explain if anyone did advise you while researching and selecting a hospital/doctor and how.	Pre consumption. Receiving advice and recomendations for selecting a healthcare provider. Leydon, Bynoe-Sutherland and Coleman (2003); Martin (2017).
— Describe and explain the positive and negative aspects you took away from your most recent endocrinology/nephrology appointment.	Service encounters. Interactions with processes, staff and servicescape. Egan et al (2015); Athlin and Conroy (2018); Ugalde et al (2019); Zhang, Xiao and Ren (2018), Drury and Inma (2010); Oliver et al (2008); Kerin et al (2019); Kohler et al (2017);Hamdan et al (2016); Bray et al (2015);
— Describe what could be done to improve your experience with endocrinology/nephrology follow-up appointments.	
— Describe your overall experience with HB's services. You can refer to positive or negative episodes during your last few visits (stories).	
— Explain what could be done to improve your overall experience with the HB.	
— Explain how you see the relationship with the medical team working. Describe the positive and negative aspects you identify in your relationship with the HB medical team (stories).	
— Explain how you would like your relationship with the medical team to develop.	
— Explain what is most important to you as a T1D/CKD patient from the moment you enter the hospital until the moment you leave.	
— Explain how your illness has affected your daily routine. Describe your main challenges and difficulties.	Post consumption. Self-management. Travlos et al (2016); Ritchie et al (2017); Knibb et al (2019); Holopainen (2017). Schildmeijer et al (2018); Tsai et al (2017)
— Explain how the illness has influenced the different areas of your life (professionally, personally, socially).	

— Explain who you ask for help and how when you have doubts or need clarification about your illness/treatment.	
— Explain what you have done to help you deal with your illness.	
— Explain what you think could be done to improve your involvement in therapy.	
— Describe if you had tried to exchange experiences with other patients with the same condition as yours and how it was.	Post consumption. Long-term support from HCPs and social circle. Graham-Wisener and Dempster (2017); Knibb et al (2019), Ponsignon, Smart and Phillips (2017); Mitchell et al (2019); May et al. (2017); Tsai et al (2017), Wilde-Larsson and Larsson (2008).
— Explain what additional support you need that you do not already have.	
— Explain if you are willing to recommend HB's services to other patients with the same condition as yours and why.	Post consumption. Willingness to recommend. Kennedy et al (2018); Wheelock et al (2014).

APPENDIX V - INTERVIEW SCRIPTS (Português)

GUIÃO DE 1ª ENTREVISTA - DOENTES REGULARES - IRC E4-5 /DT1

Data / local / entrevistado:

_____

Agradecimentos e consentimento:

Muito obrigado por ter aceite fazer parte deste trabalho de investigação. O presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB). Neste estudo iremos conduzir entrevistas para explorar e compreender a experiência dos doentes com DT1 e IRC E 4-5[9] e que são seguidos no HB. Com o seu consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o seu total anonimato. Também poderá ter a oportunidade de rever a transcrição da entrevista se assim o desejar. A sua participação é livre, pelo que não existirão quaisquer consequências se pretender/necessitar de terminar a entrevista antecipadamente.

A. <u>Experiência dos doentes desde o momento em que sentem que algo de errado se passa com a sua saúde até ao momento em que decidem consultar um médico e recebem o diagnóstico</u>.

- Como se apercebeu que algo não estava bem com a sua saúde?
- O que o levou a procurar um médico?
- Onde é que foi diagnosticado com a DT1/IRC e qual o motivo?
- Há quanto tempo recebeu o diagnóstico?
- Por quem foi aconselhado no processo de pesquisa e seleção do hospital/médico?
- Recorda-se de como foi o momento da comunicação do diagnóstico?
- Como se sentiu e/ou reagiu à notícia?
- Quem o acompanhou mais nessa altura?
- Recorda-se se o médico(a) endo/nefro, na altura, referenciou-o(a) a alguém ou algum serviço de apoio / complementar dentro ou fora do hospital?
    - Se sim, qual(ais)?

[9] Although stages 4 and 5 of renal failure were identified in this study, patients were not informed of their specific stage nor were they queried about their awareness of their current stage. This was due to the fact that some individuals remained unaware of their stage of renal failure.

— Recorda-se se o médico(a) endo/nefro providenciou fontes adicionais de informação onde pudesse pesquisar e saber mais sobre a doença?
— Procurou ouvir uma segunda opinião?
    - Se sim, a quem recorreu? E porquê?

B. Experiência dos doentes durante ao longo das suas consultas/tratamentos de rotina no HB

— Relativamente à mais recente consulta de seguimento de nefro/endo, como é que se preparou?
— Relativamente à mais recente consulta de seguimento de nefro/end, que aspetos positivos e negativos é que retirou?
— E relativamente a outras consultas anteriores dessa especialidade?
— Na sua opinião, o que é que poderá ser feito para melhorar as consultas de seguimento de nefro/endo no futuro?

— No caso de ser um doente em pré-diálise, já discutiu as diferentes modalidades de tratamento de substituição renal com o seu médico?
— Como se sente em relação ao apoio/suporte e informação que lhe fornecerem em relação à decisão que tem de tomar?
— Que pessoas ou entidades o têm apoiado mais nesta fase de decisão sobre o tratamento de substituição renal?

— Realizou alguma medicação ou tratamento injetável no hospital?
    - Se sim, em que consistiu?
    - Como foi a sua experiência com a realização do tratamento?

— No HB, para além da consulta de nefro/endo, realiza mais alguma consulta de outra especialidade ou é seguido por algum serviço complementar?
    - Se sim, qual(ais)?
        - Descreva como tem sido a sua experiência com essa(s) consulta(s) e/ou serviço(s) e com as respetivas equipas de profissionais.
        - O que poderá ser feito para melhorar a sua experiência nessa(s) consultas/serviço(s)?
    - Se não, sente falta de ser acompanhado ou gostaria de ser acompanhado por alguma especialidade ou serviço dentro do hospital, para além de nefro/endo?

— Relativamente à sua mais recente visita ao HB, como se sentiu relativamente ao ambiente geral do hospital (instalações, limpeza, recursos disponíveis, ambiente da sala de espera, etc.)?
    - Pode contar algum episódio positivo ou negativo que tenha acontecido no HB ao longo das suas últimas visitas e que tenha sido relevante para si?
    - O que sugeria para melhorar o ambiente geral do HB?

- Relativamente ao relacionamento com a equipa médica, como é que descreve a relação que tem mantido com a equipa médica que o segue no HB? E relativamente aos restantes profissionais de saúde do HB?
- Existe algum aspeto positivo ou negativo que gostasse de partilhar connosco?
- O que sugeria para melhorar esses aspetos?

- Na sua opinião, no papel de IRC E 4-5/DT1, o que é mais importante para si desde que entra no Hospital até que sai (pense de uma forma geral em todos os aspetos e situações com as quais se depara desde que marca a consulta até que abandona o Hospital).
- No caso de ter sido acompanhado noutro hospital, que principais diferenças é que identifica em relação ao HB? (pode mencionar qualquer fator positivo ou negativo relacionado com as instalações, pessoas, processos, recursos, apoio/suporte).
- Recomendaria os serviços do HB a outros doentes na mesma condição que a sua?

C. Experiência dos doentes fora do contexto hospitalar (gestão da doença no dia-a-dia).

- Até agora, como é que a doença tem influenciado as diferentes áreas da sua vida (a nível profissional, pessoal, social)?
- Descreva um dia típico seu enquanto doente IRC E 4-5/DT1.
- Como tem lidado com os hábitos diários:
    - Da terapia/medicação?
    - Da alimentação?
    - Do desporto / exercício físico
    - Das tecnologias (no caso da DT1, dos dispositivos de monitorização contínua de glicose, bombas de insulina, etc.)
- O que acha que poderia ser feito para melhorar esse(s) aspetos?
- Quando tem dúvidas ou quando precisa de esclarecimentos sobre a sua doença/tratamento/medicação, a quem pede ajuda (amigos, familiares colegas, outros doentes, profissionais de saúde)? E como?
- O que costuma fazer no seu dia a dia para o ajudar a lidar com a sua doença? Por dar-nos exemplos?
- Já procurou trocar experiências com outros doentes na mesma condição que a sua?
    - Como se sentiu?
    - Através de que meios entrou em contacto com outros doentes?
    - Como gostaria de poder contactar com outros doentes na mesma condição que a sua para partilha de experiências?

D. Aspetos adicionais de clarificação

- Gostaria de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

E. Contextualização /enquadramento dos doentes recorrentes

- Localidade
- Data nascimento

- Nível de escolaridade
- Profissão atual
- Seguradora de saúde
    - se existir, qual?
    - motivo da adesão?

- Com que frequência pratica desporto ou atividade físico-desportiva?
    - Não pratica
    - Residual (menos de 3 vezes por semana)
    - Regular (3 ou mais vezes por semana)
- É fumador/a?
    - Se sim, quantos cigarros por semana?
- Com que frequência consome bebidas alcoólicas[10]?
    - Nunca
    - Uma vez por mês ou menos
    - Duas a quatro vezes por mês
    - Duas a três vezes por semanas
    - Quatro ou mais vezes por semana

[10] AUDIT Alcohol Use Disorders Identification Test ((https://auditscreen.org/cmsb/uploads/audit_portuguese.pdf)

GUIÃO DE 2ª ENTREVISTA (FOLLOW-UP) - DOENTES IRC E 4-5 /DT1

Data / local / entrevistado:

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Agradecimentos e consentimento:

Muito obrigado por ter aceite continuar a fazer parte deste trabalho de investigação. Relembro que o presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB). Com esta entrevista procuramos, em particular, identificar possíveis alterações na experiência dos doentes, seis meses depois da nossa última conversa. Com o seu consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o seu total anonimato. Também poderá ter a oportunidade de rever a transcrição da entrevista se assim o desejar. A sua participação é livre, pelo que não existirão quaisquer consequências se pretender/necessitar de terminar a entrevista antecipadamente.

A. <u>Mudanças na experiência dos doentes (DT1/IRC E 4-5) no contexto hospitalar (consultas de seguimento e tratamentos no HB)</u>

- Desde a nossa última conversa, mudou alguma coisa na forma como se preparou para esta mais recente consulta de seguimento de nefro/endo?
- Desde a nossa última conversa, mudou alguma coisa na forma como as consultas de seguimento de nefro/endo são realizadas?
    - Se sim, pode explicar mais detalhamente o que é que mudou?
- Na sua opinião, o que é que poderá ser feito para melhorar as consultas de seguimento de nefro/endo no HB?

- Desde a nossa última conversa, houve alguma progressão no estadio da sua doença?
- Desde a nossa última conversa, já discutiu as diferentes modalidades de tratamento de substituição renal com o seu médico?
    - Se sim, pode descrever como correu?
    - E como se sentiu?
- Desde a nossa última conversa, que pessoas ou entidades o têm apoiado mais nesta fase de decisão sobre o tratamento de substituição renal?

— Desde a nossa última conversa, realizou alguma medicação e/ou tratamento no hospital?
    - Se sim, em que consistiu?
    - E como se sentiu?

— Desde a nossa última conversa, realizou mais alguma consulta de outra especialidade ou foi seguido por algum serviço complementar?
    - Se sim, indique quais e descreva como tem sido a sua experiência com essa(s) consulta(s) e/ou serviço(s) e com as respetivas equipas de profissionais.
    - O que poderá ser feito para melhorar a sua experiência nessa(s) consultas/serviço(s)?
    - Se não realizou nenhuma consulta mais, sente falta de ser acompanhado ou gostaria de ser acompanhado por alguma especialidade ou serviço dentro do hospital, para além de nefrologia? Qual e porquê?

— Desde a nossa última conversa, mudou alguma coisa na forma como se sente dentro do HB?
— Pode contar algum episódio positivo ou negativo que tenha acontecido desde a última vez que conversámos e que tenha sido relevante para si? (pode relatar qualquer interação que tenha ocorrido com pessoas, processos, instalações, ...).
— Desde a nossa última conversa, houve alguma mudança no seu relacionamento com a equipa médica do HB?
    - Se sim, pode explicar mais detalhamente o que é que mudou?

— Na sua opinião, no papel de um doente IRC E 4-5/DT1, o que é mais importante para si desde que entra no Hospital até que sai (pense de uma forma geral em todos os aspetos e situações com as quais se depara desde que marca a consulta até que abandona o Hospital).
— Desde a nossa última conversa, continuaria a recomendar os serviços do HB a outros doentes na mesma condição que a sua?

B. <u>Mudanças / alterações na experiência dos doentes (DT1/IRC E 4-5) fora do contexto hospitalar (gestão da sua doença no dia a dia)</u>

— Desde a nossa última conversa, houve alguma mudança na forma como a doença tem influenciado as diferentes áreas da sua vida (a nível profissional, pessoal, social)?
— Desde a nossa última conversa, houve alguma mudança na sua rotina diária?
— Desde a nossa última conversa, houve alguma mudança na forma como tem lidado com os hábitos diários de:
    - terapia/medicação?
    - nutrição?
    - desporto/atividade ísica?
    - Outros?
— Desde a nossa última conversa, houve alguma mudança relativamente a onde vai procurar ajuda quando tem dúvidas ou quando precisa de esclarecimentos sobre a sua doença/tratamento/medicação?

— Desde a nossa última conversa, houve alguma mudança relativamente às atividades que costumava praticar para o ajudar a lidar com a doença/para se distrair?
— Desde a última vez que falamos, já procurou trocar experiências com outros doentes na mesma condição que a sua?
    - Como é que o fez?
    - Como é que se sentiu?

C. <u>Análise e discussão dos comentários dos doentes (diários)</u>
— Poderia partilhar os seus registos ao longo destes 6 meses?
— Relativamente a esta situação que reporta (...)
    - Quando e onde aconteceu?
    - Porque é que é que decidiu registar no diário?
    - Que emoções lhe provocou?

D. <u>Aspetos adicionais de clarificação</u>
— Gostaria de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

E. <u>Contextualização /enquadramento dos doentes (DT1/IRC E 4-5)</u>
— Desde a nossa última conversa houve alguma mudança na prática de desporto/consumo de álcool/consumo de tabaco? Se sim, qual foi?

GUIÃO DE ENTREVISTA – PROFISSIONAIS DE SAÚDE (MÉDICOS, DIRETORES DE SERVIÇO E ENFERMEIROS)

Data / local / entrevistado:

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Agradecimentos e consentimento:

Muito obrigado por ter aceite fazer parte deste trabalho de investigação. O presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB).Neste estudo iremos conduzir entrevistas com profissionais de saúde que prestam cuidados de saúde a doentes DT1 e IRC E4-5. O objetivo é explorar e compreender a experiência dos profissionais de saúde do HB enquanto prestadores de cuidados de saúde a doentes com DT1 e IRC E 4-5, bem como compreender a sua perceção sobre a experiência desses mesmos doentes, ao longo da sua jornada. Com o seu consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o seu total anonimato. A sua participação é livre, pelo que não existirão quaisquer consequências se pretender/necessitar de terminar a entrevista antecipadamente.

A. <u>Contextualização /enquadramento:</u>

- Data nascimento
- Localidade
- Número de anos de experiência profissional
- Número de anos no serviço e no hospital
- Experiência profissional noutros hospitais (se existente)

B. <u>Funções, responsabilidades e rotinas dos profissionais de saúde dos serviços de nefrologia/endocrinologia do HB:</u>

- Quais são as suas principais atividades / funções e responsabilidades no serviço de nefrologia/endocrinologia do HB?
- Na sua opinião, como é trabalhar no serviço de nefro/endo do HB?
- Que principais aspetos positivos e negativos é que encontra?

C. <u>Experiência dos profissionais do HB em interação com doentes DT1/IRC E 4-5 no HB (consultas/tratamentos):</u>

— Descreva como é que tipicamente decorre uma primeira consulta com estes doentes.
  - Que obstáculos encontra (se existirem) nas primeiras consultas com estes doentes?
  - E quais são os aspetos facilitadores (se existirem)?
  - Gostaria de partilhar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha sido marcante com estes doentes nas primeiras consultas?
  - Na sua opinião, o que poderá ser feito para melhorar a sua experiência na realização das primeiras consultas com estes doentes?

— Descreva como é que tipicamente decorre uma consulta de seguimento com estes doentes.
  - Que obstáculos (se existirem) encontra nas consultas de seguimento com estes doentes
  - E quais são os aspetos facilitadores (se existirem)?
  - Gostaria de partilhar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha sido marcante com doentes em consulta de seguimento?
  - Na sua opinião, o que poderá ser feito para melhorar a sua experiência na realização das consultas de seguimento com este doentes?

— Descreva que tratamentos (enfermagem) tem por hábito prestar a estes doentes?
  - Que obstáculos encontra (se existirem) na interação com estes doentes?
  - E quais são os aspetos facilitadores (se existirem)?
  - Gostaria de partilhar algum episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com estes doentes durante os tratamentos e que o/a tenha marcado?
  - Na sua opinião, o que poderá ser feito para melhorar a sua experiência na realização dos tratamentos a esses doentes?

— Em geral, como é que descreve a relação que tem mantido com os doentes?
  - Que aspetos positivos e negativos é que identifica na relação que mantém com esse grupo de doentes?
  - O que é que poderia ser feito para melhorar a sua relação com os seus doentes?

— Tem por hábito referenciar o doente a alguém ou algum serviço de apoio / complementar dentro ou fora do hospital? Se sim, a quem/ qual?
— Tem por hábito providenciar algum tipo de fonte adicional de informação aos doentes para que eles possam pesquisar e saber mais sobre a doença?
— Presta algum tipo de apoio ou acompanhamento extra consulta aos doentes?

- Se sim, como? (através de que canais?)
  - Quais as vantagens e limitações dos meios que usa?
- Na sua opinião, que outros mecanismos de interação poderiam existir para ajudar a prestar um melhor acompanhamento a estes doentes?
  - E de que forma é que poderia(m) ser operacionalizado(s)?

— No caso dos doentes IRC (E 4-5), que principais dificuldades encontra a discutir as diferentes modalidades de tratamento de substituição renal com os seus doentes?
  - De que forma tenta ultrapassar/gerir essas limitações?
— O que poderá ser feito para melhorar o envolvimento dos doentes nas terapias de substituição renal?

D. <u>Perceção dos profissionais relativamente à experiência dos doentes (dentro do contexto hospitalar – consultas e ambiente geral do hospital)</u>

— Na sua perceção, como é que os doentes tipicamente se sentem e comportam quando recebem o diagnóstico na consulta de nefro/endo?
— Em geral, os doentes procuram ouvir uma segunda opinião após o diagnóstico?
— Na sua perceção, como é que os doentes tipicamente se sentem e comportam durante as consultas de seguimento de enfro/endo?
— Na sua opinião, o que poderá ser feito para melhorar a experiência destes doentes em consulta (quer as primeiras consultas quer as de seguimento)?
— Na sua perceção, como é que os doentes tipicamente se sentem e comportam durante as consultas de seguimento de enfro/endo?
— Na sua opinião, o que poderá ser feito para melhorar a experiência destes doentes com o serviço de enfermagem do serviço de nefro/endo?

— Na sua perceção, como tem sido a interação dos doentes com os profissionais do serviço? E com os profissionais do hospital, de uma forma geral?
— Na sua opinião, o que poderá ser feito para melhorar a experiência destes doentes com os profissionais de saúde do serviço e do HB?

— Na sua perceção, como tem sido a experiência dos doentes com o ambiente geral do hospital e com os recursos disponíveis?
— Na sua opinião, o que poderá ser feito para melhorar a experiência destes doentes no HB?

E. <u>Perceção dos médicos (endo/nepro) relativamente à experiência dos doentes (fora do contexto hospitalar – gestão da doença no dia a dia)</u>

— Na sua perceção, de que forma é que a doença afeta as diferentes áreas da vida dos doentes (a nível profissional, pessoal, social)?
— O que poderá ser feito para o ajudar a minimizar esses impactos na vida desses doentes?
— Na sua perceção, como é que os doentes tentam lidar com a sua doença diariamente?

— O que poderá ser feito para o ajudar os doentes a lidar melhor com a sua doença /condição diariamente?
— Na sua perceção, como é a adesão dos doentes à medicação e tratamento/medicação diária?
— Quais os principais obstáculos com que os doentes se deparam, na gestão da sua doença, diariamente?
— Na sua opinião, o que poderá ser feito para contornar esses obstáculos?
— Na sua opinião, como poderíamos potenciar uma aproximação entre estes doentes na mesma condição para que pudessem beneficiar de trocas de experiências?

F. Aspetos adicionais de clarificação

— Gostaria de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

GUIÃO DE ENTREVISTA – FOCUS GROUP – NUTRICIONISTAS (T1D)

Data / local / entrevistado:

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Agradecimentos e consentimento:

Muito obrigado por terem aceite fazer parte deste trabalho de investigação. O presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB). Neste estudo iremos conduzir um focus group com profissionais de saúde do HB nomeadamente nutricionistas responsáveis por prestar cuidados a doentes DT1. O objetivo é explorar e compreender a experiência dos profissionais de saúde do HB (nutricionistas) enquanto prestadores de cuidados de saúde a doentes com DT1, bem como compreender a sua perceção sobre a experiência desses mesmos doentes, ao longo da sua jornada. Com o vosso consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o vosso total anonimato. A vossa participação é livre, pelo que não existirão quaisquer consequências se pretenderem/necessitarem de terminar a entrevista antecipadamente.

A. <u>Contextualização /enquadramento dos nutricionistas:</u>

- Data nascimento
- Localidade
- Número de anos de experiência profissional
- Número de anos no serviço e no hospital
- Experiência profissional noutros hospitais (se existente)

B. <u>Funções, responsabilidades e rotinas dos nutricionistas no HB e no serviço:</u>

- Quais são as vossas principais atividades / funções e responsabilidades no serviço?
- Na vossa opinião, como é trabalhar no serviço de nutrição do HB?
- Que principais aspetos positivos e negativos é que encontram?

C. <u>Experiência dos nutricionistas do HB em interação com doentes DT1 no HB (consultas):</u>

- Descrevam como é que tipicamente decorrem as primeiras consultas e as consultas de seguimento de nutrição com os doentes?
- Que principais diferenças existem entre as primeiras consultas e as de seguimento?

- Que obstáculos encontram (se existirem) nas consultas com estes doentes?
- E os aspetos facilitadores (se existirem)?
- Têm por hábito providenciar algum tipo de fonte adicional de informação aos doentes para que eles possam pesquisar e saber mais sobre as o comportamento alimentar associado à sua condição?
- Gostariam de partilhar algum episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenham tido com estes doentes nas vossas consultas e que os/as tenham marcado?
- Na vossa opinião, o que poderá ser feito para melhorar a vossa experiência na realização das consultas com estes doentes?
- Como é que descrevem a relação que têm mantido com estes doentes?
- Que aspetos positivos e negativos é que identificam na relação que mantêm com os doentes?
- O que é que poderia ser feito para melhorar a vossa relação com os doentes?
- Prestam algum tipo de apoio ou acompanhamento extra consulta aos doentes?
    - Se sim, como e em que circunstâncias?
    - Quais as vantagens e limitações dos meios que usam?
- Na vossa opinião, que outros mecanismos de interação poderiam existir para ajudar a prestar um melhor acompanhamento a estes doentes?
    - E de que forma é que poderia(m) ser operacionalizado(s)?

D. Perceção dos nutricionistas do HB relativamente à experiência dos doentes DT1 (dentro do contexto hospitalar – consultas e ambiente geral do hospital):

- Na vossa perceção, como é que os doentes DT1 se sentem e se comportam durante as consultas de nutrição?
- Na vossa opinião, o que poderá ser feito para melhorar a experiência e a adesão dos doentes às consultas de nutrição?
- Na vossa perceção, como tem corrido a interação dos doentes com a equipa de profissionais do serviço? e com a equipa do HB em geral?
- Na vossa opinião, o que poderia ser feito para melhorar a experiência dos doentes no que respeita aos relacionamentos com os profissionais de saúde do serviço e do HB?
- Na vossa perceção, como tem sido a experiência dos doentes com o ambiente geral do hospital e com os recursos disponíveis?
- Têm conhecimento de algum descontentamento ou desconforto dos doentes em relação a esses aspetos?
    - Se sim, quais?
- Na vossa opinião, o que poderá ser feito para melhorar a experiência dos doentes com o ambiente geral do HB?

E. Perceção dos nutricionistas do HB relativamente à experiência dos doentes DT1 (fora do contexto hospitalar – gestão da doença no dia a dia):

- Na vossa perceção, e tendo em consideração as especificidades do plano alimentar desses doentes, como é que tem sido a adesão deles ao plano?
- Na vossa perceção, quais os principais obstáculos no cumprimento do plano e curto e longo prazo?
- Na vossa opinião, o que poderá ser feito para melhorar a adesão dos doentes ao plano/ terapêutica alimentar?
- E que outros obstáculos os doentes encontram, na gestão diária da sua doença?
- Na vossa opinião, o que poderia ser feito para contornar ou controlar melhor esses obstáculos?
- Na vossa opinião, como poderíamos potenciar uma aproximação entre estes doentes na mesma condição para que pudessem beneficiar de trocas de experiências?

F. Aspetos adicionais de clarificação:

- Gostariam de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

GUIÃO DE ENTREVISTA – NUTRICIONISTAS (IRC E 4-5)

Data / local / entrevistado:

_____

Agradecimentos e consentimento:

Muito obrigado por ter aceite fazer parte deste trabalho de investigação. O presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB). Neste estudo iremos conduzir entrevistas com profissionais de saúde do HB nomeadamente nutricionistas responsáveis por prestar cuidados a doentes IRC. O objetivo é explorar e compreender a experiência dos profissionais de saúde do HB (nutricionistas) enquanto prestadores de cuidados de saúde a doentes com IRC E 4-5 , bem como compreender a sua perceção sobre a experiência desses mesmos doentes, ao longo da sua jornada. Com o seu consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o seu total anonimato. A sua participação é livre, pelo que não existirão quaisquer consequências se pretender/necessitar de terminar a entrevista antecipadamente.

A. Contextualização /enquadramento dos nutricionistas:

- Data nascimento
- Localidade
- Número de anos de experiência profissional
- Número de anos no serviço e no hospital
- Experiência profissional noutros hospitais (se existente)

B. Funções, responsabilidades e rotinas dos nutricionistas no HB e no serviço:

- Quais são as suas principais atividades / funções e responsabilidades no serviço?
- Na sua opinião, como é trabalhar no serviço de nutrição do HB?
- Que principais aspetos positivos e negativos é que encontra?

C. Experiência dos nutricionistas do HB em interação com doentes IRC E 4-5 no HB (consultas):

- Descreva como é que tipicamente decorrem as primeiras consultas e as consultas de seguimento de nutrição com os doentes?
- Que principais diferenças existem entre as primeiras consultas e as de seguimento?
- Que obstáculos encontra (se existirem) nas consultas com estes doentes?

- E os aspetos facilitadores (se existirem)?
- Tem por hábito providenciar algum tipo de fonte adicional de informação aos doentes para que eles possam pesquisar e saber mais sobre as o comportamento alimentar associado à sua condição?
- Gostaria de partilhar algum episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com estes doentes nas vossas consultas e que os/as tenham marcado?
- Na sua opinião, o que poderá ser feito para melhorar a sua experiência na realização das consultas com estes doentes?
- Como é que descreve a relação que tem mantido com estes doentes?
- Que aspetos positivos e negativos é que identificam na relação que mantém com os doentes?
- O que é que poderia ser feito para melhorar a sua relação com os doentes?
- Presta algum tipo de apoio ou acompanhamento extra consulta aos doentes?
    - Se sim, como e em que circunstâncias?
    - Quais as vantagens e limitações dos meios que usa?
- Na sua opinião, que outros mecanismos de interação poderiam existir para ajudar a prestar um melhor acompanhamento a estes doentes?
    - E de que forma é que poderia(m) ser operacionalizado(s)?

C. <u>Perceção dos nutricionistas do HB relativamente à experiência dos doentes DT1 (dentro do contexto hospitalar – consultas e ambiente geral do hospital):</u>

- Na sua perceção, como é que os doentes DT1 se sentem e se comportam durante as consultas de nutrição?
- Na sua opinião, o que poderá ser feito para melhorar a experiência e a adesão dos doentes às consultas de nutrição?
- Na sua perceção, como tem corrido a interação dos doentes com a equipa de profissionais do serviço? e com a equipa do HB em geral?
- Na sua opinião, o que poderia ser feito para melhorar a experiência dos doentes no que respeita aos relacionamentos com os profissionais de saúde do serviço e do HB?
- Na sua perceção, como tem sido a experiência dos doentes com o ambiente geral do hospital e com os recursos disponíveis?
- Tem conhecimento de algum descontentamento ou desconforto dos doentes em relação a esses aspetos?
    - Se sim, quais?
- Na sua opinião, o que poderá ser feito para melhorar a experiência dos doentes com o ambiente geral do HB?

D. <u>Perceção dos nutricionistas do HB relativamente à experiência dos doentes IRC E 4-5- (fora do contexto hospitalar – gestão da doença no dia a dia):</u>

- Na sua perceção,e tendo em consideração as especificidades do plano alimentar desses doentes, como é que tem sido a adesão deles ao plano?

- Quais os principais obstáculos no cumprimento do plano e curto e longo prazo?
- Na sua opinião, o que poderá ser feito para melhorar a adesão dos doentes ao plano/ terapêutica alimentar?
- E que outros obstáculos os doentes encontram, na gestão diária da sua doença?
- Na sua opinião, o que poderia ser feito para contornar ou controlar melhor esses obstáculos?
- Na sua opinião, como poderíamos potenciar uma aproximação entre estes doentes na mesma condição para que pudessem beneficiar de trocas de experiências?

F. Aspetos adicionais de clarificação:

- Gostariam de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

GUIÃO DE ENTREVISTA - CUIDADORES INFORMAIS

Data / local / entrevistado:

_____

Agradecimentos e consentimento:

Muito obrigado por ter aceite fazer parte deste trabalho de investigação. O presente estudo insere-se no contexto de desenvolvimento de uma tese de doutoramento cujo principal objetivo é compreender a experiência dos doentes crónicos com Diabetes Tipo-1 (DT1) e Insuficiência Renal Crónica em estadios avançados (IRC E 4-5) ao longo da sua jornada e do tempo. O termo "jornada" define o conjunto de todas as etapas pelas quais o doente passa desde o momento em que ele reconhece sintomas até que abandona o hospital/clínica e passa a gerir a sua condição no dia a dia. Assim, através do estudo da experiência dos doentes com patologias crónicas, este estudo objetiva contribuir para uma melhoria do bem-estar dos doentes e para uma melhoria dos serviços de saúde que lhes são prestados por parte do Hospital de Braga (HB). Neste estudo iremos conduzir entrevistas com cuidadores informais de doentes IRC E 4-5. O objetivo é explorar e compreender a experiência dos CI enquanto tratadores de doentes IRC E4-5, bem como compreender a sua perceção sobre a experiência desses mesmos doentes, ao longo da sua jornada. Com o seu consentimento, gostaríamos de gravar esta entrevista para efeitos de análise de dados, salvaguardando, porém, o seu total anonimato. A sua participação é livre, pelo que não existirão quaisquer consequências se pretender/necessitar de terminar a entrevista antecipadamente.

A. <u>Experiência dos CI nas primeiras consultas, consultas de seguimento e tratamentos dos doentes com IRC E4-5:</u>

- Acompanhou o doente nas primeiras consultas de nefrologia?
- Conte-nos como foi a sua experiência a acompanhar o doente nessas primeiras consultas?
- Gostaria de partilhar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com a equipa de profissionais de saúde, nas primeiras consultas e que o/a tenha marcado?
- Na sua opinião, o que poderá ser feito para melhorar a experiência dos CI que acompanham os doentes nas primeiras consultas?

- Tem por hábito acompanhar o doente nas consultas de seguimento?
- Quando foi a última vez que o acompanhou?
- Conte-nos como foi a sua experiência com as consultas de seguimento.
- Gostaria de partilhar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com a equipa de profissionais de saúde, nas consultas de seguimento e que o/a tenha marcado?
- Na sua opinião, o que poderá ser feito para melhorar a sua experiência enquanto CI do doente nas consultas de seguimento?

— Tem por hábito acompanhar o doente para a realização de tratamentos no HB?
— Quando foi a última vez que o acompanhou a um tratamento no HB?
— Relativamente a essa vez, conte-nos como foi a sua experiência como acompanhante na realização do tratamento do doente.
— Gostaria de partilhar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com a equipa de enfermagem/auxiliar nessas consultas e que o/a tenha marcado?
— Na sua opinião, o que poderá ser feito para melhorar a sua experiência enquanto CI do doente na realização dos tratamentos?

— Relativamente à sua mais recente visita ao HB, como se sentiu relativamente ao ambiente geral do hospital (instalações, limpeza, recursos disponíveis, ambiente da sala de espera, etc.)?
— Pode contar algum episódio positivo ou negativo que tenha acontecido no HB ao longo das suas últimas visitas e que tenha sido relevante para si?
— O que sugeria para melhorar o ambiente geral do HB?

— Relativamente ao relacionamento com a equipa médica, como é que descreve a relação que tem mantido com a equipa médica que o segue no HB? E relativamente aos restantes profissionais de saúde do HB?
— Existe algum aspeto positivo ou negativo que gostasse de partilhar connosco?
— O que sugeria para melhorar esses aspetos?

— Relativamente à mais recente visita ao HB, conte-nos como se sentiu com o ambiente geral do hospital.
— Pode contar algum um episódio (se existir) relativo a qualquer interação (positiva ou negativa) que tenha tido com a equipa de profissionais nas mais recentes idas ao hospital e que o/a tenha marcado?
— Na sua opinião, o que poderá ser feito para melhorar o ambiente geral do hospital?

— Como é que descreve a relação que tem mantido com a equipa de profissionais do HB?
— Que aspetos positivos e negativos é que identifica na relação que mantém com eles?
— Na sua opinião, o que é que poderá ser feito para melhorar a sua relação com a equipa de profissionais do HB?

B.<u>Experiência do CI na interação com o doente no dia-a-dia:</u>
— Que apoio/suporte é que presta ao doente diariamente?
— Descreva-nos um dia típico enquanto CI.
— No geral, como tem sido a experiência de cuidar de um doente IRC E 4-5 diariamente?
— Quais os principais desafios inerentes ao papel de um CI?
— Na sua opinião, o que poderá ser feito para conseguir exercer melhor as suas atividades de apoio/suporte diariamente?

C. Perceção dos CI sobre a experiência dos doentes com IRC E 4-5 (dentro e fora do contexto hospitalar) e a perceção sobre o seu próprio envolvimento nessas experiências:

- Tem conhecimento das opções (hospitais/médicos) que o doente procurou inicialmente e como procurou?
- Qual foi o seu papel nesse processo?
- Na sua perceção, como foi a experiência do doente com as primeiras consultas?
- Na sua opinião, o que poderá ser feito para melhorar a experiência dos doentes nas primeiras consultas?
- Na sua perceção, como tem sido a experiência do doente com as consultas de seguimento?
- Na sua opinião, o que poderá ser feito para melhorar a experiência dos doentes nas consultas de seguimento?
- Na sua perceção, como tem sido a experiência do doente com os tratamentos realizados no HB?
- Na sua opinião, o que poderá ser feito para melhorar a experiência do doente com os tratamentos realizados no HB?

- Na sua perceção, como tem sido a experiência do doente com o ambiente geral do hospital? E com o serviço de nefrologia?
- Na sua opinião, o que poderá ser feito para melhorar a experiência do doente quando se encontra no hospital? E no serviço de nefrologia?

D. Perceção dos CI sobre a influência da doença no dia-a-dia do doente:

- Na sua perceção, como é que a doença tem influenciado as diferentes áreas da vida do doente (a nível profissional, pessoal, social)?
- O que é que o doente costuma fazer no seu dia a dia para o ajudar a lidar com a sua doença? Por dar-nos alguns exemplos?
- O doente procura saber mais sobre a sua doença? A que meios é que recorre?
- Na sua perceção, como é que o doente tem lidado com a medicação / tratamentos diários?
- Que principais obstáculos / dificuldades é que identifica? Como é que o/a procura ajudar?
- O que poderia ser feito para melhorar a adesão do doente à terapia/medicação?
- Para além de si, quem é que lhe tem prestado maior apoio/suporte diariamente? (amigos, familiares colegas, outros doentes, profissionais de saúde)?
- E como é que têm prestado esse apoio/suporte?
- Na sua visão, o que deveria ser feito para melhorar o apoio fornecido ao doente e a outros doentes na mesma condição?
- De que forma se poderia potenciar uma aproximação entre doentes na mesma condição para que pudessem beneficiar de trocas de experiências?

E. Aspetos adicionais de clarificação:

- Gostaria de acrescentar algo mais ao que foi falado ou algum ponto de clarificação?

F. Contextualização /enquadramento dos CI:

— Data de nascimento
— Localidade
— Idade
— Nível de escolaridade
— Profissão atual
— Que tipo de relação mantém com o doente (ex: familiar, amigo...)?
— Vive com o/a doente?

APPENDIX VI - INFORMANTS DETAILED INFORMATION

Informant	Gender	Age	Location	Level of Education	Employment status	Health insurance	Smoking habits	Drinking alchol	Physical activity
T1D_1. Amandine	Female	31	Braga district	Higher education	Non active	No health insurance	Nonsmoker	No alcohol	Regular physical activity
T1D_2. Victoriah	Female	20	Braga district	Higher education	Non active	No health insurance	Nonsmoker	No alcohol	Regular physical activity
T1D_3. Carol	Female	56	Braga district	High school	Non active	No health insurance	Smoker	No alcohol	No physical activity
T1D_4. Doug	Male	21	Other north locations	High school	Non active	Health insurance	Nonsmoker	Regular drinking	Regular physical activity
T1D_5. Doninic	Male	39	Braga district	High school	Active	No health insurance	Smoker	Residual	Residual physical activity
T1D_6. Joe	Male	22	Braga district	higher education	Non active	Health insurance	Smoker	Regular drinking	Regular physical activity
T1D_7. Julio	Male	50	Braga district	Basic /primary school	Active	No health insurance	Smoker	No alcohol	No physical activity
T1D_8. Josef	Male	27	Braga district	High school	Non active	Health insurance	Smoker	Regular drinking	Regular physical activity
T1D_9. Juliaanne	Female	25	Braga district	Higher education	Non active	health insurance	Nonsmoker	No alcohol	No physical activity
T1D_10. Marylin	Female	24	Braga district	High school	Active	No health insurance	Smoker	Residual drinking	Regular physical activity
ESRF_1. Antoine	Male	51	Other north locations	Higher education	Active	No health insurance	Nonsmoker	Residual	Regular physical activity
ESRF_2. Cliston	Male	82	Braga district	Higher education	Non active	health insurance	Nonsmoker	Regular drinking	Residual physical activity
ESRF_3. Daniyal	Male	51	Braga district	Basic /primary school	Non active	No health insurance	Nonsmoker	No alcohol	No physical activity
ESRF_4. Frantz	Male	71	Braga district	Basic /primary school	Non active	No health insurance	Nonsmoker	Regular drinking	No physical activity

ESRF_5. Franke	Male	70	Other north locations	Basic /primary school	Active	No health insurance	Nonsmoker	Regular drinking	No physical activity
ESRF_6. Lourdez	Female	64	Braga district	Basic /primary school	Non active	No health insurance	Nonsmoker	No alcohol	Residual physical activity
ESRF_7. Rosaire	Female	47	Other north locations	Basic /primary school	Non active	No health insurance	Nonsmoker	No alcohol	No physical activity
ESRF_8. Rosale	Female	77	Braga district	Basic /primary school	Non active	No health insurance	Nonsmoker	Residual drinking	Residual physical activity
ESRF_9. Ray	Male	84	Braga district	Higher education	Non active	Health insurance	Nonsmoker	No alcohol	No physical activity

Informant	Gender	Level of education	N (years of medical experience)	N (years at the Hospital of Braga)
Nutritionist 3, Endocrinology	Female	Bachelor	8	8
Nutritionist 2, Endocrinology	Female	Bachelor	7	4
Endocrinologist 2	Female	Master degree	8	1,5
Nutritionist 5, Endocrinology	Female	Bachelor	8	2
Endocrinologist 3	Female	Master degree	26	2
Nutritionist 4, Endocrinology	Female	Master degree	8	2
Nurse, Endocrinology 2	Male	Bachelor	37	5
Nurse, Endocrinologiy 1	Female	Master degree	14	12
Endocrinlogist 1	Female	PhD Candidate	10	1.5
Nurse 1, Endocrinology	Female	Bachelor	23	8
Nephrologist 1	Female	Master degree	20	1,5
Nephrologist 2	Female	Master degree	13	4
Nurse, Nephrology 1	Female	Master degree	26	22
Nutritionist, Nephrology 1	Female	Master degree	12	10
Nephrologist 3	Male	Master degree	30	8

Informant	Gender	Level of education	Job	Age
FAM_1	Female	Bachelor	Reformed	70
Informal caregiver_1	Female	High School	Unemployed	25
Informal caregiver_2	Female	High School	Reformed	46
Informal caregiver_3	Female	Basic /primary school	Works in a nursing home	55

*all informants have been assigned pseudonyms to preserve confidentiality.