Universidade do Minho
Escola de Psicologia

Fábio Martim Sousa e Santos

Contribuição dos Fatores Psicológicos para a Cicatrização de Lesões por Queimaduras na Pele e Qualidade de Vida em Crianças: Um Estudo Longitudinal

abril de 2024

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Fábio Santos

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Trabalho efetuado sob a orientação da
Professora Doutora Maria da Graça Pereira Alves

abril de 2024

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CONTRIBUIÇÃO DOS FATORES PSICOLÓGICOS PARA A CICATRIZAÇÃO DE LESÕES POR QUEIMADURAS NA PELE E QUALIDADE DE VIDA EM CRIANÇAS: UM ESTUDO LONGITUDINAL

Resumo

As lesões por queimaduras na pele constituem um marcante problema de saúde pública e, apesar de serem na sua maioria preveníveis, permanecem como uma das principais causas de morbilidade e mortalidade na infância, a nível mundial. Em Portugal, 20% dos casos são crianças com idade inferior aos cinco anos. Estas lesões traumáticas impactam negativamente a qualidade de vida relacionada com a saúde (QVRS) destas crianças e desencadeiam vários *stressores* familiares. O presente trabalho apresenta três estudos organizados em capítulos que visam aprofundar o conhecimento do impacto das lesões por queimaduras em idade pediátrica no funcionamento psicossocial e familiar, e nos resultados de saúde da criança. O primeiro capítulo apresenta um estudo de revisão sistemática da literatura que sistematizou e sintetizou o conhecimento científico de 33 anos de investigação relativamente aos fatores/preditores e consequências do *distress* parental neste contexto. O segundo capítulo apresenta um estudo qualitativo que descreveu as perceções e experiências de 46 pais de crianças em idade pré-escolar (dos zero aos seis anos) com lesões por queimaduras não intencionais durante o internamento hospitalar. O último capítulo apresenta um estudo longitudinal quantitativo que analisou diferenças ao nível dos sintomas de *distress* dos pais (i.e., ansiedade, depressão e stress traumático), *coping* parental, funcionamento familiar, qualidade da cicatriz e QVRS da criança, ao longo de quatro momentos: (T0) durante o internamento hospitalar; (T1) um mês após a alta hospitalar; (T2) três meses após; e (T3) seis meses após. Além disso, analisou o papel mediador do funcionamento familiar na relação entre o *distress* parental e a qualidade da cicatriz da criança. Os resultados mostraram que estes pais apresentam uma acentuada vulnerabilidade emocional e psicossocial, sobretudo durante a fase do internamento hospitalar. O ajustamento psicossocial dos pais (*coping* e sintomas de *distress*) e os resultados da QVRS da criança melhoraram até seis meses após a alta, à exceção do funcionamento familiar, que decresceu significativamente quando comparado à avaliação inicial. Verificou-se ainda um efeito de mediação total do funcionamento familiar na relação entre o *distress* e a qualidade da cicatriz. Por fim, apresentam-se implicações para a teoria e investigação, para a prática e para o treino de profissionais, bem como considerações societais sobre o impacto dos estudos.

Palavras-chave: cicatrização, crianças em idade pré-escolar, *distress* parental, lesões por queimaduras, qualidade de vida

CONTRIBUTION OF PSYCHOLOGICAL FACTORS TO BURN INJURIES HEALING AND QUALITY OF LIFE IN CHILDREN: A LONGITUDINAL STUDY

Abstract

Burn injuries are a major public health problem and, despite being mostly preventable, remain one of the main causes of morbidity and mortality in childhood worldwide. In Portugal, children under the age of five account for 20% of all cases. These traumatic injuries have a negative impact on these children's health-related quality of life (HRQoL) and trigger several family stressors. This work presents three studies organized into chapters that aim to deepen knowledge about the impact of pediatric burn injuries on psychosocial and family functioning, and on children's health outcomes. The first chapter presents a systematic literature review that systematized and synthesized the scientific knowledge of 33 years of research into the factors/predictors and consequences of parental distress in this context. The second chapter presents a qualitative study that described the perceptions and experiences of 46 parents of pre-school children (aged zero to six years) with unintentional burn injuries during hospital stay. The final chapter presents a quantitative longitudinal study that analyzed differences in parental distress symptoms (i.e. anxiety, depression, and traumatic stress), parental coping, family functioning, scar quality, and the child's HRQoL at four different moments: (T0) during hospital stay; (T1) one month after hospital discharge; (T2) three months later; and (T3) six months later. It also analyzed the mediating role of family functioning in the relationship between parental distress and the child's scar quality. The results showed that these parents display marked emotional and psychosocial vulnerability, especially during the hospital stay phase. Parents' psychosocial adjustment (coping and distress symptoms) and the child's HRQoL outcomes improved up to six months after discharge, except for family functioning, which decreased significantly when compared to the baseline assessment. Family functioning fully mediated the relationship between distress and scar quality. Finally, implications for theory, research, practice, and professional training are presented, as well as societal considerations on the impact of the studies.

Keywords: burn injuries, healing, parental distress, preschool children, quality of life

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LISTA DE ABREVIATURAS E ACRÓNIMOS

ASDS – *Acute Stress Disorder Scale*

BDI – *Beck Depression Inventory*

CHIP – *Coping Health Inventory for Parents*

CI – *Confidence Interval*

DASS-21 – *Depression Anxiety Stress Scale-21*

FAD-GF – *Family Assessment Device - General Functioning*

GGS – *Global Guilt Scale*

HADS – *Hospital Anxiety and Depression Scale*

HRQoL – *Health-related quality of life*

IES – *Impact of Event Scale*

IES-R – *Impact of Event Scale-Revised*

LoS – *Hospital length of stay*

M – *Mean*

NHLBI – *National Heart, Lung, and Blood Institute*

PMC – *Child's pre-existing medical condition*

PMTS – *Pediatric Medical Traumatic Stress*

QVRS – Qualidade de vida relacionada com a saúde

PRISMA – *Preferred Reporting Items for Systematic Reviews and Meta-analyses*

PSI – *Parenting Stress Index*

PTSD – *Posttraumatic stress disorder*

PTSS – *Posttraumatic stress symptoms*

QoL – *Quality of life*

SD – *Standard deviation*

SE – *Standard error*

STAI – *State-Trait Anxiety Inventory*

TAPQoL – *TNO-AZL Preschool Children Quality of Life Questionnaire*

TBSA – *Total body surface area*

UAG MC – *Autonomous Management Unit of Women and Children*

VSS – *Vancouver Scar Scale*

WHO – *World Health Organization*

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INTRODUÇÃO

De acordo com a Organização Mundial de Saúde, as lesões por queimaduras na pele são um preocupante problema de saúde pública a nível mundial, e correspondem a uma das principais causas de anos de vida saudável perdidos por morte prematura, doença ou incapacidade em países subdesenvolvidos ou em desenvolvimento (World Health Organization [WHO], 2023). Apesar de serem, na sua maioria evitáveis, estima-se que este tipo comum de lesões físicas provoque cerca de 180 mil mortes por ano (WHO, 2023). Estudos epidemiológicos recentes mostram que parece existir uma tendência ascendente no número de novos casos (e.g., Yakupu et al., 2022), verificando-se uma especial incidência durante a primeira infância (Emond et al., 2016; Kemp et al., 2014). Por sua vez, devido aos progressivos avanços na medicina e no conhecimento especializado no tratamento destas lesões, as taxas de mortalidade associadas têm vindo a decrescer significativamente ao longo dos últimos anos (Smolle et al., 2017; Yakupu et al., 2022) remetendo para a necessidade de compreender as implicações a curto, médio e a longo-prazo que podem resultar desta experiência potencialmente traumática (e.g., Patterson et al., 2023; Ryan et al., 2015), essencialmente a partir de uma perspetiva biopsicossocial. A literatura recente sugere que as lesões por queimaduras devem ser vistas como uma condição crónica de saúde, pelas suas consequências dinâmicas e complexas ao longo do tempo, nomeadamente em termos de resultados de saúde e a nível do funcionamento psicossocial (Abouzeid et al., 2022). Uma revisão sistemática atual, centrada nas lesões por queimadura em idade pediátrica, realçou potenciais lacunas em determinadas áreas de conhecimento que possibilitariam uma visão mais abrangente e compreensiva acerca deste fenómeno e do seu impacto, em particular a carência de estudos focados em fatores socioambientais (e.g., papel da família) e educacionais, incluindo a sensibilização comunitária (Nassar et al., 2023). De facto, tendo em consideração que a maioria destas lesões são acidentais e decorrem, sobretudo, do desconhecimento dos pais sobre comportamentos preventivos e identificação de potenciais riscos domésticos (Moore et al., 2022), abordar e aprofundar o conhecimento no que concerne ao papel da família torna-se determinante, não só numa perspetiva de prevenção, mas também numa perspetiva de compreensão do ajustamento psicossocial no rescaldo do evento.

Uma expressiva proporção dos casos necessita de cuidados hospitalares imediatos após a queimadura que, dependendo dos indicadores de gravidade da lesão como a área total de superfície corporal queimada (TBSA) e a profundidade da queimadura, podem implicar a necessidade de internamento (Krasnoff et al., 2021; Palmieri et al., 2016). De acordo com uma revisão sistemática focada na classificação, identificação e processo de regeneração tecidular no domínio das lesões por queimadura (Abazari et al., 2020), a profundidade da queimadura é atualmente classificada como epidérmica (1.º grau), superficial parcial (2.º grau superficial), profunda parcial (2.º grau profunda),

profunda completa (3.º grau) e profunda completa + (3.º grau). O período de internamento é variável, mas sabe-se que é, tipicamente, mais prolongado, quando comparado ao de outras lesões pediátricas (e.g., Krasnoff et al., 2021). Durante esse período, existem vários *stressores* secundários ao evento principal (i.e., lesão por queimadura), designadamente os procedimentos cirúrgicos (e.g., enxertos de pele), que podem ser extremamente desafiantes e aumentar a vulnerabilidade dos pacientes e das suas famílias (Lernevall et al., 2020). Por conseguinte, evidências recentes sugerem que a forma como os pais reagem (emocional e psicologicamente) durante determinados procedimentos médicos, pode influenciar a reação e o ajustamento psicológico das crianças (Bakker et al., 2013; Brown et al., 2019a) ou, inclusive conduzir a um atraso no processo de recuperação das mesmas (e.g., reepitelização mais lenta; Brown et al., 2019b). De facto, parece existir uma coocorrência entre os sintomas experienciados pelos pais e os sintomas experienciados pelos seus filhos, nomeadamente sintomas de stress traumático (Egberts et al., 2018). Não obstante, o período após a alta hospitalar é igualmente marcado por diversos desafios e exigências familiares (Bakker et al., 2013; Lernevall et al., 2023), destacando-se o processo de cicatrização como um dos principais fatores contributivos, sendo as cicatrizes descritas na literatura como uma das consequências mais adversas resultantes deste tipo de lesões (e.g., Spronk et al., 2021). No processo de cicatrização estão envolvidos vários mecanismos fisiológicos (e.g., bioquímicos, celulares) que visam a reparação dos tecidos danificados pela lesão, compreendendo diferentes fases: hemóstase e inflamação (fase exsudativa), fase proliferativa e fase de remodelação (Abazari et al., 2020). À semelhança do que acontece noutras populações com feridas agudas, está documentado na literatura que existe uma relação significativa entre elevados níveis de stress psicológico e um atraso no processo da cicatrização destas lesões (Brown et al., 2019b). Contudo, ainda não é completamente claro (e.g., pela escassez de estudos longitudinais) como é que o ajustamento emocional e psicossocial dos pais (e.g., sintomas de stress traumático) influencia este processo, sobretudo em crianças em idade pré-escolar (zero aos seis anos), que além de estarem mais vulneráveis ao risco de lesão (Emond et al., 2016), são altamente dependentes das suas famílias (e.g., na satisfação das suas necessidades emocionais, psicológicas, socias) devido a características específicas da sua fase de desenvolvimento (Rimmer et al., 2015).

O Modelo Integrativo de Stress Traumático Pediátrico (*The Integrative Model of Pediatric Medical Traumatic Stress*; PMTS) postulado por Kazak et al. (2006), decursivo de acumulados anos de investigação científica e prática clínica no âmbito dos cuidados médicos pediátricos, fornece um robusto quadro teórico que promove uma compreensão mais integrada a respeito do impacto de determinadas condições de saúde em idade pediátrica com potencial traumático. Este modelo teórico, embora seja

genérico, tem um enfoque particular nas doenças oncológicas e nas lesões na infância, procurando esclarecer as influências (inter)relacionais dos sintomas psicológicos dos pais e os das crianças, nomeadamente sintomas de stress traumático. Situando-se num paradigma biopsicossocial, este racional teórico providencia alvos específicos para orientar a avaliação e intervenção com os pacientes pediátricos e, em particular, com as suas famílias, considerando que estas apresentam um aumentado risco de vulnerabilidade biopsicossocial ao longo da trajetória da condição médica, que influenciam os resultados das crianças. De acordo com este modelo, existem três fases principais que ajudam a compreender a evolução dos sintomas e o risco de desenvolvimento de stress traumático: (I) peri-trauma: durante e imediatamente após o evento de saúde potencialmente traumático (e.g., período entre a ocorrência da lesão por queimadura e o internamento); (II) respostas precoces, contínuas e evolutivas (e.g., perceções de risco de vida, sintomas de stress traumático); e (III) stress traumático a longo-prazo (e.g., após a conclusão dos tratamentos). Na fase I (peri-traumática), os autores esclarecem que uma determinada condição de saúde em idade pediátrica pode ser traumática para umas famílias e para outras não, uma vez que a mesma não é percecionada objetivamente por todas as famílias da mesma maneira, sendo precisamente a sua natureza subjetiva que a torna traumática. Além disso, sugerem que as respostas iniciais das crianças e dos seus pais aquando do evento, podem ter um papel preditivo na evolução dos sintomas de stress traumático ao longo da trajetória da doença/lesão. Na fase II, destacam como os múltiplos desafios que os pacientes pediátricos e as famílias enfrentam logo após a primeira fase, podem ter repercussões variadas, nomeadamente resistência à adesão ao tratamento e exacerbação de reações traumáticas aos procedimentos médicos. Por fim, na fase III, os autores consideram que não devemos generalizar a crença de que os sintomas de stress traumático diminuem, por si só, com o tempo, destacando que os pais são tipicamente mais sintomáticos e estão em maior risco para o desenvolvimento de stress traumático a longo-prazo do que as crianças. Kazak et al. (2006) assumem ainda cinco pressupostos determinantes para uma visão mais clara do ajustamento psicossocial da criança e da família nestas circunstâncias: 1) eventos de saúde potencialmente traumáticos partilham comunalidades entre si, independentemente das especificidades da condição clínica (e.g., os sintomas de stress traumático dos pais de crianças com cancro podem ser semelhantes aos dos pais de crianças com lesões físicas); 2) existe uma variedade de reações comuns em resposta a estes eventos potencialmente traumáticos, o que sugere que determinadas respostas podem ser normativas e não necessariamente traumáticas; 3) existe uma diversidade de fatores pré-existentes ao nível do funcionamento psicológico individual e familiar que influenciam o risco de stress traumático; 4) a adoção de uma lente desenvolvimental sobre o trauma é crucial para a sua compreensão; e 5) uma

abordagem socio-ecológica ou contextual é o ideal para a intervenção. Para cada uma das fases descritas anteriormente, baseado nestes pressupostos, os autores recomendam adaptações à intervenção. Por exemplo, a fase I deve ser focada nas práticas informadas pelo trauma e na intervenção precoce, a fase II em avaliar, prevenir e/ou reduzir os sintomas de stress traumático, e por último, a fase III deve ser centrada na redução desses sintomas. Uma recente atualização a este modelo, proposta por Price et al. (2016), realça que a evolução dos sintomas de stress traumático pode ser flutuante no tempo e está dependente das especificidades da trajetória da condição médica apresentada pela criança e da fase de tratamento, preconizando, com efeito, uma denominação mais compreensiva das fases anteriormente descritas: (I) fase peri-traumática (que inclui respostas iniciais imediatamente após a ocorrência do evento de saúde potencialmente traumático e durante as primeiras semanas); (II) fase aguda dos cuidados (fase ativa do tratamento que inclui, entre outros, os procedimentos cirúrgicos e as suas implicações); e (III) fase dos cuidados continuados ou alta dos cuidados (geralmente iniciada quando a criança deixa de correr riscos, por exemplo, de complicações, e os tratamentos tornam-se menos ativos). Esta revisão realça ainda a importância das perceções subjetivas dos pais (e.g., sentimentos de culpa, perceção de risco de vida) como um importante foco da avaliação e intervenção ao longo das diferentes fases, por desempenhar um papel preditivo para o desenvolvimento de stress traumático. Além disso, Price et al. (2016) apoiam os pressupostos anteriores e acrescentam um novo: 6) os sintomas de stress traumático afetam os resultados de saúde da criança (e.g., qualidade de vida relacionada com a saúde [QVRS]).

Mais recentemente, a medição da QVRS, que se refere a um amplo construto de natureza multidimensional, tem sido reconhecida como tendo um papel coadjuvante na compreensão do estado geral de saúde (e.g., emocional, físico, social) após lesões por queimaduras na pele (van Loey et al., 2012). De facto, vários estudos têm concluído que as perceções dos pais sobre a QVRS de crianças vítimas de lesões por queimaduras (forma mais comum de medição nestes casos), são muito similares à perceção das próprias (e.g., Pan et al., 2015). Embora evidências recentes mostrem que há uma melhoria da QVRS nas lesões por queimaduras em idade pediátrica ao longo do tempo (Koljonen et al., 2013; Rashaan et al., 2019; Spronk et al., 2018, 2023), são necessários mais estudos longitudinais para compreender o seu impacto, tal como sugerido por outros autores (e.g., Patterson et al., 2023). Considerando o sexto pressuposto do Modelo Integrativo de PMTS (Kazak et al., 2006; Price et al., 2016), torna-se, de facto, imperioso avaliar a QVRS nesta população pediátrica, partindo de uma perspetiva familiar, até porque as lesões por queimadura em idade pediátrica despoletam um conjunto implicações multifatoriais que, além de impactarem significativamente a qualidade de vida geral da criança

(Townsend et al., 2023), comprometem o bem-estar e funcionamento familiar (Bakker et al., 2013; Lernevall et al., 2023; Wickens et al., 2024). Além disso, um estudo verificou que a idade da criança e o funcionamento familiar foram os únicos preditores significativos de QVRS, sugerindo que idade mais precoce na criança aquando da lesão e um pior funcionamento familiar contribuem significativamente para uma pior QVRS (Landolt et al., 2002).

O Modelo Conceptual de QVRS (*Conceptual Model of Burn Scar Health-Related Quality of Life*), proposto por Simons et al. (2016), é um modelo teórico específico para as lesões por queimaduras na pele, decursivo da análise das perspetivas das próprias vítimas (em idade pediátrica e adulta), que visa promover a compreensão do impacto deste fenómeno traumático, complexo e dinâmico, nos resultados de saúde dos sobreviventes. Com efeito, este modelo fornece um suporte teórico atualizado e compreensivo, que reflete os efeitos diretos e indiretos de um conjunto de fatores (proximais e distais) na QVRS. De acordo com os autores, existe um fator proximal (sintomas específicos decursivos da lesão) e sete fatores distais (funcionamento emocional, funcionamento físico, funcionamento cognitivo, funcionamento social, intervenções específicas, características do ambiente e características individuais), que impactam diretamente ou através da mediação de outros fatores, os resultados de saúde relacionados com as cicatrizes e a qualidade de vida geral ao longo do tempo. Testar este modelo, numa perspetiva familiar e longitudinal, pode constituir um primeiro passo para colmatar algumas das lacunas previamente identificadas, especialmente no que concerne ao conhecimento das lesões por queimadura em idade pré-escolar. Contudo, ainda em relação a essa faixa do desenvolvimento, levantam-se outras questões emergentes, tais como: que fatores contribuem para o *distress* parental (e.g., ansiedade, depressão, stress traumático)? Quais as implicações do *distress* parental, para os próprios e para as crianças? Que fatores, em concreto, constituem obstáculos ao ajustamento emocional e psicossocial dos pais durante o internamento hospitalar e que podem originar potenciais dificuldades no pós-alta (e.g., a nível familiar, na recuperação da criança)? Como é que estes sintomas evoluem ao longo do tempo? Qual é, de resto, o papel da família nestas relações complexas?

A presente tese procura dar resposta a algumas destas questões, fornecendo contributos importantes a respeito do impacto das lesões por queimaduras na pele durante a infância (zero aos seis anos) no funcionamento psicossocial e familiar, e resultados de saúde da criança, através de uma lente biopsicossocial, sendo sustentada empiricamente pelos modelos teóricos supramencionados. Um dos fatores que motivou o seu desenvolvimento, foi o retrato deste fenómeno na realidade nacional. Em Portugal, um quinto das vítimas são crianças com idade inferior aos cinco anos como resultado de acidentes que ocorreram em ambiente doméstico/familiar (Santos et al., 2016, 2019). A maior parte

das hospitalizações, na ordem dos 43%, registam-se na região Norte do país (Santos et al., 2019). Os dados disponíveis referem que o tempo médio de internamento são nove dias (Santos et al., 2019) e os custos, por doente, ultrapassam os oito mil euros anuais (Santos et al., 2016), posicionando Portugal acima da média europeia (Brusselaers et al., 2010). Apesar destes indicadores, poucos estudos se têm centrado neste fenómeno em idade pediátrica, para além de uma perspetiva socioeconómica, demográfica e/ou meramente clínica (e.g., Santos et al., 2016, 2019). Não se conhecem estudos publicados que tenham adotado uma perspetiva biopsicossocial ou que tivessem um enfoque familiar e psicossocial, cumulativamente. Além disso, apenas recentemente foi criada a primeira unidade pediátrica especializada no tratamento de lesões por queimadura na região Norte. Deste modo, caracterizar-se esta população e as suas famílias, considerando variáveis sociodemográficas e clínicas, psicossociais, familiares e de saúde, bem como identificar necessidades específicas e elucidar sobre se os dados em Portugal convergem ou divergem com o preconizado pela literatura internacional, pode ser útil para informar futuras políticas públicas de saúde e auxiliar o desenvolvimento de programas de intervenção baseados na evidência. Intervenções devidamente orientadas para além dos benefícios diretos para estas famílias e crianças, poderão reduzir os custos públicos (e.g., redirecionando recursos) e diminuir a sobrecarga relacionada no Serviço Nacional de Saúde.

O presente trabalho está focado em três principais estudos que se encontram organizados em capítulos. O primeiro capítulo irá responder mais diretamente às duas primeiras questões anteriormente colocadas, apresentado um estudo de revisão sistemática da literatura intitulado "*Parental Distress Following Pediatric Burn Injuries: A Systematic Review of 33 Years of Research*", que sistematiza e sumariza o conhecimento científico de 33 anos de investigação no tema. Os objetivos principais dessa revisão passarão por explorar, analisar e sintetizar a literatura existente no que concerne a: (a) fatores e/ou preditores de *distress* em pais de crianças vítimas de lesões por queimaduras não intencionais; (b) consequências do *distress* parental para os pais e para as crianças.

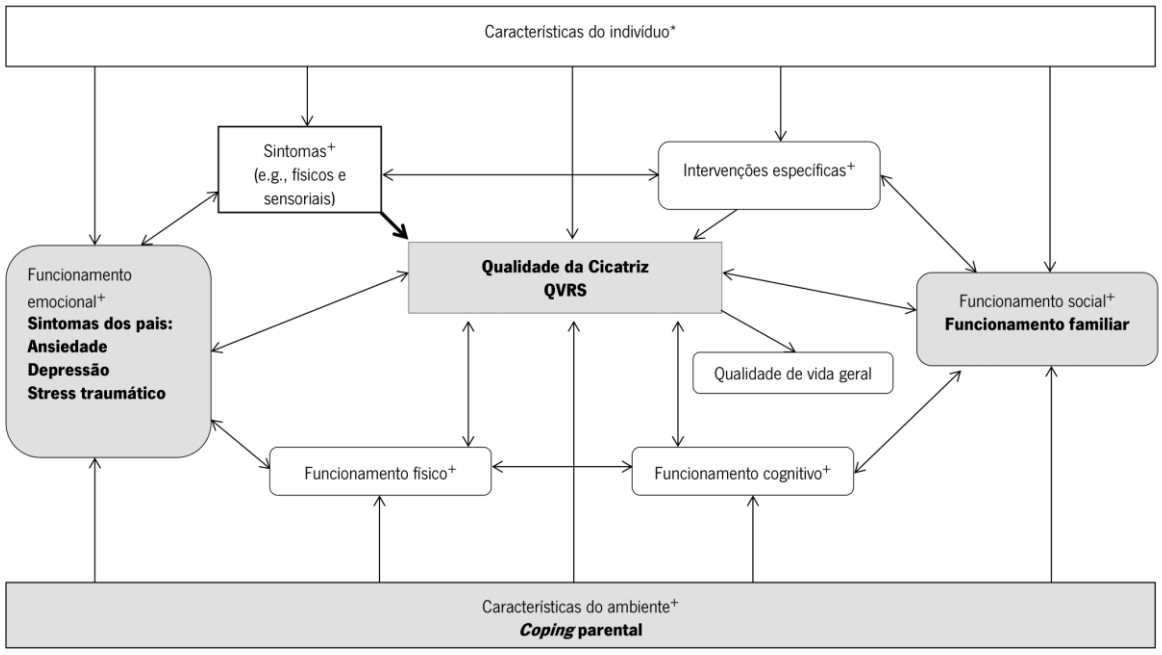
O segundo capítulo apresenta um estudo qualitativo intitulado "*Perceptions and Experiences of Parents of Burn-Injured Children during Hospital Stay: A Need for Integrated Care*" que incidirá de uma forma mais aprofundada na compreensão e descrição das perceções e experiências dos pais de crianças em idade pré-escolar que foram vítimas de lesões por queimaduras não intencionais, durante o internamento hospitalar.

Por último, o terceiro capítulo incide num estudo longitudinal quantitativo intitulado "*Longitudinal Changes on Burn Scar and Health-Related Quality of Life in Pediatric Burn Patients: The Mediating Role of Family Functioning*". Este estudo procurará analisar diferenças ao nível das variáveis psicossociais dos

pais (i.e., sintomas de ansiedade, depressão e stress traumático, e *coping* parental), variáveis familiares (i.e., funcionamento familiar) e variáveis de resultados de saúde da criança (i.e., qualidade da cicatriz e QVRS) ao longo de quatro momentos temporais: durante o internamento hospitalar (T0); um mês após a alta hospitalar (T1); três meses após a alta hospitalar (T2); e seis meses após a alta hospitalar (T3). Além disso, também analisará o papel mediador do funcionamento familiar na relação entre os sintomas de ansiedade, depressão e stress traumático dos pais, e a qualidade da cicatriz da criança. A fundamentação teórica deste último estudo assentará no Modelo Conceptual de QVRS nas queimaduras (Simons et al., 2016). As adaptações necessárias ao modelo original são apresentadas na Figura 1. As dimensões destacadas a cinza correspondem aos fatores distais e de resultado utilizados, com a respetiva indicação das variáveis em estudo (a negrito).

Figura 1

Modelo adaptado com base no Conceptual Model of Burn Scar Health-Related Quality of Life (Simons et al., 2016)



Nota. *inclui componentes mistas que podem ou não sofrer mudanças ao longo do tempo | +O impacto destas componentes sofre mudanças ao longo do tempo

CAPÍTULO 1:

Parental Distress Following Pediatric Burn Injuries: A Systematic Review of 33 Years of Research

[Manuscrito submetido para publicação]

Abstract

Burns are a common cause of unintentional injuries in childhood and a major global public health issue. Parents of pediatric burn patients constitute a vulnerable group for psychological distress. The present systematic review aimed to synthesize the existing evidence on the factors/predictors and consequences of parental distress following pediatric burn injuries. According to PRISMA guidelines, Web of Science, PubMed, and PsycINFO databases were searched until November 2021. Of the thirty-eight articles included, only fourteen were longitudinal. Two reviewers independently assessed the methodological quality using an established tool, and most were of fair quality. Twenty-eight studies explored factors/predictors of parental distress, twenty studies identified its consequences and eleven studies reported subgroup differences. Parents' and children's sociodemographic, psychological, psychosocial, family, and burn-related variables were significantly associated/contributed to parental distress. According to the results, initial levels of parental distress were considered a strong predictor of long-term distress. Results also suggested that parental distress was a significant potential risk factor for children's traumatic symptoms, behavior problems, and worse health outcomes, including quality of life, with mothers being the most affected. Most parental distress symptoms decreased over time. Our findings underlined the need for routine parent psychosocial screening and the implementation of trauma-informed multidisciplinary care.

Keywords: parental distress, pediatrics, burns, mental health, family, systematic review

Introduction

In recent years, the World Health Organization (WHO) has stated that burn injuries are a critical public health problem, accounting for around 180,000 deaths per year (WHO, 2023). Although mortality rates are currently showing a downward trend, the number of new cases has been increasing globally (Yakupu et al., 2022). For the pediatric population, that tendency is not linear, and several factors may explain that variability (e.g., age and stage of child development, country income level) (Duke et al., 2015; Kyu et al., 2016).

Pediatric burns are the third most common cause of unintentional injuries worldwide (Palmieri, 2016), and the leading cause of mortality and disability, particularly at younger ages and in developing countries (Alonge & Hyder, 2014; Forjuoh, 2006; Kyu et al., 2016; Palmieri, 2016). The prevalence of burn injuries in children younger than five years old is around 10% and in older children about 9.7%, with an incidence of 42 and 14 cases per 1000 person-years, respectively (Emond et al., 2016). Hence, children account for almost 50% of all burn cases (Dissanaike & Rahimi, 2009) and are four times more likely to be burned than adults (Legrand et al., 2020).

Unintentional pediatric burn injuries usually result from household accidents and scalds, particularly from hot liquids, and thermal burns, are among the most frequent causes (Armstrong et al., 2021; Drago, 2005; Forjuoh, 2006). It is well established that children represent a risk group for a burn injury due to their unpredictable behavior and developmental phase, which leads them to have a lower risk perception and a longer reaction time (Toon et al., 2011). Furthermore, pediatric burns deserve special attention compared to adult burns, as children have particular characteristics, such as a higher body surface area to mass ratio, developmental barriers (e.g., low capacity to express their needs), and anatomical features (e.g., smaller legs, thinner skin) that differentiate treatment and make it more challenging (Palmieri, 2016; Sharma & Parashar, 2010). For these reasons, burn-injured children face many physical and psychological challenges, especially due to burn-related trauma, and, as a result, are significantly dependent on their families to meet their needs (Tully et al., 2022). In fact, the available evidence suggests that parents of burn-injured children play a key role in the child's recovery process (e.g., maintenance of care, school re-entry), predominantly on emotional and psychosocial levels (e.g., Andrews et al., 2018; Bakker, Maertens et al., 2013; Lernevall et al., 2021). However, these parents appear to be more affected by the burn event than the children themselves (Egberts et al., 2018), which compromises their ability to support and meet the needs of a burn-injured child (Saxe et al., 2005).

A growing body of literature has found that parents of burn-injured children experience high rates of posttraumatic stress symptoms (PTSS), psychological morbidity (i.e., depressive and anxiety

symptoms), and feelings of guilt, particularly in the first months after the burn incident (Bakker, Maertens et al., 2013). For example, within the inpatient stage, 44% and 69% of parents were found to report clinically significant depression and anxiety, respectively (Phillips & Rumsey, 2008). Moderate to extremely severe scores of parental stress, anxiety, and depression symptoms, were also found in the first month post-burn (De Young et al., 2014). Therefore, the first three months post-burn have been established as a potential risk period for parental distress (McGary et al., 2015). Although most of these symptoms tend to diminish over time, some parents continue to report significant symptoms of psychological distress that may persist for many years (Bakker, Maertens et al., 2013; De Young et al., 2014; Egberts et al., 2018; El Hamaoui et al., 2006; Phillips & Rumsey, 2008). However, most of these parents do not develop posttraumatic stress disorder (PTSD; De Young et al., 2014). Despite that, the prevalence of a major depressive disorder in mothers of a burn-injured child is over 35%, which is significantly higher than in the general population (El Hamaoui et al., 2006). Kent et al. (2000) found similar results on anxiety as well, pointing out that mothers are a vulnerable group for developing psychological sequelae in response to their child's burn injury. In fact, mothers tend to report more distress symptoms than fathers and are usually the child's primary caregivers, which may explain these results (e.g., Bakker et al., 2012; Graf et al., 2011).

Parental distress may result from disruptions in “normal” parenting, namely significant parental concerns often related to financial issues and child factors (e.g., emotional, psychosocial, and behavioral problems), and worsens with exposure to additional stressors (Ross et al., 1998), such as pediatric illnesses or injuries (Kazak et al., 2006). Recent similar systematic reviews in pediatric cancer patients (Sultan et al., 2016) and, more specifically, in childhood acute lymphoblastic leukemia (Ferraz et al., 2024), describe parental distress as a multifactorial construct that refers primarily to symptoms of depression, anxiety and traumatic stress, uncertainty, and other mental health problems or mood disturbances. Thus, parental distress can be measured using specific psychological symptom inventories (e.g., for anxiety, acute stress), mixed distress scales, or quality of life (QoL) subscales (Ferraz et al., 2024; Sultan et al., 2016). In this particular case, witnessing the child's burn injury and participating in the medical procedures that are typically painful and traumatic for the child, contributes to the parents’ distress (McGarry et al., 2015), as well as, the child's age and gender, namely being young and female (Bakker et al., 2012); poorer family functioning (Phillips & Rumsey, 2008), burn-related factors (e.g., a higher percentage of total body surface area [%TBSA]) and parents' sociodemographic characteristics (e.g., race/ethnic minority backgrounds; Townsend et al., 2023). Financial concerns are also considered

another source of stress for these parents, with the greatest costs associated with higher %TBSA and flame burns (Ter Meulen et al., 2016).

Understanding the risk factors for parental distress in this population may be useful not only to help health professionals improve the quality of care (beyond the physical treatment of burns) but also to raise awareness of the need to monitor and include these parents in the child's therapeutic plan, especially since recent evidence indicates the co-occurrence of traumatic stress symptoms and reactions in parents and children (e.g., Egberts et al., 2018). Other studies found significant associations between parental and child psychological symptoms following the burn event, primarily PTSS (e.g., De Young et al., 2014) and parental acute distress (Brown et al., 2019a, 2019b), which predicts greater child distress and less coping behavior (Brown et al., 2019a). In fact, beyond the consequences for themselves, parental distress may lead to the development and maintenance of child traumatic symptoms (Bakker, Maertens et al., 2013; De Young et al., 2014; Saxe et al., 2005), and appears to be a major contributor to negative outcomes in children with burn injuries, in particular low QoL (Townsend et al., 2023).

The Integrative Model of Pediatric Medical Traumatic Stress (Kazak et al., 2006) corroborates the relationship between the traumatic reactions of pediatric patients and their parents, indicate that in some cases parents exhibit greater symptom severity, which in turn decreases their active coping responses and affects children's adjustment over time. According to this model, there are three phases (i.e., peri-trauma [Phase I], early, ongoing, and evolving responses [Phase II]; and longer-term [Phase III]) that represent the subjective experience of the family and children, and potentially expected traumatic stress responses along the trajectory of a given traumatic medical event and its treatment, such as pediatric burns (Kazak et al., 2006). An update of this conceptual framework highlighted the critical role of subjective appraisals and responses to trauma (e.g., feelings of guilt, perceived threat to the child's life) as a strong predictor of traumatic stress symptoms and added the importance of a family-centered approach, as family responses immediately after the medical event occurs that may predict the course of the traumatic symptomatology in parents and children, over time (Price et al., 2016). Moreover, Price et al. (2016) renamed the three phases of the model (i.e., peri-trauma, acute medical care, and ongoing care/discharge from care, respectively) and underlined the importance of understanding that traumatic reactions are a process that varies according to the trajectory and severity of the pediatric illness/injury. Therefore, the authors suggest that there is an important need to systematically screen and assess these families throughout the different medical phases in order to monitor significant changes, prevent or minimize the severity of the traumatic symptomatology, and improve the delivery of trauma-informed care (Price et al., 2016).

Given the prevalence of unintentional pediatric burns, the numerous risk factors for parental distress, and their severity and potential consequences for both parents and children, there is a critical need to fully understand the scope and nature of parental distress following pediatric burn injuries. There is also a need to address and identify the factors/predictors of parental distress and its consequences in response to pediatric burns to reduce parental distress symptoms, prevent the development of PTSD, minimize the impact on child outcomes, and optimize future family-centered practice and trauma-informed multidisciplinary care.

To our knowledge, this is the first systematic review on this topic, which may indicate that parents of burn-injured children continue to be substantially neglected in the care process and that their needs are poorly recognized and underserved. To date, only one systematic review on the psychological impact of pediatric burn injuries has been published (Woolard et al., 2021). However, the mentioned review focused on children's mental health outcomes, excluding articles exclusively related to parents' psychological outcomes (Woolard et al., 2021). An integrative review focusing on the support needs of parents of burn-injured children was also found, although the inclusion criteria were limited to studies describing the support provided to parents strictly related to the inpatient phase, and seven studies were included in the formal analysis, of which only three were quantitative (Lernevall et al., 2020).

The present systematic review aims to explore, evaluate, and synthesize the existing research: (1) on factors/predictors of distress in parents of children with unintentional burn injuries and (2) on the consequences of parental distress in parents themselves and burn-injured children. Differences between (i) children's age groups, (ii) parents' gender, (iii) burn depth, and (iv) %TBSA burned will also be explored. We expect that many factors/predictors explain and contribute to parents' distress, including parents' and children's sociodemographic factors (e.g., minority race, being a mother, low socioeconomic status, young children), burn-related factors (e.g., higher %TBSA), psychological factors (e.g., psychological comorbidities), and family factors (e.g., poorer family functioning). We also expect parental distress consequences to extend to children (e.g., behavioral problems) since parents and children symptomatology is related (Andrews et al., 2018; Brown et al., 2019a, 2019b; Egberts et al., 2018) and parental distress seems to negatively and directly influence children's outcomes (e.g., Bakker, Maertens et al., 2013; De Young et al., 2014; Townsend et al., 2023).

Method

Search strategy and selection criteria

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Mother et al., 2009) and the review protocol was registered on

PROSPERO, the international prospective register of systematic reviews (registration number: CRD42021293723).

The databases Web of Science, PubMed, and PsycINFO were systematically searched on November 18, 2021, for English-language peer-reviewed articles published from inception to 2021. The search strategy was developed based on similar systematic reviews and with consultation with a subject matter expert, and used comprehensive keywords and MeSH terms covering: parents, distress, and pediatric burn injuries (see Supplementary Material 1 for search strategy). Additional search methods have been used to complement the results obtained (e.g., backward and forward search).

To be eligible for inclusion in this review, articles had to meet the following criteria: a) include parents of children with unintentional burn injuries (aged one month to 18 years); b) include quantitative data on parental distress in response to their children's burn injuries; and c) cross-sectional and longitudinal observational studies. Parental distress can be assessed from various measures, involving self-report questionnaires of symptoms of depression (e.g., Beck Depression Inventory; BDI), anxiety (e.g., State-Trait Anxiety Inventory; STAI) and stress (e.g., Parenting Stress Index; PSI), feelings of guilt (e.g., Global Guilt Scale; GGS), acute stress (e.g., Acute Stress Disorder Scale; ASDS), PTSS (e.g., Impact of Event Scale-Revised; IES-R), and/or general distress scales (e.g., Depression Anxiety Stress Scale-21; DASS-21). Review articles (i.e., systematic reviews and meta-analyses), qualitative studies, book chapters, commentaries, dissertations, case reports, grey literature, and animal studies were excluded from this review. Outcomes had to be determined from a correlation coefficient and/or regression/path analysis in order to identify factors and predictors of parental distress, respectively, as well as its consequences.

Study selection and data extraction

After removing duplicates using ZOTERO, the titles, and abstracts of potentially relevant articles were independently reviewed by two authors (MS and AF) for eligibility. References were managed using ZOTERO and Rayyan. At the eligibility phase, all full-text articles were independently reviewed by the same two authors against the inclusion criteria. Disagreements or any doubts were resolved through discussion between the two authors until a consensus was reached and no doubts remained. It was not necessary to involve the third author in this process. Cohen's kappa coefficient was used to determine the inter-rater agreement, and an almost perfect agreement was obtained ($k = .91$) (McHugh, 2012).

Data from the included studies were extracted by the two independent authors (MS and AF) using a standardized form developed for this review and confirmed by the third author (MGP) for clarity and consistency. Data extraction included the authors, year of the publication, country, study design, sample size by gender for parents and children, age of the participants, %TBSA burned, hospital length of stay

(LoS), distress measures, assessment time point(s), and main findings, and was sorted by type of outcomes (i.e., factors/predictors and subgroup differences, and consequences) (see Supplementary Material 2 for the summary table of included articles).

Quality assessment

The National Heart, Lung, and Blood Institute (NHLBI) Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies was used to assess the quality of the included studies. This tool has been widely used for quality assessment of observational and cross-sectional studies and tested to detect potential flaws in the methodology or study implementation (NHLBI, 2021). Each of the 14 items was rated as *Yes*, *No*, *Not Applicable*, or *Not Reported* to assess the internal validity of the studies. The final quality scores range from *Poor*, *Fair*, to *Good*. MS and AF independently assessed the quality of the included studies, and any disagreements were resolved through discussion. The inter-rater agreement for the overall quality rating, using Cohen's kappa coefficient, was strong (k = .88) (McHugh, 2012).

Results

Main results

A total of 7408 articles was identified through database searches (3243 from PsycINFO, 2589 from Web of Science, and 1576 from PubMed). The articles were exported to ZOTERO and, after removing duplicates (n = 851), 6557 unique records were screened by title and abstract. Comprehensive screening yielded a total of 87 eligible articles for full-text evaluation, although three articles were not retrieved. Articles that raised doubts, in the previous phase, were included for full-text reading. Therefore, the full text of the remaining 84 articles was reviewed. From the full-text analysis, 38 articles fulfilled the inclusion criteria, and 46 articles were excluded. No eligible articles were found from the additional search methods (e.g., reference screening). A flow diagram, according to PRISMA guidelines (Moher et al., 2009), was used to summarize the article selection process (Figure 1.1).

[Figure 1.1]

Characteristics of included studies

Of the 38 included studies, fourteen were published between 1988 and 2012, and 24 were published after 2013, which shows a growing interest in this topic in the last decade. Most of the included studies were conducted in Europe (55.26%), North America (26.32%), and Australia (13.16%) specifically: the United States (n = 10), the Netherlands and Belgium simultaneously (n = 9), Sweeden (n = 6), Australia (n = 5), England (n = 3), Switzerland (n = 2), the Netherlands (n = 1), Morocco (n = 1) and Mexico (n = 1). Only 14 (36.84%) studies had a longitudinal design (Bakker et al., 2010, 2014; Bakker, Van der Heijden et al., 2013; De Young et al., 2014; Egberts et al., 2016, 2017, 2018, 2020; Hall et al.,

2006; Kent et al., 2000; Pan et al., 2015; Parrish et al., 2019; Suurmond et al., 2020; Tyack & Ziviani, 2003), and 24 (63.16%) were cross-sectional. Sample sizes ranged from 28 (El Hamaoui et al., 2006) to 407 (Parrish et al., 2019) parents and their children, with four articles focusing exclusively on mothers (Bakker et al., 2010; Egberts et al., 2020; El Hamaoui et al., 2006; Kent et al., 2000) and one study that included primary caregivers other than parents (i.e., three grandmothers and a sister; Quezada et al., 2016). Of the 34 articles that include both parents, the vast majority included more mothers (n = 27) and seven articles did not indicate parents' gender (Blakeney et al., 1993; Enlow et al., 2019; Parrish et al., 2019; Saxe et al., 2005; Stewart et al., 2019; Stoddard et al., 2006; Tyack & Ziviani, 2003). Regarding the pediatric sample, most studies included more male than female children (n = 35), two studies did not indicate the sample by gender (Blakeney et al., 1993; El Hamaoui et al., 2006) and only one included more female children (Stoddard et al., 2006). The mean age of the child ranged from 1.57 (Stewart et al., 2019) to 14 years (Pan et al., 2015), with a mean %TBSA burned ranging from 1.85 (Brown et al., 2019b) to 37.20% (LeDoux et al., 1998). The average LoS ranged from 1.73 (Haag & Landolt, 2017) to 25 days (Saxe et al., 2005).

The assessment time points diverged considerably among the studies. Of the 24 studies that measured parental distress at a one-time point, nine were conducted during the first few months post-burn injury (Bakker et al., 2012; Blakeney et al., 1993; Cella et al., 1988; Haag & Landolt, 2017; Hawkins et al., 2019; McGarry et al., 2013; Saxe et al., 2005; Stewart et al., 2019; Stoddard et al., 2006), two studies at the first dressing change (Brown et al., 2019a, 2019b) and one during clinic appointments/summer camp registration (Enlow et al., 2019), two studies between three months and one year after the burn incident (Odar et al., 2013; Quezada et al., 2016), eight studies between six months and six years after (Blakeney et al., 1993; El Hamaoui et al., 2006; Graf et al., 2011; LeDoux et al., 1998; Phillips & Rumsey, 2008; Sveen et al., 2016; Sveen & Willebrand, 2018; Willebrand et al., 2018), and three studies up to nine years post-burn (Willebrand & Sveen, 2016a, 2016b; Willebrand et al., 2011). One study included two time bands since it included two different groups of participants (i.e., admission of pediatric acute burn patients and a recovery group; Blakeney et al., 1993). Regarding longitudinal studies, eight studies used two assessment time points (Bakker et al., 2014; Egberts et al., 2016, 2018; Hall et al., 2006; Kent et al., 2000; Pan et al., 2015; Parrish et al., 2019; Suurmond et al., 2020), 4 studies used three (Bakker et al., 2010; De Young et al., 2014; Egberts et al., 2020; Tyack & Ziviani, 2003), and two studies used four assessment time points (Bakker, Van der Heijden et al., 2013; Egberts et al., 2017). At the initial contact, the most commonly reported time points were within the first days/month after the burn incident (n = 10), followed by prior to skin healing, three, six, and 12 months

post-burn. At subsequent assessment time points, the most common were three months (n = 5), 12 months (n = 5), 18 months (n = 4), and six months post-burn (n = 3). One study used an assessment moment more than 18 months after the burn injury (i.e., two and 11 years post-burn; Bakker et al., 2010).

Twenty-eight different distress measures were described in the included studies. The most commonly used instruments were the Impact of Event Scale (IES; n = 13), IES-R (n = 7), the Hospital Anxiety and Depression Scale (HADS; n = 6), and DASS-21 (n = 4). All included studies used validated, reliable, and standardized measures to assess overall parental distress. Nevertheless, seven studies that measured several indicators of distress showed weaknesses in assessing parental feelings of guilt. Specifically, one study used The Brief COPE's self-blame subscale, which consists of only two questions (De Young et al., 2014), five studies used a single item (i.e., "*To what extent do the following emotions apply when you think about the accident that caused the burn?*"; Bakker et al., 2010, 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017; Suurmond et al., 2020), and one study included four items (non-validated) that were inspired by another guilt scale (Sveen & Willebrand, 2018) (see Supplementary Material 2 for further details).

Quality assessment

The NHLBI assessment tool was used to rate the methodological quality of the included articles (see Supplementary Material 3). Most of the studies were of fair quality (n = 24), nine were of good quality and five were of poor quality. The main potential risks of bias identified in the studies were the lack of measurement and adjustment of potential confounding variables regarding their impact on the relationship between the independent variables and the outcome(s), specifically related to the study design (e.g., insufficient timeframe, exposure of interest was not assessed prior to the outcome or more than once) that did not allow a meaningful analysis of a causal relationship between exposure and outcome. In addition, most studies used a convenience sample, and nine studies did not report the rate of eligible participants. The most common strengths among the studies included a clear definition and specification of the objectives and study population and a precise and detailed explanation of the independent and dependent variables. It is important to note that the tool selected is intended to identify potential flaws that may compromise the generalization and interpretation of results, not a "fatal flaw".

Study findings

Regarding specific study results, based on our research questions, 28 articles identified factors/predictors of parental distress, 20 articles found consequences of parental distress for both the parents and the burn-injured child, and 11 reported subgroup differences. Given the wealth of the results

found, it was considered relevant to examine the differences in parental distress over time since the burn event occurred. These results are described in detail below. In addition, to obtain a more comprehensive picture of parental distress, a graphic model was constructed (Figure 1.2). The resulting model, based on the main results found, represents the factors/predictors and consequences of parental distress in line with the Integrative Model of Pediatric Medical Traumatic Stress (Kazak et al., 2006) and its recent update (Price et al., 2016), in order to offer empirical implications for clinical practice and future research.

[Figure 1.2]

Factors/Predictors of parental distress

Of the 28 articles that reported factors/predictors of parental distress, 11 studies explored predictors (Bakker et al., 2010, 2012; Bakker, Van der Heijden et al., 2013; De Young et al., 2014; Egberts et al., 2017, 2020; Haag & Landolt, 2017; Hawkins et al., 2019; Parrish et al., 2019; Phillips & Rumsey, 2008; Willebrand & Sveen, 2016a), although five of them had a cross-sectional design (Bakker et al., 2012; Haag & Landolt, 2017; Hawkins et al., 2019; Phillips & Rumsey, 2008; Willebrand & Sveen, 2016a). Notwithstanding, several factors were associated and/or contributed to parental distress, including sociodemographic characteristics of both parents and children, and psychological, psychosocial, family, and burn-related variables.

Sociodemographic variables. Fourteen studies examined sociodemographic variables of parents and/or children and their relationship with parental distress following the burn event. Regarding children's sociodemographic characteristics, negative associations were found between the child's age and parental distress at the first assessment (within two weeks post-burn; De Young et al., 2014), parental PTSS (Hawkins et al., 2019; Odar et al., 2013), parental symptoms of intrusion (Egberts et al., 2017), anxiety, depression and feelings of guilt (Hawkins et al., 2019), and maternal PTSS at the first-month post-burn (Egberts et al., 2016, 2018). Also, the child's age negatively predicted parents' avoidance symptoms (Egberts et al., 2017), and two studies found a positive contribution of child's age and gender (female) to parent couples' intrusion symptoms (Bakker et al., 2012), as well as to parental symptoms of avoidance and intrusion (Bakker, Van der Heijden et al., 2013). On the other hand, Egberts et al. (2017) found that child gender (male) positively predicted parental avoidance symptoms. In addition, Sveen et al. (2016) and Parrish et al. (2019) found that child gender (female) was significantly associated with greater symptoms of parental PTSD and distress over time, respectively. In sharp contrast, one study found no significant associations between the age and gender of the child and maternal depression (El Hamaoui et al., 2006). Child minority race was also found significantly associated with higher parental distress (Parrish et al., 2019; Stewart et al., 2019). Regarding parents, low educational level was

significantly associated with higher state anxiety (Tyack & Ziviani, 2003), and low socioeconomic status with maternal depressive symptoms (El Hamaoui et al., 2006). Parents' age (younger) was significantly associated with higher parental PTSS (Hawkins et al., 2019), and mother's younger age contributed to greater parental anxiety and depressive symptoms (Phillips & Rumsey, 2008). In addition, parental gender (female) contributed positively to parents' intrusion and avoidance symptoms (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017), and parental age contributed negatively to parent couples' intrusion symptoms (Bakker et al., 2012). Despite that, Odar et al. (2013) reported no significant associations between parental sociodemographic variables (e.g., age, ethnicity, educational level, marital status) and parental PTSS, and another study found no significant associations between mothers' age and educational level and maternal depression (El Hamaoui et al., 2006).

Psychological variables. Seventeen studies analyzed the psychological factors of parental distress indicators. The following results have been divided into subcategories to help understand the factors/predictors that potentially explain/contribute to parental distress: 1) Parents' psychological attributes (e.g., emotional state, perceptions, personality traits); 2) Parents' internal coping resources and protective factors (e.g., resilience); and 3) Child's psychological factors (e.g., internalizing and externalizing problems).

First, at the inpatient stage, lower parental extraversion was strongly associated with parental depressive symptoms and lower parental emotional stability contributed to parental anxiety symptoms (Phillips & Rumsey, 2008). The perceived threat to the child's life was significantly associated with parents' PTSS (Egberts et al., 2017) and contributed positively to parent couples' intrusion and avoidance symptoms (Bakker et al., 2012) and to parents' intrusion symptoms (Bakker, Van der Heijden et al., 2013; Egberts et al., 2017). Previous history of parental trauma was negatively associated with parental feelings of guilt and positively predicted parental PTSS one month after the burn incident (De Young et al., 2014). Feelings of guilt and anger were significantly associated with parents' PTSS (Egberts et al., 2017) and positively predicted parent couples' avoidance and intrusion symptoms (Bakker et al., 2012). Individually, parents' feelings of anger (Bakker, Van der Heijden et al., 2013) and guilt (Bakker, Van der Heijden et al., 2013; Egberts et al., 2017) positively predicted parents' PTSD symptoms. Also, feelings of guilt and the interaction between guilt feelings and burn severity significantly predicted maternal PTSS (Bakker et al., 2010). No significant associations were found between burn-specific guilt and parents' depressive symptoms; however, general guilt was positively associated with parents' depressive symptoms, and embitterment with parents' pessimistic and suicidal thoughts (Sveen & Willebrand, 2018). One study found that injury-related fear avoidance predicted higher parental PTSD symptoms (Willebrand

& Sveen, 2016a). Shame was positively associated with parental feelings of guilt, PTSS, and symptoms of anxiety and depression, and contributed positively to parental anxiety, depression, and PTSS (Hawkins et al., 2019). Mothers' trauma-related emotions were also analyzed (Egberts et al., 2020) and the results showed that higher long-term emotions were positively associated with maternal PTSS and symptoms of depression. Acute self-conscious emotions were also positively associated with maternal symptoms of depression across all the time points and with PTSS in the first-month post-burn. Long-term basic emotions, 12 months after the first assessment, positively predicted maternal PTSS and symptoms of depression 18 months later, and acute self-conscious emotions in the first month predicted higher maternal symptoms of depression 18 months later (Egberts et al., 2020).

Second, parental coping (i.e., planful problem solving) was negatively associated with parental trait anxiety and depression, and negative reappraisals were negatively associated with parental trait anxiety (Tyack & Ziviani, 2003). In addition, four studies identified positive psychology variables that were significantly related to parental distress. Thus, self-compassion was negatively associated with parental depression and PTSS, and contributed negatively to parental symptoms of depression (Hawkins et al., 2019). Hopelessness was positively associated with parental mood disturbances and symptoms of avoidance and depression (Cella et al., 1988). Parent/caregiver resilience was negatively associated with PTSD symptoms (McGarry et al., 2013; Quezada et al., 2016), and symptoms of avoidance and hyperarousal in female caregivers (Quezada et al., 2016), although no significant associations were found with parental symptoms of depression, anxiety, and stress (McGarry et al., 2013).

Finally, Quezada et al. (2016) found that the child's resilience was negatively associated with symptoms of intrusion in female caregivers, and positively associated with symptoms of intrusion, avoidance, and hyperarousal in male caregivers. Parents' observations of the child's internalizing problems were significantly associated with parental PTSS up to 12 months post-burn (Egberts et al., 2016). In this line, children's psychiatric problems were positively associated with parents' trait anxiety (Tyack & Ziviani, 2003), psychological comorbidities with parents' PTSD symptoms (Willebrand & Sveen, 2016a), and premorbid emotional and behavioral problems with parents' PTSS one and six months post-burn (De Young et al., 2014). Higher child PTSS were significantly associated with higher parental PTSS (Odar et al., 2013). Furthermore, concurrent child PTSS positively predicted parental PTSS one and six months post-burn (De Young et al., 2014), and children's PTSD symptoms mediated the relationship between children's dissociation and parental PTSD symptoms, and between TBSA and parental PTSD symptoms (Hall et al., 2006).

Psychosocial variables. Five studies examined the relationship between psychosocial variables and parental symptoms of distress. Perceived lack of support was significantly associated with parental symptoms of anxiety and depression (Willebrand & Sveen, 2016b). In this line, social support was negatively associated with parental symptoms of avoidance, anxiety, and depression (Cella et al., 1988). Tyack and Ziviani (2003) also found that social support was negatively associated with parental anxiety (state and trait) and the number of social support networks with depression. In addition, social functioning was significantly associated with mothers' diagnosis of depression (using MINI interview and DSM-IV criteria; El Hamaoui et al., 2006). Despite that, one study reported no significant associations between the level of social support received and parental PTSS (Odar et al., 2013).

Family variables. Only three studies analyzed the relationship between family variables and parental distress. Hall et al. (2006) found that conflict with extended family (pre-trauma) was significantly associated with parental anxiety and PTSD symptoms. Other family-related pre-trauma variables, such as a higher number of family mental health diagnoses and the level of previous family stress, were significantly associated with higher parental PTSS (Odar et al., 2013). In addition, poor family functioning contributed significantly to parental symptoms of anxiety and depression (Phillips & Rumsey, 2008). Interestingly, Hall et al. (2006) also found that parents' acute anxiety and PTSD symptoms were mediated by increased parent-child conflict post-trauma.

Burn-related variables. Twenty-one studies examined child burn-related variables associated with parental distress. Several studies found that the child's %TBSA was positively associated with overall parental distress (Parrish et al., 2019; Stewart et al., 2019), and more specifically with cognition and mood subscale of PCL-5 (Sveen et al., 2016), mood disturbance (Cella et al., 1988) and symptoms of intrusion (Cella et al., 1988; Egberts et al., 2017), dissociation, anxiety (Hall et al., 2006), PTSD (Hall et al., 2006; Willebrand & Sveen, 2016a), and PTSS (Brown et al., 2019b; De Young et al., 2014). Regarding parents' gender, a higher %TBSA was significantly associated with maternal depression (El Hamaoui et al., 2006) and avoidance symptoms (Haag & Landolt, 2017), hyperarousal symptoms in male caregivers (Quezada et al., 2016), and negative mood and symptoms of intrusion and arousal in both mothers and fathers (Haag & Landolt, 2017). In addition, the child's %TBSA predicted positively parental symptoms of intrusion (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017) and avoidance (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013), and parental distress at the initial visit (Parrish et al., 2019). One study found a negative association between child's wound depth (e.g., superficial-partial) and parental symptoms of anxiety and depression (Brown et al., 2019b). In contrast, other positive associations were found between child's pain and parental acute stress symptoms (Stoddard et al.,

2006), the number of dressing changes and mother's negative mood and father's intrusion symptoms (Haag & Landolt, 2017), the cause of the burn and parental PTSS (Odar et al., 2013), LoS and parental PTSS (Hawkins et al., 2019) and PTSD symptoms (Willebrand & Sveen, 2016a), and between days in hospital and mothers' intrusion, arousal, and negative mood, and fathers' intrusion, dissociation, arousal, and negative mood (Haag & Landolt, 2017). Clinical complications (e.g., amputation, secondary infection) and burn in several children at the same time or of an only child were significantly associated with maternal depression (El Hamaoui et al., 2006). In addition, fewer days since burn injury was significantly associated with greater parental distress in the first assessment and predicted parental distress (Parrish et al., 2019). Also, the number of invasive procedures predicted positively parental PTSS one and six months post-burn (De Young et al., 2014), and the fact that the burn accident occurred at home predicted positively symptoms of avoidance (Bakker et al., 2012; Egberts et al., 2017). Interestingly, one study found a potential moderating role of a child's burn-related variable (i.e., permanent scars) in the relationship between maternal feelings of guilt and PTSS, whereas no significant associations were found between the number of scarred body zones and maternal PTSS 11 years later (Bakker et al., 2010). In addition, no significant associations were found between burn size and maternal PTSS (Bakker et al., 2010) and parenting stress scores (Blakeney et al., 1993), nor between TBSA and symptoms of anxiety and depression in parents (Phillips & Rumsey, 2008) or mothers (Kent et al., 2000). Odar et al. (2013) also reported no other significant associations between child burn-related variables (e.g., days since the burn, witnessed the accident) and overall parental PTSS.

Consequences of parental distress

Twenty studies identified several consequences of parental distress on parents and/or their children. Eight of these studies explored the predictive role of parental distress (Brown et al., 2019a; De Young et al., 2014; Egberts et al., 2020; Parrish et al., 2019; Quezada et al., 2016; Saxe et al., 2005; Tyack & Ziviani, 2003; Willebrand et al., 2011), although only four of them were longitudinal (De Young et al., 2014; Egberts et al., 2020; Parrish et al., 2019; Tyack & Ziviani, 2003). Moreover, five studies explored the mediating role of parental distress (Haag & Landolt, 2017; Hall et al., 2006; Quezada et al., 2016; Saxe et al., 2005; Stoddard et al., 2006), and one study the moderating role of caregivers' symptoms of anxiety and depression (Enlow et al., 2019). Psychological and burn care and child health/functional outcomes were identified.

Psychological outcomes. Sixteen studies analyzed the potential psychological consequences of parental distress. Similar to a previous subsection, the results were divided into subcategories: 1)

Parents' psychological consequences; 2) Child's maladaptive psychological responses (e.g., traumatic symptoms); and 3) Child's coping behavior and protective factors (e.g., resilience).

First, three longitudinal studies identified parents' psychological consequences as a result of their distress. One of the most recent studies included in this review concluded that the initial level of parental distress was the only significant predictor of later parental distress (Parrish et al., 2019). Egberts et al. (2020) also found that early maternal symptoms of depression predicted long-term maternal PTSS (but the reverse was not the case). In addition, one study found that parental acute dissociation played a mediating role in the relationship between pre-trauma and burn-related variables (i.e., conflict with extended family and TBSA, respectively) and parental PTSD symptoms (Hall et al., 2006).

Second, several studies found significant associations between parents and children's traumatic reactions (Egberts et al., 2018; Enlow et al., 2019; Graf et al., 2011; Haag & Landolt, 2017; Hall et al., 2006). Positive associations were found between mothers and children's PTSD symptoms (Graf et al., 2011); mothers' acute stress symptoms and fathers' intrusion symptoms with children's arousal/intrusion symptoms (Haag & Landolt, 2017); parents' anxiety/PTSD symptoms with child PTSD symptoms (Hall et al., 2006), and between caregivers' anxiety symptoms and child PTSS (Enlow et al., 2019). Also, maternal PTSS in the first-month post-burn and both parents' PTSS three months later were positively associated with the child's self-reported PTSS (Egberts et al., 2018). Despite that, Haag and Landolt (2017) found that only mothers' intrusion, avoidance, and negative mood were positively associated with children's avoidance/cognitions, and Graf et al. (2011) found no significant associations between fathers' and children's PTSD symptoms. In addition, parental PTSS 12 months post-burn was associated with parental reports of child internalizing problems (Egberts et al., 2016), and greater parental acute stress symptoms were associated with more child behavior problems (internalizing and externalizing) at three and 12 months post-burn (Bakker et al., 2014). Haag and Landolt (2017) found similar results with maternal acute stress symptoms 19 days post-burn, on average. Regarding child mood, one study found a significant relationship between parental distress and child irritability (Stewart et al., 2019). Three studies explored the contributory role of parental distress to the child's maladaptive psychological outcomes, while three studies and another one investigated its mediating and moderating role, respectively. In particular, parental anxiety, depression, and stress symptoms within two weeks post-burn positively predicted child PTSS one month later, and concurrent parental PTSS positively predicted child PTSS one and six months post-burn (De Young et al., 2014). Parental symptoms of anxiety, depression, and PTSD contributed positively to children's psychological difficulties (i.e., emotional symptoms, conduct problems, hyperactivity/inattention, and peer problems), and negatively to children's

prosocial behavior (Willebrand et al., 2011). Similarly, parents' symptoms of acute stress contributed significantly to children's symptoms of acute stress (Saxe et al., 2005). The relationship between %TBSA and child acute stress symptoms was mediated by parents (Saxe et al., 2005) and mothers' acute stress symptoms (Haag & Landolt, 2017). Also, parents' acute stress symptoms mediated the relationship between child pain and child acute stress symptoms (Stoddard et al., 2006). Caregiver anxiety and depressive symptoms played a moderating role in the relationship between child distraction coping and child PTSS (Enlow et al., 2019). Therefore, it seems that children who used more distraction coping strategies reported lower PTSS when caregiver anxiety was higher. Curiously, when caregiver depression was lower, children who used more distraction coping strategies reported more PTSS (Enlow et al., 2019).

Finally, two studies found consequences on children's coping behavior and protective factors. At the first dressing change, Brown et al. (2019a) found that parental pre-procedural anxiety, PTSS, and guilt were negatively associated with child coping behavior, and parental symptoms of anxiety and depression contributed to less child coping, mediated through less parental coping-promoting behavior. Also, the same authors reported that parental PTSS and feelings of guilt contributed positively to child distress behavior, mediated through parental distress-promoting behavior. More than three months after the burn incident, a study found that symptoms of caregiver intrusion were a strong negative predictor of the child's resilience, explained by the level of caregiver avoidance symptoms (Quezada et al., 2016).

Burn care and child health/functional outcomes. One study found that parents' depressive symptoms were negatively associated with the parents' overall perception of the quality of pediatric burn care, information routines and illness, and caring processes, and parents' PTSS with information routines, caring processes, and participation (Willebrand et al., 2018). Child health and functional outcomes related to burn wound care were also identified in four studies. Specifically, at the first dressing change, parental acute PTSS was positively associated with child's delayed re-epithelialization (Brown et al., 2019b). In addition, Brown et al. (2019b) also reported that parental symptoms of anxiety and depression, PTSS, trauma-related guilt, and pre-procedure fear were positively associated with parent reports of the child's pre-procedure pain, while trauma-related parental guilt was positively associated with parent reports of the child's peak-procedural pain. Similarly, within 32 days post-burn, parental distress was positively associated with child post-burn pruritus, sleep onset, and sleep disturbance (Stewart et al., 2019). Six months after the burn incident, Tyack and Ziviani (2003) found that parental anxiety (state and trait) and depression symptoms were positively associated with the child's behavior problems and significantly predicted the variance in functional outcome of children, using the Vineland Adaptive Behavior Scales-Survey Form (VABS-SF). Finally, mothers' PTSS were negatively

associated with several subscales of the child's QoL, such as satisfaction with the child's current state and emotional health at six months post-burn, and positively associated with parental concern at six and 18 months post-burn (Pan et al., 2015). The same authors also found similar results regarding fathers' PTSS, which were positively associated with their observation of the child's itch (at six and 18 months post-burn), family disruption, and parental concern at six months after the burn event, while negatively associated with satisfaction with the current state and emotional health at six months, and appearance six and 18 months later (Pan et al., 2015).

Subgroup differences

Of the 11 studies that explored subgroup differences, six studies examined differences between mothers and fathers, four longitudinal studies on changes in parental distress over time, and two on TBSA. Regarding differences between the parents' gender, five studies found that mothers showed more early guilt feelings and anger (Bakker, Van der Heijden et al., 2013), higher levels of avoidance and intrusion symptoms (Bakker, Van der Heijden et al., 2013; Egberts et al., 2017), PTSD symptoms (Bakker et al., 2012), and higher mean scores of acute stress symptoms (Haag & Landolt, 2017) and depression in the first-month post-burn and PTSS three months later than fathers (Suurmond et al., 2020). Despite that, Bakker, Van der Heijden et al. (2013) found that differences between the parent's gender in terms of avoidance symptoms decreased over time. Furthermore, one study reported no significant differences between mothers and fathers within one week post-burn (McGarry et al., 2013).

Two studies concluded that symptoms of parental distress decreased significantly over time. Specifically, there was a significant decrease in symptoms of anxiety, depression, stress, PTSD, and PTSS between one and 6 months post-burn (De Young et al., 2014), and in the mean scores of parental symptoms of depression and PTSS between the first month and 18 months post-burn (Egberts et al., 2020). Two studies focusing on maternal symptoms found similar results in mean PTSS scores from one to 11 years post-burn (Bakker et al., 2010), and in symptoms of depression from the first assessment (within three days of admission) to six months post-burn (Kent et al., 2000). Regarding maternal anxiety symptoms, although there was a slight decrease over time, the mothers continued to show high anxiety up to six months later (Kent et al., 2000).

Finally, LeDoux et al. (1998) and McGarry et al. (2013) reported no significant differences based on TBSA in symptoms of parental distress one to five years post-burn, and within one-week post-burn, respectively.

Discussion

The current review aimed to document and comprehensively identify the factors/predictors and consequences of parental distress following pediatric burn injuries, summarizing 33 years of research on the topic. This systematic review contributes to a more comprehensive picture of parental distress in the phenomenon under study, providing a helpful graphic model that allows an integrated understanding of the nature and scope of parents' psychological distress in response to their child's unintentional burn injury and the course and outcomes of their symptoms, according to the medical phases/over time. To the best of our knowledge, it is also the first systematic review to focus on the reasons that explain and contribute to parental distress and its consequences for parents themselves and their children in one of the most common non-fatal traumatic injuries in childhood.

The qualitative synthesis of the 38 included studies revealed a growing interest in screening parental distress following their children's burn injuries in recent years, which is in line with the current recommendations of the American Burn Association. Despite that, a large number of pediatric burn centers do not formally assess parental distress and there is no consensus on which specific domains should be screened, nor on which measures should be used (e.g., Parrish et al., 2019; Pelley et al., 2013). Therefore, given the importance of implementing universal and targeted psychological screening covering these parents to improve outcomes for burn-injured children and their families (Patterson et al., 2023), it is essential to know a set of consensual, valid, and reliable distress measures, and understand and address the potential risk factors for parental distress, as well as its consequent implications, in order to inform future interventions and improve the delivery of trauma-informed care. In line with a previous systematic review on parental distress in childhood acute lymphoblastic leukemia (Ferraz et al., 2024), a clinical population that shares some commonalities with pediatric burn patients (e.g., challenging clinical trajectory, invasive and distressing medical procedures; Price et al., 2016), similar categories of factors/predictors and consequences of parental distress were found. Regarding factors/predictors, five categories were identified in this review: parents' and children's sociodemographic, psychological, psychosocial, family, and burn-related variables. Regarding parental distress consequences, psychological and burn care and child health/functional outcomes were found. In addition, based conceptually on the Pediatric Medical Traumatic Stress framework (Kazak et al., 2006; Price et al., 2016), the results found in this review were also distributed according to the different medical phases of pediatric injuries (including pre-trauma), in order to clarify and illustrate the relationships between the categories found and parental distress, providing specific intervention targets for each of these phases.

Our findings showed that parents of burn-injured children reported higher levels of psychological distress symptoms, particularly in the period immediately after the burn event (e.g., De Young et al., 2014; Hall et al., 2006; Kent et al., 2000; Parrish et al., 2019), and many factors seem to explain and/or exacerbate these symptoms. Pre-trauma variables, including pre-existing issues and conditions (e.g., previous history of parental trauma, family mental health diagnoses) and sociodemographic characteristics of parents and children, were related to an increase in parental distress symptoms and should be identified beforehand to prevent the risk of burn injuries (e.g., through educational campaigns) and mitigate its impact on parents' psychological adjustment. The latter issue is particularly relevant, not only to improve the parents' psychological outcomes but also because parental distress negatively influences the psychological adjustment and recovery of these children (Woolard et al., 2021). A study by Enns et al. (2016) corroborates that burn injuries compromise parents' health outcomes and may negatively impair any pre-existing condition (e.g., physical, psychiatric). In addition, it is imperative to identify a history of family mental health illness or related problems early on, as the family's mental state prior to the burn incident, appears to increase the predisposition to develop PTSS later on (Odar et al., 2013). Further research is needed to clarify the role of pre-existing family variables, including parents' personality traits (e.g., low extraversion, low emotional stability) and previous levels of family stress, in the development and exacerbation of parental distress symptoms in this context. Age and gender of parents and children were also related to parental distress in most of the studies that examined these demographic variables (e.g., Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; De Young et al., 2014; Egberts et al., 2016, 2017, 2018; Hawkins et al., 2019; Parrish et al., 2019; Phillips & Rumsey, 2008; Sveen et al., 2016). Mothers, young parents, and parents of younger and female children who have sustained a burn injury appear to be more vulnerable to developing distress symptoms, in particular traumatic responses (e.g., avoidance and intrusion symptoms). Despite that, some contradictory results were also found. For example, Odar et al. (2013) and El Hamaoui et al. (2006) found no significant relationships between parents'/mothers' age and distress symptoms. On the other hand, Egberts et al. (2017) found that children's male gender was a significant predictor of parental avoidance symptoms. However, this contradictory evidence may be explained by the characteristics of the sample (e.g., a disproportionate number of participants, studies focusing only on mothers), study design, assessment time point(s) (e.g., number of days since burn injury), and the distress measures used. Future studies should take into account the aspects mentioned to shed light on these conclusions. In addition, other important considerations regarding sociodemographic variables were found, namely the child's ethnicity (Parrish et al., 2019; Stewart et al., 2019), and parents' educational level (Tyack & Ziviani, 2003) and

socioeconomic status (El Hamaoui et al., 2006). A recent study focused on parents of burn-injured children with an ethnic minority background corroborates the fact that belonging to an ethnic minority increases the likelihood of experiencing psychological distress (Suurmond et al., 2020). Also, Townsend et al. (2023) found that parents with a minority ethnic background had higher PTSS when compared to non-ethnic minority parents. The various barriers to psychosocial care (e.g., cultural and language obstacles), medical communication difficulties, and lack of social support perceived by ethnic minority parents may help to understand these results (Suurmond et al., 2020). Moreover, the costs associated with pediatric burn care are high, so it is important to provide more accessible options and services (e.g., outpatient services) that take into account the socioeconomic status of parents, which would reduce unnecessary hospital admissions (through a more careful evaluation) and allow resources to be redirected, as suggested in other studies (e.g., Ter Meulen et al., 2016). In fact, addressing and understanding this sociodemographic profile of vulnerability is a critical need, and future intervention programs should include a module that focuses on the financial support available, in order to reduce the economic burden on parents.

In the peri-trauma phase (i.e., first few weeks post-burn), the psychological variables of the parents linked to distress were the perceived threat to the child's life (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017), feelings of guilt and anger (e.g., Bakker et al., 2012; Egberts et al., 2017), injury-related fear avoidance (Willebrand & Sveen, 2016a), and shame (Hawkins et al., 2019). These findings were expected and are consistent with the literature on pediatric medical trauma, which suggests that parents' perceptions and appraisals towards the medical event play a determining role in the development of traumatic responses (Price et al., 2016). Since psychological responses after traumatic situations are subjective and depend on each individual's internal resources, it is crucial to identify and mobilize coping strategies and promote protective factors, including positive psychology variables, such as self-compassion (Hawkins et al., 2019), hope (Cella et al., 1988), and resilience (McGarry et al., 2013; Quezada et al., 2016). Curiously, none of the included studies examined the role of uncertainty, similar to another systematic review on parental distress which also described uncertainty as an indicator of distress (Ferraz et al., 2024). Nevertheless, Smith et al. (2015) argued that uncertainty is an important sub-dimension of distress in families with children who have a serious medical condition due to its challenging trajectory (e.g., life-threatening and unpredictable nature). Furthermore, uncertainty compromises parents' ability to cope with their child's condition and threatens overall family well-being (Sultan et al., 2016). In this line, future studies should examine the role of uncertainty in parents of burn-injured children from the admission phase, and also consider other variables that may

be protective factors for parental distress (e.g., gratitude, spirituality, posttraumatic growth). In addition, Cella et al. (1988) suggested that social support often plays a buffering role against distress, and found a negative association between social support and parental symptoms of avoidance, anxiety, and depression within four days of admission. In fact, our results seem to suggest that psychosocial variables (e.g., social functioning, social support) are important over time, regardless of the medical phase. Willebrand and Sveen (2016b) concluded that although the lack of support was significantly associated with parental psychological morbidity, it was not associated with any sociodemographic or burn-related variables, underlining the importance of a multidisciplinary approach focused on parents' mental health needs. Thus, more longitudinal studies across the burn injury trajectory are needed to examine the impact of psychosocial variables on parental distress. Among burn-related variables, TBSA proved to be the strongest predictor of parental distress symptoms (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017; Parrish et al., 2019), and permanent physical scarring had a moderating effect on mothers' PTSS (Bakker et al., 2010). Intervention programs should therefore consider markers of burn severity (e.g., burn depth, TBSA) and prognostic factors to manage its impact on parents' adjustment and prevent the development of traumatic reactions. A family-centered approach would also be beneficial, not only to provide support to parents but also because it is a recommended practice to optimize the clinical outcomes within pediatric burn care (Storey et al., 2021). A recent study on the impact of the family-centered empowerment model in burn-injured children's outcomes and on parental stress found promising results, with a reduction in parental symptoms and an improvement in the children's QoL (Mohammadzadeh et al., 2023). In fact, psychological interventions that involve the family of pediatric burn patients can potentially lead to double gains for both families and children (Quezada et al., 2016). Moreover, this care plan model, based on the family's strengths, perceptions, and demands (Mohammadzadeh et al., 2023), may also be adopted as a pathway to improve family functioning, which was also a family variable that contributed to parental distress (Phillips & Rumsey, 2008) and prevent long-term maladaptive reactions (e.g., Egberts et al., 2020).

During the acute medical care phase, which includes burn wound healing, active treatment, and subsequent implications (Price et al., 2016), attention should be paid to the traumatic symptoms of pediatric burn patients, given its significant relationship with parental traumatic reactions (Odar et al., 2013), and in the following phase (i.e., ongoing care or discharge from care) child's internalizing problems should also be targeted (Egberts et al., 2016). Also, concurrent child PTSS positively predicted parental PTSS one and six months post-burn (De Young et al., 2014), while the children's PTSD symptoms and the increased parent-child conflict post-trauma played a mediator role between children's dissociation

and parental PTSD symptoms, and between parents' acute anxiety and PTSD symptoms, respectively (Hall et al., 2006). However, more research is needed to determine a clear direction and establish causal relationships between children's and parents' traumatic symptoms, due to the methodological limitations (e.g., the use of dichotomous variables) and the small sample size of the studies involved.

Regarding the consequences of parental distress for the parents themselves, only baseline levels of distress symptoms were shown to be a strong predictor of long-term distress (Egberts et al., 2020; Parrish et al., 2019), suggesting that, to be effective, intervention must begin in the peri-trauma period, screening for risk and acting early to prevent the development of long-term maladaptive responses. This conclusion is consistent with recent evidence that suggests the urgent need to include caregivers of pediatric burn patients in the care plan from the beginning of the adjustment process, providing them with the necessary skills to actively participate in the child's treatment and maintain care over time, without neglecting their own needs (Hsu, 2023). Hsu (2023) also suggested that an intervention focused on caregivers' PTSD symptoms could lead to an improvement in their QoL, given the significant relationship between the two variables. Despite that, these results should be interpreted with caution, since one study focused exclusively on mothers (Egberts et al., 2020) and another did not control for the effect of potential confounding factors (e.g., ethnic minority status) that may influence parents' initial psychological responses (Parrish et al., 2019).

As expected, the consequences of the distress extended to the children. Our findings suggest that parental distress is a significant potential risk factor for children's traumatic symptoms, in particular symptoms of acute stress (Haag & Landolt, 2017; Saxe et al., 2005) and PTSD (Graf et al., 2011; Hall et al., 2006), PTSS (De Young et al., 2014; Egberts et al., 2018; Enlow et al., 2019), and behavior (e.g., Bakker et al., 2014; Haag & Landolt, 2017; Willebrand et al., 2011) and mood problems (Stewart et al., 2019). The child's coping responses and protective factors may also be negatively affected by parental distress symptoms (Brown et al., 2019a; Enlow et al., 2019; Quezada et al., 2016), and future studies should investigate longitudinally these relationships. A previous empirical review on psychological sequelae in response to pediatric burn injuries corroborates that the child's psychosocial outcomes were highly associated with family and caregiver variables, suggesting that the way the family, especially the parents, react to the situation directly influences the child's adjustment (Bakker, Maertens et al., 2013). Given the traumatic nature of the medical event, understanding that parental distress symptoms affect not only themselves (e.g., daily functioning, parenting practices; Price et al., 2016) but also children in different ways (e.g., low resilience; Quezada et al., 2016), is an important step in drawing up specific guidelines to inform clinical practices. However, few studies have explored the consequences of parental

distress beyond the child's psychological dimension. For example, evidence on the role of parental distress symptoms in children's health and functional outcomes is scarce. The main results emphasize the importance of parental distress for children's health outcomes, including delayed re-epithelialization, pre- and peak-procedural pain (Brown et al., 2019b), post-burn pruritus and sleep problems (Stewart et al., 2019), and also positively predicted variance in functional outcome of children (Tyack & Ziviani, 2003). An original finding of this review was higher levels of parental distress negatively influenced parent-reported burn outcomes six and 18 months post-burn (Pan et al., 2015). This result is in line with recent evidence that has found a significant relationship between higher levels of parental PTSS and poorer QoL in burn-injured children (Townsend et al., 2023). Therefore, more longitudinal studies are needed to clarify the contribution of parental psychological factors to children's health outcomes over time, including QoL, particularly in preschool children.

Subgroup differences were also examined in 11 studies (Bakker et al., 2010, 2012; Bakker, Van der Heijden et al., 2013; De Young et al., 2014; Egberts et al., 2017, 2020; Haag & Landolt, 2011; Kent et al., 2000; LeDoux et al., 1998; McGarry et al., 2013; Suurmond et al., 2020), although, contrary to our expectations, none of the included studies explored the differences regarding burn depth (e.g., superficial partial-thickness versus full-thickness) and children's age groups. In addition, no significant differences based on TBSA in parental distress symptoms were found (LeDoux et al., 1998; McGarry et al., 2013). This result was unexpected since TBSA was a significant predictor of parental distress (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017; Parrish et al., 2019). The small sample size (e.g., 35 pediatric burn survivors; LeDoux et al., 1998), discrepancies between the participants' burn characteristics, and conservative statistical approaches (McGarry et al., 2013), may have influenced these results. Differences regarding the gender of parents highlighted mothers as the most affected group (Bakker et al., 2012; Bakker, Van der Heijden et al., 2013; Egberts et al., 2017; Suurmond et al., 2020). Interestingly, one study reported no significant differences between mothers and fathers within one-week post-burn, suggesting that their psychological reactions in response to the burn event seemed not to differ at an early stage (McGarry et al., 2013). However, it is not surprising that mothers of burn-injured children report more symptoms of distress than fathers, not only because they are typically the child's primary caregivers, but also because of their high perception of responsibility (Sveen & Willebrand, 2018). This is consistent with previous literature on other serious pediatric medical conditions (e.g., Ferraz et al., 2024). In addition, maternal symptoms seem to persist over longer periods (Egberts et al., 2020; Kent et al., 2000), and further research with a longitudinal design is needed to verify this possible trend over time. Four studies also highlight that overall symptoms of parental distress

tend to decrease over time (Bakker et al., 2010; De Young et al., 2014; Egberts et al., 2020; Kent et al., 2000); however, these results should be interpreted with caution and symptoms of distress should not be underestimated, given the key role of parents during the course of the burn injury treatment, namely in the child's adjustment and recovery (e.g., Bakker, Maertens et al., 2013; De Young et al., 2014; Woolard et al., 2021). Taken together, our findings suggest that is imperative to screen for the risk of developing distress symptoms from the peri-trauma phase and to monitor parents' mental health needs throughout the trajectory of the burn injury, recognizing the pressing need to provide support and promote self-care and psychological resources (e.g., emotional regulation, active coping strategies) to improve the adjustment and QoL outcomes of both parents and children, as proposed in the designed model (Figure 1.2).

Limitations

The present systematic review is conditioned by some limitations that must be acknowledged when interpreting the results found, since only nine studies achieved a good quality rating (Bakker et al., 2014; Brown et al., 2019b; Cella et al., 1988; Egberts et al., 2018; Enlow et al., 2019; Hawkins et al., 2019; Kent et al., 2000; Parrish et al., 2019; Tyack & Ziviani, 2003). The vast majority of the studies included had a cross-sectional design (63.16%), limiting causal inferences and the proper determination of predictor variables. To ensure rigor, predictor variables in cross-sectional studies were described in this review as "contributors variables". Furthermore, the lack of use of common measures to assess symptoms of parental distress and the scarcity of validated guilt-specific instruments (Bakker et al., 2010, 2012; Bakker, Van der Heijden et al., 2013; De Young et al., 2014; Egberts et al., 2017; Suurmond et al., 2020; Sveen & Willebrand, 2018), makes it difficult to compare results between studies and to draw solid conclusions about the role of parental feelings of guilt. The heterogeneity of the sample characteristics (e.g., 71% of the studies included more mothers than fathers, four studies focused exclusively on mothers), and the fact that most of the studies were conducted in Europe (55.26%), also compromises the generalizability of the results. Finally, the scope of this review was limited to the studies published up to November 18, 2021, and, as this research topic is a rapidly evolving field, studies published after that date were not included in the present formal analysis (e.g., Hsu, 2023; Townsend et al., 2023). In an attempt to overcome this limitation, some of these studies were used to discuss the present findings.

Conclusion

This is the first review to systematically examine, identify, and describe the factors/predictors and consequences of parental distress following pediatric burn injuries over 33 years of research. Our

results highlight that the impact of unintentional pediatric burns on the family sphere is undeniable, and also raise several implications (e.g., psychological, psychosocial, family) for informing clinical practice, research, and mental health-related policies (e.g., educational prevention), along the burn injury trajectory (i.e., pre- and peri-trauma phase, acute medical care phase, and ongoing care phase). Given the various potential risk factors for parental distress and the resulting consequences for both children and parents, early and ongoing psychosocial assessment of parents and evidence-based mental health interventions are paramount. Therefore, addressing and targeting parental psychological factors in the recovery process of children who sustained a burn injury should be an area of special focus for the healthcare team within pediatric burn care, in order to shift towards a preventive paradigm and promote optimal primary (e.g., children's QoL) and secondary outcomes (parents' psychological adjustment, which helps in maintaining effective care post-discharge). Pediatric burn units should include a multidisciplinary team (e.g., pediatric surgeons, clinical and health psychologists), establish a standardized assessment protocol, and also adopt a trauma-informed care model to cover the mental health needs of these parents and prepare for the post-discharge phase, thereby improving children's health outcomes.

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Figure 1.1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of the study selection process

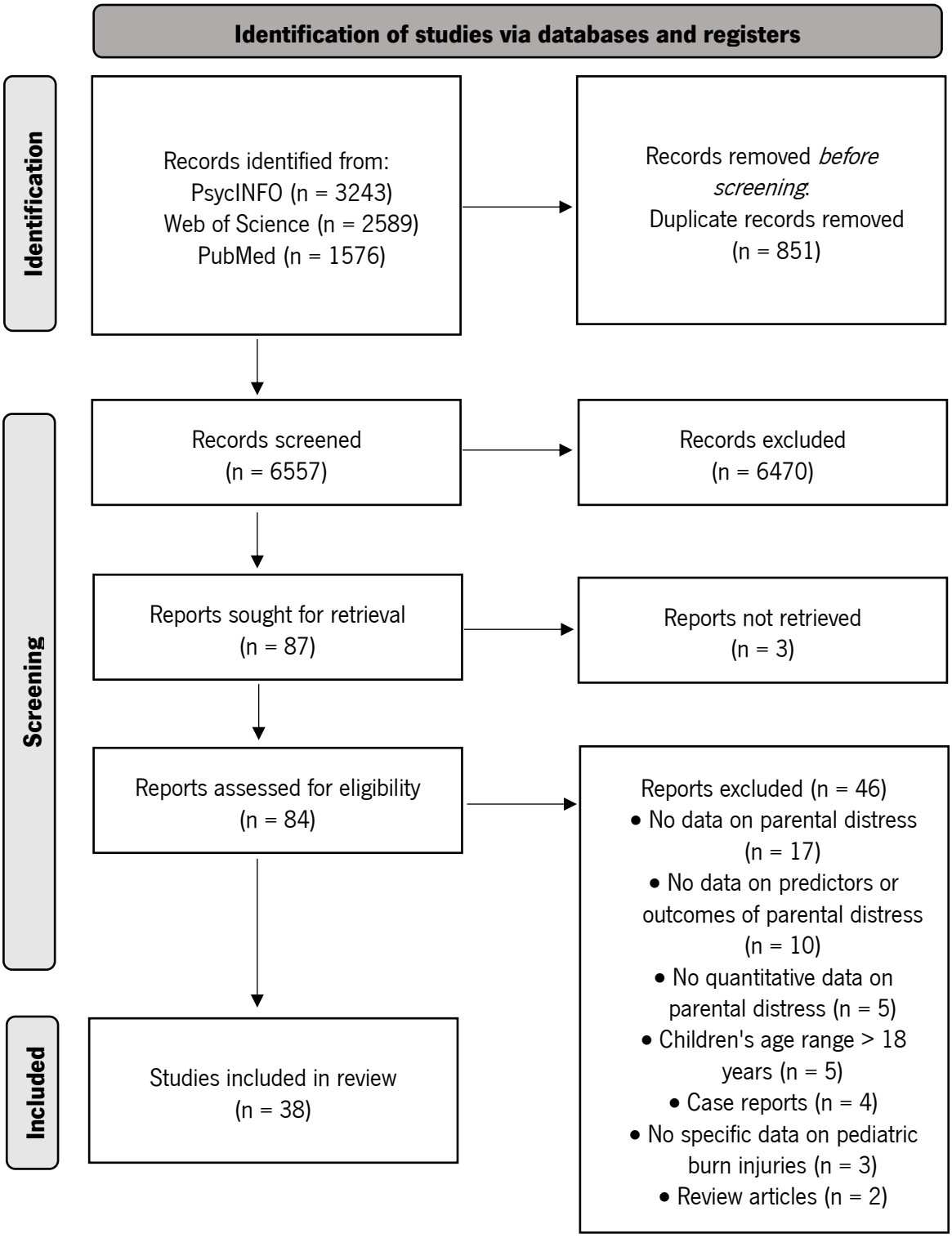
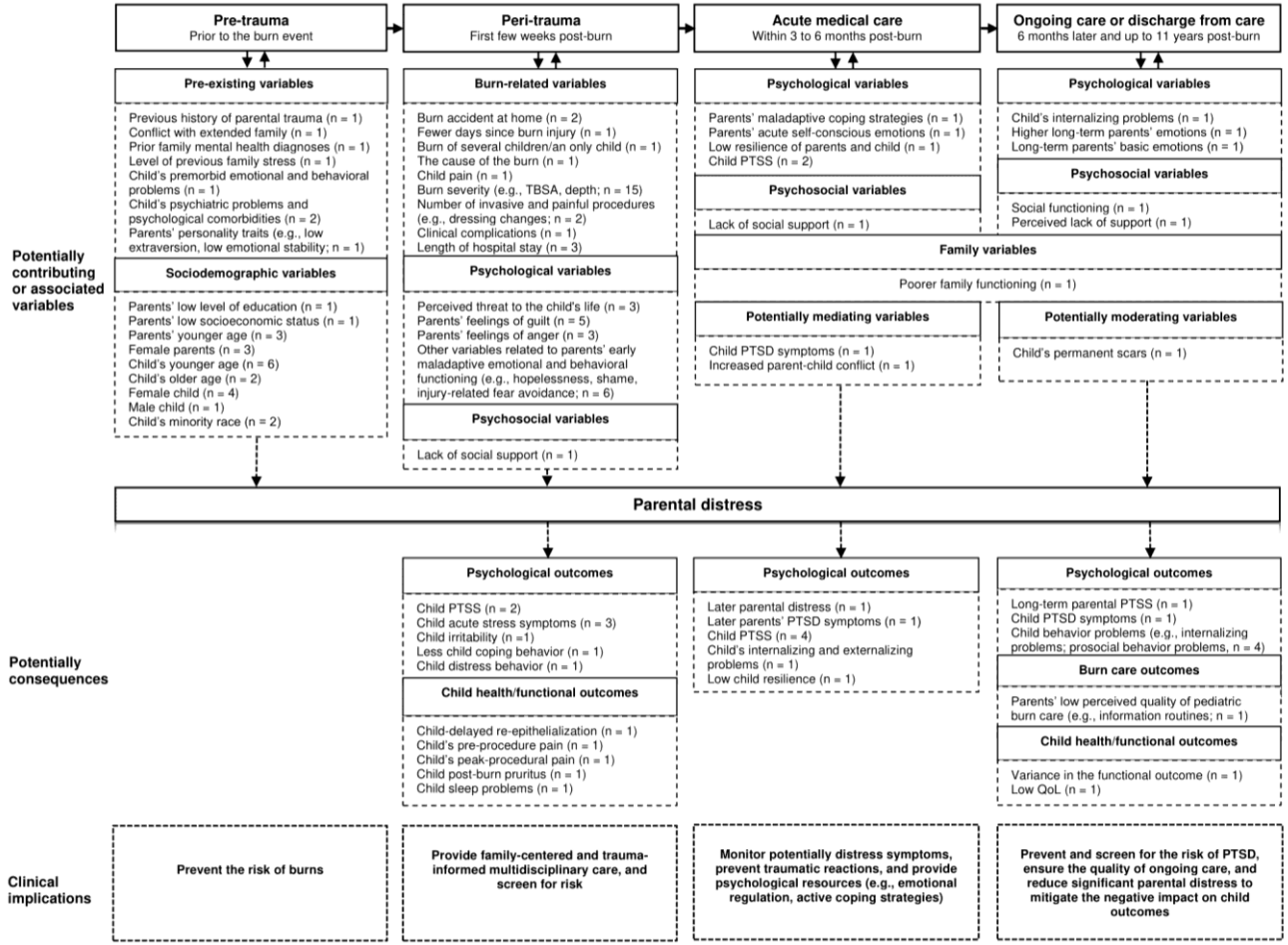


Figure 1.2

Graphical model of the factors/predictors and consequences of parental distress following pediatric burn injuries found in this review



Note. The model was adapted from the Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress (Kazak et al., 2006; Price et al., 2016), including the number of the articles exploring each variable, medical phases, and goals for intervention and clinical practice.

Supplementary Material 1

Search Strategy

Keywords were derived from the research literature. The search strategy combines the following terms:

1.PubMed

Filters: English/From inception to 2021/Humans

Advanced search

(parent* OR mother* OR father* OR maternal OR paternal OR caregiver* OR famil* OR "parent-child relation*")

AND (distress* OR anxi* OR depress* OR "traumatic stress" OR stress* OR "stress disorder*" OR "posttraumatic stress" OR "post-traumatic stress" OR "PTSD" OR "PTSS" OR "acute stress" OR psychopatholog* OR psychiatr* OR "psychological adjustment" OR "psychological disorder*" OR "psychological morbidit*" OR psychosomatic* OR "adjustment disorder" OR "quality of life" OR "mental health" OR "mental disorder*" OR "emotional disturbance*" OR uncertainty OR guilt*)

AND (burn* OR scald OR thermal OR "burn wound" OR "burn injur*")

AND (child* OR pediatric* OR paediatric* OR toddler* OR infant* OR preschool* OR adolescen* OR youth* OR teen*)

AND NOT (burnout)

2.Web of Science

Filters: English/From inception to 2021/Article

Note. It does not allow to put Human as filter.

Basic search: [Web of Science Core Collection]

(parent* OR mother* OR father* OR maternal OR paternal OR caregiver* OR famil* OR "parent-child relation*")

AND (distress* OR anxi* OR depress* OR "traumatic stress" OR stress* OR "stress disorder*" OR "posttraumatic stress" OR "post-traumatic stress" OR "PTSD" OR "PTSS" OR "acute stress" OR psychopatholog* OR psychiatr* OR "psychological adjustment" OR "psychological disorder*" OR "psychological morbidit*" OR psychosomatic* OR "adjustment disorder" OR "quality of life" OR "mental health" OR "mental disorder*" OR "emotional disturbance*" OR uncertainty OR guilt*)

AND (burn* OR scald OR thermal OR "burn wound" OR "burn injur*")

AND (child* OR pediatric* OR paediatric* OR toddler* OR infant* OR preschool* OR adolescen* OR youth* OR teen*)

AND NOT (burnout)

3.PsycINFO

Filters: Peer-reviewed/English/From inception to 2021/Humans

Advanced search

(parent* OR mother* OR father* OR maternal OR paternal OR caregiver* OR famil* OR "parent-child relation*")

AND (distress* OR anxi* OR depress* OR "traumatic stress" OR stress* OR "stress disorder*" OR "posttraumatic stress" OR "post-traumatic stress" OR "PTSD" OR "PTSS" OR "acute stress" OR psychopatholog* OR psychiatr* OR "psychological adjustment" OR "psychological disorder*" OR "psychological morbidit*" OR psychosomatic* OR "adjustment disorder" OR "quality of life" OR "mental health" OR "mental disorder*" OR "emotional disturbance*" OR uncertainty OR guilt*)

AND (burn* OR scald OR thermal OR "burn wound" OR "burn injur*")

AND (child* OR pediatric* OR paediatric* OR toddler* OR infant* OR preschool* OR adolescen* OR youth* OR teen*)

AND NOT (burnout)

Supplementary Material 2

Summary table of included articles

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Factors/predictors of parental distress/subgroup differences										
Cella (1988) United States	28M 8F	33.3	16G 20B	2	14%	-	IES BDI POMS SSAI	CS	Within 4 days of admission	Parental hopelessness was positively associated with parental avoidance and depressive symptoms, and mood disturbances. Also, child burn-related variables (e.g., %TBSA) were associated with parental intrusion symptoms and mood disturbance. Social support was negatively associated with parental symptoms of avoidance, anxiety, and depression.
Blakeney (1993) United States	89P	-	-	-	5-98%	-	PSI	CS	1 to 3 days post-burn (admission) – acute burn group	Child burn size was not associated with the parenting stress scores (including any of the subscales) of parents of children with acute burns.
LeDoux (1998) United States	32M 2F	-	6G 29B	13.25 (2.70)	37.20% (21.88)	-	BDI IES	CS	1 to 5 years post-burn	No significant differences were found based on TBSA in parental symptoms of depression and PTSS.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Kent (2000) England	40M	-	18G 22B	19.2 months (10.2)	8.5% Range: 1-25%	6.5 (10.9)	HADS	L	T1: within 3 days of admission T2: 6 months later	No significant relationships were found between TBSA and maternal symptoms of depression and anxiety. Although there was a slight decrease in anxiety symptoms from T1 to T2, mothers continued to exhibit high anxiety at T2. However, only depression symptoms decreased significantly from T1 to T2.
Tyack (2003) Australia	69P	-	69C	9.75 (2.74)	5.77% (7.47)	-	STAI BDI	L	T1: Prior to skin healing T2: At skin healing T3: 6 months post-burn	Lower parental education level was associated with higher state anxiety. Child psychiatric problems were positively associated with parental trait anxiety. Social support was negatively associated with parental anxiety (state and trait) and depression (only for the number of social support networks subscale). Also, coping (planful problem solving) was negatively

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										associated with parental trait anxiety and depression. Coping negative reappraisals was negatively associated with parental trait anxiety.
El Hamaoui (2006) Morocco	28M	34.5 (8.7)	28C	8.2 (2.7)	38.3% (11.2)	-	HARS HDRS MINI	CS	6 months to 5 years post-burn	Higher %TBSA, clinical complications (e.g., amputation, secondary infection), and low socioeconomic status were significantly associated with maternal depressive symptoms. Also, burn of several children at the same time or of the only child was significantly associated with maternal depressive symptoms. Social functioning was associated with mothers' major depressive disorder. No significant associations were found between the child's age and gender, mother's age, and educational level with maternal depression.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Hall (2006) United States	54M 8F	-	19G 43B	11.45 Range: 6-17	16.9% Range: 1-85%	24	BSI PCL-C SASRQ	L	T1: immediately following the burn event T2: 3 months post-burn	TBSA was positively associated with parents' anxiety symptoms, dissociation, and PTSD symptoms. Pre-trauma variables (i.e., conflict with extended family) were significantly associated with parents' anxiety and PTSD symptoms. The relationship between parental acute anxiety and PTSD symptoms was mediated by post-trauma increased parent-child conflict. In addition, the relationship between TBSA and parental PTSD symptoms was mediated by children's PTSD symptoms. Children's PTSD symptoms mediated the relationship between children's dissociation and parental PTSD symptoms.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Stoddard (2006) United States	52P	-	22G 30B	-	14.1% (14.46)	14.94 (21.60)	SASRQ	CS	Within 3 days of admission or medically stable	Child pain was positively associated with parental acute stress symptoms.
Phillips (2008) England	56M 16F	-	Inpatient group: 10B 6G Outpatient group: 23G 33B	Inpatient group: 2.6 (3.4)	Inpatient group: 12.9% (6.7)	-	HADS	CS	Time band 1: within 6 months since burn incident Time band 2: 6-24 months Time band 3: > 2 years	At the inpatient stage, lower parental extraversion was significantly associated with parental depression symptoms, whereas TBSA and related subjective measures were not significantly associated with parental anxiety and depression symptoms. Younger age of the mother, poorer family functioning, and lower parental emotional stability contributed to parental anxiety. Moreover, younger age of the mother and poorer family functioning contributed to parental depression.
Bakker (2010) The Netherlands	48M	32.33 (4.07)	20G 28B	3.00 (2.76)	2.60 body zones (2.28)	13.02 (15.44)	IES	L	T1: 1 year post-burn T2: 2 years after T3: 11 years after	The mean maternal PTSS scores decreased significantly from T1 to T3. The burn severity and the number of

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										scarred body zones were not significantly associated with maternal PTSS and PTSS at T3, respectively. Guilt feelings and the interaction between burn severity and feelings of guilt predict maternal PTSS. Permanent scarring appeared to moderate the relationship between maternal guilt feelings and PTSS.
Bakker (2012) The Netherlands and Belgium	182M 154F	M: 31 (5.3) F: 35.8 (5.8)	67G 126B	1.8 (0.9)	7.5% (6.5)	11.4 (10.6)	IES	CS	1 to 4 weeks after admission	Mothers showed higher PTSD symptoms than fathers. Child gender, age, and burn size positively contributed to parent couples' intrusion symptoms, as well as, parent gender (female), feelings of anger and guilt, and perceived threat to the life of their child. Parent age negatively contributed to parent couples' intrusion symptoms. Burn size, domestic burn accidents, parent gender (female), feelings of guilt and anger, and

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										perceived threat to the life of their child positively contributed to parent couples' avoidance symptoms.
Bakker, Van der Heijden (2013) The Netherlands and Belgium	186M 159F	M: 31.9 (5.3) F: 35.7 (5.8)	69G 129B	1.8 (0.9)	7.5% (6.4)	11.2 (10.4)	IES	L	T1: within the first month after the burn incident T2: 3 months after T3: 12 months after T4: 18 months post-burn	Mothers reported higher early guilt feelings and anger than fathers. Also, mothers showed higher avoidance and intrusion symptoms than fathers. For avoidance symptoms, the differences between the parents' genders decreased over time. Parent gender (female), parental feelings of anger, child gender (female) and age, and %TBSA, contributed positively to parental symptoms of avoidance and intrusion. Also, parental feelings of guilt and perceived threat to the life of their child positively predicted parental intrusion symptoms.
McGarry (2013)	46M 17F	-	21G 37B	8 months	4.12% (4.05)	-	IES DASS-21	CS	Within 1-week post-burn	Parental resilience was negatively associated with

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Australia				to 16 years						parental PTSD symptoms, intrusion, and hyperarousal symptoms. No significant associations were found between parental resilience and parental anxiety, depression, and stress symptoms. No significant associations were found between burn-related factors (e.g., TBSA, surgery) and parental distress, nor significant differences between fathers and mothers.
Odar (2013) United States	37M 8F	27.68 (6.73)	14G 31B	21.85 months (12.50)	2.67% (2.40)	3.51 (5.94)	PCL-S	CS	During outpatient appointments	Younger child age, higher child PTSS, a higher number of family mental health diagnoses, and level of previous familial stress were significantly associated with higher parental PTSS. No significant associations were found between the level of social and burn-related factors (e.g., days since the burn, witnessed the accident) with

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										parental PTSS, except for the cause of burn, which was significantly associated with parental PTSS. Also, no significant associations were found between parental demographic factors (e.g., age, ethnicity, education level, marital status) and parental PTSS.
De Young (2014) Australia	111M 9F	32.88 (5.36)	59G 61B	2.66 (1.49)	3.16% (4.35)	-	PDS DASS-21	L	T1: within 2 weeks post-burn T2: 1 month after T3: 6 months after	Parental anxiety, depression, and stress symptoms decreased significantly over time. Parental PTSD symptoms and PTSS also decreased significantly from T2 to T3. Child age was negatively associated with parental distress at T1. Prior history of parental trauma was negatively associated with parental guilt at T2. Prior history of parental trauma, child premorbid emotional and behavioral problems, %TBSA,

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										and number of invasive procedures were positively associated with parental PTSS at T2 and T3. Concurrent child PTSS positively predicted parental PTSS at T2 and T3. Number of invasive procedures positively predicted parental PTSS at T2 and T3, and prior history of parental trauma positively predicted parental PTSS at T2.
Egberts (2016) The Netherlands and Belgium	85M 65F	M: 43.1 (5.6) F: 45.9 (6.2)	25G 65B	13.9 (2.4)	10% (12.3)	19.4 (29.7)	IES	L	T1: first-month post-burn T2: 12 months after	Child age was negatively associated with maternal PTSS at T1. Parents' observations of the child's internalizing problems were significantly associated with parental PTSS over time.
Quezada (2016) Mexico	35M 16F	38.96 (8.43)	22G 29B	12 (3)	31% (19)	-	DTS	CS	More than 3 months post-burn (outpatients)	Caregiver resilience was negatively associated with caregivers' PTSD symptoms (i.e., intrusion, avoidance, and hyperarousal symptoms). Also, caregiver resilience was negatively associated with

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										female caregivers' symptoms of avoidance and hyperarousal. Pediatric patient resilience was negatively associated with intrusion symptoms of female caregivers, and positively associated with intrusion, avoidance, and hyperarousal symptoms of male caregivers. Also, %TBSA was positively associated with hyperarousal symptoms in male caregivers.
Sveen (2016) Sweeden	42M 20F	38	22G 27B	5.8 (3.6)	9.2% (7.0)	7.3 (7.8)	PSS-14 MADRS IES-R PCL-5	CS	0.8 to 5.6 years post-burn	Female gender of the child was significantly associated with higher parental PTSD symptoms (i.e., total scale, arousal and reactivity symptoms, and cognition and mood). Parents' cognition and mood subscale of PCL-5 were positively associated with %TBSA.
Willebrand (2016a) Sweeden	107P	-	38G 68B	-	9.4% (10.7)	11.0 (35.7)	IES-R	CS	0.1 to 9.0 years post-burn	Child %TBSA, hospital length of stay, and psychological comorbidity were positively

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										associated with parental PTSD symptoms. Injury-related fear avoidance predicted higher parental PTSD.
Willebrand (2016b) Sweeden	101P	-	40G 66B	6.6 (7.3)	8.7% (8.9)	9.0 (31.3)	IES-R HADS	CS	0.1 to 9.0 years post-burn	Lack of support was significantly associated with parental anxiety and depressive symptoms.
Egberts (2017) The Netherlands and Belgium	111M 91F	M: 42.1 (5.9) F: 44.7 (6.4)	35G 83B	12.9 (3.0)	9.6% (11.8)	20.1 (32.5)	IES	L	T1: first-month post-burn T2: 3 months after T3: 12 months after T4: 18 months after	Child age (younger) and %TBSA were associated with parental intrusion symptoms. Parent gender (female) and feelings of guilt positively predicted parental intrusion and avoidance symptoms. Perceived threat to the life of their child and %TBSA positively predicted parental intrusion symptoms and child age negatively predicted. Child gender (male) and domestic burn accidents positively predicted parental avoidance symptoms.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Haag (2017) Switzerland	138M 128F	-	56G 82B	2.18 (0.91)	3.7% (4.32)	1.73 (3.71)	ASDS	CS	On average 19 days post-burn	Mothers showed higher symptoms of avoidance and intrusion than fathers. Mothers showed higher mean scores of acute stress symptoms than fathers. %TBSA was positively associated with maternal intrusion, avoidance, arousal, and negative mood, and fathers' intrusion, arousal, and negative mood. Days in the hospital were positively associated with maternal intrusion, arousal, and negative mood, and fathers' intrusion, dissociation, arousal, and negative mood. Dressing changes were positively associated with maternal negative mood and fathers' intrusion. %TBSA positively predicted fathers' acute stress symptoms.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Egberts (2018) The Netherlands and Belgium	90M 74F	M: 42.4 (6.1) F: 44.8 (6.6)	31G 69B	-	8.8% (10.3)	18 (29)	IES	L	T1: first-month post-burn T2: 3 months after	Child age (younger) was significantly associated with maternal PTSS at T1.
Sveen (2018) Sweeden	41M 20F	-	22G 26B	5.8 (3.7)	9.2% (7)	7.3 (7.6)	MADRS	CS	0.8 to 5.6 years post-burn	General guilt was positively associated with parental depressive symptoms (total scale). Embitterment was positively associated with parental pessimistic and suicidal thoughts. No significant associations were found between burn-specific guilt and parental depressive symptoms.
Brown (2019b) Australia	69M 14F	32.44 (5.43)	36G 47B	2.95 (1.74)	1.85% (2.14)	-	PC-PTSD GGS PHQ-4 VAS-A	CS	At the first dressing change	Child higher %TBSA was significantly associated with higher levels of parental PTSS, pre-procedure fear, and symptoms of anxiety and depression. Child wound depth was negatively associated with parental

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										symptoms of anxiety and depression.
Hawkins (2019) England	63M 28F	33.62 (8.78)	29G 42B	4.18 (4.48)	3.88% (3.67)	3.88 (3.67)	IES-R DASS-21 TRGI	CS	First 8 weeks post-burn	Child age (younger) was significantly associated with higher levels of parental symptoms of anxiety and depression, PTSS, and guilt feelings. Length of hospitalization was positively associated with parental PTSS. Parent age (younger) was significantly associated with higher parental PTSS. Shame was positively associated with parental symptoms of anxiety and depression, PTSS, and feelings of guilt. In contrast, self-compassion was negatively associated with parental depressive symptoms and PTSS. Also, shame positively predicted parental symptoms of anxiety and depression, and PTSS. Self-compassion

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										negatively predicted parental symptoms of depression.
Parrish (2019) United States	T1: N = 407 T2: N = 130	-	T1: N = 407C T2: N = 130C	T1: 5.05 (4.46) T2: 4.64 (4.59)	T1: 4.15% (5.19) T2: 5.34% (6.90)	-	SPRINT	L	T1: initial visit T2: subsequent follow-up	Child gender (female), child ethnic minority status, higher %TBSA, and fewer days since burn injury were significantly associated with higher parental distress at T1. Child gender (female) was significantly associated with higher parental distress at T2. Child minority race, fewer days since burn, and higher %TBSA predicted parental distress at T1.
Stewart (2019) United States	-	-	105G 151B	1.57 (0.75)	3.99% (4.25)	-	SPRINT	CS	screened within 32 days post-burn	Child minority race and higher %TBSA were significantly associated with higher parental distress.
Egberts (2020) The Netherlands and Belgium	296M	35.64 (7.40)	97G 198B	Young cohort: 1.79 (0.92) School-aged	8.17% (8.70)	13.95 (18.90)	IES HADS	L	T1: first-month post-burn T2: 12 months after T3: 18 months after	Higher long-term emotions were positively associated with maternal PTSS and symptoms of depression. Acute self-conscious emotions were positively associated with

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
				cohort: 12.91 (2.96)						maternal PTSS and symptoms of depression at T1 and were only related to depressive symptoms across the time points. Long-term basic emotions at T2 positively predicted maternal PTSS and symptoms of depression at T3, and acute basic emotions at T2 negatively predicted. Also, higher acute self-conscious emotions at T1 predicted higher maternal depressive symptoms at T3. The mean scores of parental symptoms of depression and PTSS decreased significantly from T1 to T3.
Suurmond (2020) The Netherlands and Belgium	120M 106F	-	-	-	-	-	HADS-D IES	L	T1: first-month post-burn T2: 3 months after	In general, mothers showed higher mean scores of depressive symptoms (T1) and PTSS (T2) than fathers.

Consequences of parental distress

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Tyack (2003) Australia	69P	-	69C	9.75 (2.74)	5.77% (7.47)	-	STAI BDI	L	T1: Prior to skin healing T2: At skin healing T3: 6 months post-burn	Parental anxiety (state and trait) and depression symptoms were positively associated with child behavior problems. Parents' anxiety and depressive symptoms contributed significantly to the variance in functional outcome of children at T3.
Saxe (2005) United States	-	-	24G 48B	11.20 (3.51)	17.58% (1-85%)	25 (22.77)	SASRQ	CS	After admission (about 10 days post-burn)	Parents' acute stress symptoms predict children's acute stress symptoms. Also, parents' acute stress symptoms mediated the relationship between %TBSA and child acute stress symptoms.
Hall (2006) United States	54M 8F	-	19G 43B	11.45 Range: 6-17	16.9% Range: 1-85%	24	BSI PCL-C SASRQ	L	T1: immediately following the burn event T2: 3 months post-burn	Parental anxiety and PTSD symptoms were positively associated with child PTSD symptoms. The relationship between TBSA and parental PTSD symptoms was mediated by parental acute dissociation. Moreover, parental

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										dissociation mediated the relationship between conflict with extended family (pre-trauma) and parental PTSD symptoms.
Stoddard (2006) United States	52P	-	22G 30B	-	14.1% (14.46)	14.94 (21.60)	SASRQ	CS	Within 3 days of admission or medically stable	Parental acute stress symptoms mediated the relationship between child pain and acute stress symptoms.
Graf (2011) Switzerland	76P	-	32G 44B	32 months (9.5)	7.6% (7.4)	14.5 (20.1)	PDS	CS	About 15 months post-burn	PTSD symptoms of mothers were positively associated with children's PTSD symptoms. PTSD symptoms of fathers were not significantly associated with children's PTSD symptoms.
Willebrand (2011) Sweeden	57M 37F	-	35G 59B	8.0 (3.9)	9.4% (11.2)	11.7 (37.9)	HADS IES-R	CS	0.3 to 9.0 years post-burn	Parental symptoms of anxiety, depression, and PTSD were positively associated with child psychological difficulties (i.e., emotional symptoms, conduct problems, hyperactivity/inattention, and peer problems), whereas parental anxiety and

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										depression symptoms were negatively associated with child prosocial behavior. Parental anxiety and depression symptoms positively contributed to the child's psychological difficulties and negatively to prosocial behavior.
Bakker (2014) The Netherlands and Belgium	150M 125F	M: 32.2 (5.2) F: 36.0 (5.5)	54G 101B	1.8 (0.9)	7.7% (6.8)	11.3 (10.8)	IES	L	T1: 3 months post-burn T2: 12 months after	Greater parental acute stress symptoms were associated with more child behavior problems (internalizing and externalizing) at T1 and T2.
De Young (2014) Australia	111M 9F	32.88 (5.36)	59G 61B	2.66 (1.49)	3.16% (4.35)	-	PDS DASS-21	L	T1: within 2 weeks post-burn T2: 1 month after T3: 6 months after	Parental anxiety, depression, and stress symptoms at T1 positively predicted child PTSS at T2. Concurrent parental PTSS positively predicted child PTSS at T2 and T3.
Pan (2015) The Netherlands	54M 41F	M: 44 (6) F: 46 (6)	89C	14 (2)	10% (13)	19 (30)	IES	L	T1: 6 months post-burn T2: 18 months later	Mothers' PTSS were negatively associated with several children's QoL subscales. Fathers' PTSS were positively

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
and Belgium										associated with their observation of the child's itch (at T1 and T2), family disruption, and concern at T1. Also, fathers' PTSS were negatively associated with satisfaction with the current state and emotional health at T1 and appearance at T1 and T2.
Egberts (2016) The Netherlands and Belgium	85M 65F	M: 43.1 (5.6) F: 45.9 (6.2)	25G 65B	13.9 (2.4)	10% (12.3)	19.4 (29.7)	IES	L	T1: first-month post-burn T2: 12 months after	Parental PTSS at T2 were associated with parental reports of child internalizing problems.
Quezada (2016) Mexico	35M 16F	38.96 (8.43)	22G 29B	12 (3)	31% (19)	-	DTS	CS	More than 3 months post-burn (outpatients)	Caregivers' intrusion symptoms strongly predicted pediatric patients' resilience, explained by the level of avoidance symptoms. In sum, lower caregiver PTSD symptoms contributed to higher resilience in pediatric burn patients.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
Haag (2017) Switzerland	138M 128F	-	56G 82B	2.18 (0.91)	3.7% (4.32)	1.73 (3.71)	ASDS	CS	On average 19 days post-burn	Greater maternal acute stress symptoms were significantly associated with greater child acute stress symptoms. Also, %TBSA was indirectly associated with greater child acute stress symptoms through maternal acute stress symptoms (but not through fathers' acute stress). Thus, the relationship between %TBSA and child acute stress symptoms was mediated by maternal acute stress symptoms. Maternal acute stress (all subscales) and fathers' intrusion were positively associated with child intrusion. Maternal intrusion, dissociation, arousal, and fathers' intrusion were positively associated with child arousal. Maternal intrusion, avoidance, and negative mood

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										were positively associated with child avoidance/cognitions.
Egberts (2018) The Netherlands and Belgium	90M 74F	M: 42.4 (6.1) F: 44.8 (6.6)	31G 69B	-	8.8% (10.3)	18 (29)	IES	L	T1: first-month post-burn T2: 3 months after	Maternal PTSS at T1 and both parents' PTSS at T2 were positively associated with the child's self-reported symptoms.
Willebrand (2018) Sweeden	42M 20F	37.3 (6.2)	22G 27B	5.8 (3.6)	9.2% (7.0)	7.3 (7.5)	IES-R MADRS	CS	0.8 to 5.6 years post-burn	Parental depressive symptoms and PTSS were negatively associated with information routines and caring processes. Parental depressive symptoms were negatively associated with overall quality grades, information illness, and parental PTSS with participation.
Brown (2019a) Australia	73M 10F	32.37 (5.31)	33G 50B	2.95 (1.72)	1.87% (2.14)	-	PC-PTSD PHQ-4 VAS-A GGS	CS	At the first dressing change	Parental pre-procedural anxiety, PTSS, and guilt were negatively associated with the child's coping behavior. Also, parental guilt was positively associated with child distress behavior.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										Parental PTSS positively predicted child distress, mediated through parental distress-promoting behavior. Parental feelings of guilt also positively predicted child distress, mediated through parental distress-promoting behavior. Parental symptoms of anxiety and depression predicted less child coping, mediated through less parental coping-promoting behavior.
Brown (2019b) Australia	69M 14F	32.44 (5.43)	36G 47B	2.95 (1.74)	1.85% (2.14)	-	PC-PTSD GGS PHQ-4 VAS-A	CS	At the first dressing change	Parental acute PTSS was associated with child delayed re-epithelialization. Parental PTSS, trauma-related guilt, symptoms of anxiety and depression, and pre-procedure fear were positively associated with parent reports of the child's pre-procedure pain. Also, parental trauma-related guilt was positively associated

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
										with parent reports of the child's peak-procedural pain.
Enlow (2019) United States	46M	-	18G 28B	12.67 (2.68)	9.18% (11.55)	11.6 (20.90)	DASS-21	CS	During clinic appointments (outpatients)/summer camp registration	Higher caregiver anxiety symptoms were significantly associated with more child PTSS. Caregiver anxiety and depressive symptoms moderated the relationship between child distraction coping and child PTSS. Children who used more distraction coping strategies reported lower PTSS when caregiver anxiety was higher. Curiously, when caregiver depression was lower, children who used more distraction coping strategies reported more PTSS.
Parrish (2019) United States	T1: 407P T2: 130P	-	T1: 186G 221B T2: 62G 68B	T1: 5.05 (4.46) T2: 4.64 (4.59)	T1: 4.15% (5.19)	-	SPRINT	L	T1: initial visit T2: subsequent follow-up	Parental distress at T1 was the only predictor of parental distress at T2.

First author (year) Country	Parents sample		Burned children sample		%TBSA, Mean (*SD*)	LoS, Mean (SD)	Distress measures	Study Design	Assessment time point(s)	Main findings
	Gender	Age Mean (*SD*)	Gender	Age Mean (*SD*)						
					T2: 5.34% (6.90)					
Stewart (2019) United States	-	-	105G 151B	1.57 (0.75)	3.99 (4.25)	-	SPRINT	CS	screened within 32 days post-burn	Parental distress was positively associated with child post-burn pruritus, mood, sleep onset, and sleep disturbance.
Egberts (2020) The Netherlands and Belgium	296M	35.64 (7.40)	97G 198B	Young cohort: 1.79 (0.92) School-aged cohort: 12.91 (2.96)	8.17% (8.70)	13.95 (18.90)	IES HADS	L	T1: first-month post-burn T2: 12 months after T3: 18 months after	Early maternal symptoms of depression predicted long-term maternal PTSS.

Note. F = Fathers; M = Mothers; P = Parents; B = Boys; C = Children; G = Girls; TBSA = Total body surface area; LoS = Hospital length of stay; HADS = Hospital Anxiety and Depression Scale; HADS-D = Hospital Anxiety and Depression Scale – Depression Scale; IES = Impact of Event Scale; IES-R = Impact of Event Scale-Revised; BDI = Beck Depression Inventory; POMS = Profile of Mood States; SSAI = Spielberger State Anxiety Inventory; STAI = State-Trait Anxiety Inventory; PSI = Parenting Stress Index; MINI = Mini International Neuro-psychiatric Interview; PC-PTSD = Primary Care-Post-Traumatic Stress Disorder; GGS = Global Guilt Scale; PHQ-4 = Patient Health Questionnaire for Depression and Anxiety-4; IVAS-A = Visual Analogue Scale for Anxiety; PDS = Posttraumatic Diagnostic Scale; DASS-21 = Depression Anxiety Stress Scale-2; HARS = Hamilton Anxiety Rating Scal; HDRS = Hamilton Depression Rating Scale; ASDS = Acute Stress Disorder Scale; BSI

= Brief Symptom Inventory; PCL-C = PTSD Checklist; SASRQ = Stanford Acute Stress Reaction Questionnaire; TRGI = Trauma-Related Guilt Inventory; PCL-S = PTSD Checklist Stressor-Specific version; SPRINT = Short Post-Traumatic Stress Disorder Rating Interview; DTS = Davidson Trauma Scale; GHQ = General Health Questionnaire; PCL-5 = PTSD Checklist for DSM-5; PSS-14 = Perceived Stress Scale-14; CS = Cross-sectional; L = Longitudinal.

Supplementary Material 3

Quality assessment scores according to the NHLBI Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Quality Rating
Cella et al., 1988	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	No	Yes	NA	No	Yes	Good
Blakeney et al., 1993	Yes	Yes	NR	No	No	No	No	Yes	Yes	No	Yes	NA	No	Yes	Fair
Ledoux et al., 1998	Yes	Yes	NR	No	No	No	No	Yes	Yes	No	Yes	NA	No	Yes	Fair
Kent et al., 2000	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Good
Tyack et al., 2003	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	NA	NR	Yes	Good
Saxe et al., 2005	Yes	Yes	NR	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
El Hamaoui et al., 2006	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Hall et al., 2006	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	NA	NR	No	Fair
Stoddard et al., 2006	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Phillips et al., 2008	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	No	Yes	NA	No	Yes	Fair
Bakker et al., 2010	Yes	Yes	NR	Yes	No	No	Yes	Yes	No	No	Yes	NA	No	No	Poor
Graf et al., 2011	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Willebrand et al., 2011	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Bakker et al., 2012	Yes	Yes	Yes	Yes	No	No	No	Yes	No	No	Yes	NA	No	No	Poor
Bakker, Van der Heijden et al., 2013	Yes	Yes	NR	Yes	No	No	Yes	Yes	No	No	Yes	NA	No	No	Poor

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Quality Rating
McGarry et al., 2013	Yes	Yes	Yes	No	No	No	No	NA	Yes	No	Yes	NA	No	No	Fair
Odar et al., 2013	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Bakker et al., 2014	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	NA	Yes	Yes	Good
De Young et al., 2014	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	No	Fair
Pan et al., 2015	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	Yes	NA	No	No	Fair
Egberts et al., 2016	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	No	Fair
Quezada et al., 2016	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Sveen et al., 2016	Yes	Yes	No	No	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Willebrand et al., 2016a	Yes	Yes	Yes	Yes	No	No	No	NA	No	No	Yes	NA	No	No	Fair
Willebrand et al., 2016b	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	No	NA	No	No	Poor
Egberts et al., 2017	Yes	Yes	Yes	Yes	No	Yes	Yes	NA	No	Yes	Yes	NA	No	No	Fair
Haag et al., 2017	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Egberts et al., 2018	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Good
Sveen et al., 2018	Yes	Yes	Yes	No	No	No	No	NA	Yes	No	No	NA	No	No	Poor
Willebrand et al., 2018	Yes	Yes	No	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Brown et al., 2019a	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	NA	No	No	Fair
Brown et al., 2019b	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	NA	No	Yes	Good

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Quality Rating
Enlow et al., 2019	Yes	Yes	NR	Yes	No	No	No	Yes	Yes	No	Yes	NA	No	Yes	Good
Hawkins et al., 2019	Yes	Yes	NR	Yes	Yes	No	No	Yes	Yes	No	Yes	NA	No	Yes	Good
Parrish et al., 2019	Yes	Yes	NR	NR	No	Yes	Yes	NA	Yes	No	Yes	NA	No	Yes	Good
Stewart et al., 2019	Yes	Yes	NR	Yes	No	No	No	NA	Yes	No	Yes	NA	No	No	Fair
Egberts et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Yes	NA	No	Yes	Yes	NA	No	Yes	Fair
Suurmond et al., 2020*	Yes	Yes	Yes	Yes	No	Yes	Yes	NA	Yes	No	No	NA	Yes	No	Fair

Note. NA = not applicable; NR = not reported; NHLBI = National Heart, Lung, and Blood Institute; *only study 1 was assessed.

CAPÍTULO 2:

Perceptions and Experiences of Parents of Burn-Injured Children during Hospital Stay: A Need for Integrated Care

Healthcare

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Abstract

Pediatric burn injuries are a critical medical condition that triggers a series of ongoing multifactorial stressors that affect both children and their families. To inform healthcare research and clinical practice, this study aimed to understand and describe the perceptions and experiences of the parents of burn-injured children during hospital stay. Forty-six parents (thirty-eight mothers) of forty-six children (eighteen girls) with a mean age of 2.28 years (*SD* = 1.52) answered ten open-ended questions. This qualitative study was conducted in a referral hospital in the northern region of Portugal. Qualitative data were analyzed using an inductive content analysis. Five key themes emerged from the data analysis: diving into the crisis of the child burn injury, being together and in good hands, becoming aware of an uncertain future, enhancing supportive care and environment, and finding ways to guide parents. Qualitative findings underlined the pressing need for integrated care within this context. Parents were significantly burdened and distressed during the inpatient phase. These parents should be included in the integrated care plan starting from admission. Understanding and addressing parents' healthcare needs and psychosocial adjustment difficulties is paramount to the development of future intervention programs and the delivery of suitable integrated healthcare.

Keywords: burns, children, parents, needs, psychological distress, psychosocial adjustment, hospital stay, integrated care, quality of life, qualitative design

Introduction

Globally, burn injuries are a worrying public health problem, particularly in low- and middle-income countries (Smolle el al., 2017; World Health Organization, 2023), and caused almost 111,300 deaths in 2019 alone, mainly among children aged 1–4 years (Yakupu et al., 2022). The World Health Organization (WHO) African and Southeast Asia regions account for almost two-thirds of all cases, and in Bangladesh, Colombia, Egypt, and Pakistan, 17% and 18% of pediatric burn injuries result in temporary and permanent disabilities, respectively (WHO, 2023). Despite these worrisome data, a recent scoping systematic review focused on burn injury prevention in low- and middle-income countries concluded that political initiatives and environmental interventions (e.g., making the home environment safer for children) remain sparse (Price et al., 2021). Furthermore, the implementation of accessible and efficient services (Ter Meulen et al., 2016) and prevention programs are crucial (Van Balen et al., 2023) since burn injuries are a leading cause of preventable mortality and morbidity in childhood worldwide (WHO, 2023), especially in preschool age (Emond et al., 2016), with a peak prevalence during the first year of life (Kemp et al., 2014). In fact, there is a higher incidence of burn injuries in children than in adults (Suman & Owen, 2020), and in early childhood, boys are at greater risk than girls (Emond et al., 2016). Scalds and contact burns are among the most recurrent causes of burn injuries, preponderantly affecting children under five years of age, on the upper torso, arms, face, and hands (Kemp et al., 2014). Although advances in medicine and healthcare have contributed to improving overall clinical outcomes and, subsequently, decreasing hospital stays and mortality rates (Smolle el al., 2017; Yakupu et al., 2022), burns remain one of the most traumatic injuries that a child and their family may experience (Wickens et al., 2024).

Pediatric burn injuries generally require long hospital stays and acute critical care when compared to other non-fatal childhood injuries (Krasnoff et al., 2021), representing a substantial economic burden, particularly in low-income areas (Ter Meulen et al., 2016). A systematic review focused on the costs of burn care concluded that the mean total healthcare costs in higher-income countries are over 88,000 dollars per patient, ranging from 704 to 717,306 dollars, with a median of 44,024 dollars, while in low- and middle-income countries, the mean total was 5,196 dollars, ranging from 102 to 15,555 dollars, with a median of 3,559 dollars (Hop et al., 2014). Furthermore, there is a worldwide trend toward an increase in the number of new cases (Yakupu et al., 2022), which raises several healthcare concerns, particularly in countries where health systems are more vulnerable (Smolle et al., 2017; Ter Meulen et al., 2016; WHO, 2023). Portugal is following this trend, with 20% of the total cases being children under five years of age (Santos et al., 2016), with a median length of hospital stay of nine days, and higher

average hospital costs than other countries (around 3,073 euros) (Santos et al., 2019). Despite this scenario, few studies on pediatric burns were conducted in Portugal, with the existing studies being mostly retrospective observational and focused on demographic and clinical burden indicators (e.g., Santos et al., 2016, 2019). Santos et al. (2019) also emphasize the need for future studies to inform healthcare services and policies, reducing related costs and thereby establishing a pediatric burn center with differentiated and specialized evidence-based services.

More broadly, and beyond economic and epidemiological issues, burn injuries have health (e.g., delayed wound healing), physical (e.g., long-term disability and disfigurement from contractures and scarring), psychological (e.g., psychological morbidity and traumatic symptoms), and social (e.g., troubled social competence) related consequences that impair the short- and long-term quality of life of pediatric patients and their families (Bakker et al., 2013; Ciornei et al., 2023; Kemp et al., 2014; Patterson et al., 2023; Spronk et al., 2018; Suman & Owen, 2020). Notwithstanding, a growing body of literature has shown that parents of burn-injured children experience a series of ongoing maladaptive responses, including significant emotional distress (Lernevall et al., 2020), feelings of guilt, blame, and shame (Hawkins et al., 2019; Kornhaber et al., 2018; Lernevall et al., 2020), clinical symptoms of psychological morbidity, such as anxiety and depression (De Young et al., 2014; Phillips & Rumsey, 2008), and traumatic reactions (Bayuo & Wong, 2021; De Young et al., 2014; Egberts, van de Schoot, et al., 2018; Hawkins et al., 2019; Willebrand & Sveen, 2016). During the first month post-burn, some parents (approximately 25%) reported symptoms that potentially indicate posttraumatic stress disorder (PTSD) (De Young et al., 2014). However, it is well documented in the literature that most of these symptoms tend to decrease over time (De Young et al., 2014; Egberts, van de Schoot, et al., 2018; Phillips & Rumsey, 2008), and hospital stay can be an opportunity for early screening and prevention (e.g., Foster et al., 2017), which should target all (nuclear) family members (Willebrand & Sveen, 2016). Thus, addressing and understanding parents' mental health needs and subjective appraisals of the child burn injury during hospital stay is expected to strengthen our knowledge of parents' potentially maladaptive responses and help to prevent their emotional and psychosocial adjustment difficulties through the design of interventions tailored to the political, economic, and sociocultural context.

Prolonged hospital stays have been significantly associated with higher parents' post-traumatic stress symptoms (PTSS; Hawkins et al., 2019) and PTSD (Willebrand & Sveen, 2016). Also, the hospital environment exacerbates psychological maladaptive responses, namely maternal distress, which suggests that mothers, who are typically the child's primary caregiver during the hospital journey, seem to be a particularly vulnerable group due to the severity of the symptoms presented (Karahan et al.,

2023; Wickens et al., 2024). A recent qualitative study by Karahan et al. (2023) found that mothers of pediatric burn patients faced severe physical and emotional distress from the burn occurrence and throughout the inpatient phase, as a result mainly of a lack of adaptive internal coping resources and professional support. In addition, a study focusing on changes in the outcomes of caregivers of burn survivors within one-year post-burn found that increased length of hospital stays contributed to a decrease in the caregivers' quality of life (Hsu, 2023). Therefore, parents' distress threatens caregivers' adjustment and leads them to experience more difficulties that may negatively impact the act of caring (e.g., meeting the child's needs) (Foster et al., 2017; Lernevall et al., 2021). The literature also shows significant changes in parental roles motivated by the unexpected demands of the hospital stay (Bayuo & Wong, 2021), such as remaining constantly vigilant to meet children's needs, which also impaired the parents' physical health (e.g., poor sleep quality and weight loss) (Ravindran et al., 2013). Hence, parents play a key role during (and after) the inpatient phase (Rimmer et al., 2015), given the child's age/stage of development and the type of treatment planned (e.g., long-term rehabilitation), making it essential to include parents in an integrated care plan that also promotes their engagement (Hsu, 2023). However, in the field of pediatric burn injuries, knowledge about parents' perceptions and experiences regarding hospital stay is scarce (Brown et al., 2020; Egberts, de Jong, et al., 2018; Karahan et al., 2023; Lernevall et al., 2021; McGarry et al., 2015; Ravindran et al., 2013; Rimmer et al., 2015), limiting the development of research-informed intervention care plans. A recent scoping systematic review highlighted the paucity of qualitative data on parents' issues and concerns regarding their children's hospital stay period (Bayuo & Wong, 2021). Given the prevalence of pediatric burn injuries and their often prolonged hospitalization (Santos et al., 2016, 2019), this knowledge is paramount to achieve an in-depth understanding of the complexity of the phenomenon in order to develop effective family-centered intervention programs.

A previous qualitative study conducted six months post-burn identified three phases that describe the parents' journey from their perspective: experiencing the accident, the inpatient phase, and returning to the community (McGarry et al., 2015). The inpatient phase was the most challenging for parents, including, particularly, witnessing the (invasive and traumatic) medical procedures, which generated significant parental distress and were described as the "worst aspect" of the whole journey (McGarry et al., 2015). Brown et al. (2020) also found that during the child's medical procedures, parents often showed multiple indicators of emotional distress (e.g., fear, uncertainty, and concerns about the potential for permanent scarring) and traumatic reactions (e.g., leaving the room while dressings were being changed). In contrast, a recent qualitative study focusing on parents' memories and appraisals of burn-injured children found that parents' highly emotional memories related to the inpatient phase (e.g.,

children's procedural pain) were not perceived as potentially intrusive (Egberts et al., 2019). Another qualitative study on parental presence or absence during child wound care corroborates these findings and suggests that parental participation in medical procedures produces a "sense of control", which can mitigate its underlying traumatic nature (Egberts, de Jong, et al., 2018). In addition, a more recent qualitative study pointed out that meeting parents' support needs during the hospital period (e.g., feeling cared for and having time to self-care) maximizes parents' contribution to the child's recovery and the maintenance of effective care (Lernevall et al., 2021). In fact, the hospital stay period is considered a critical phase (Ravindran et al., 2013) but also an important opportunity to address and guide the provision of psychological care to parents following their child's critical injuries (Foster et al., 2017).

Given all these indicators, the purpose of the present study was to study, understand, and describe the perceptions and experiences of parents of preschool children who had sustained an unintentional burn injury, during their hospital stay. This is the first study carried out in Portugal that also seeks to fill significant gaps in the literature (e.g., lack of evidence on parents' perceptions and experiences during the inpatient phase for very young burn-injured children), thereby informing future clinical practices and the delivery of suitable integrated healthcare.

Materials and Methods

Design

This qualitative study is part of a larger longitudinal research project on the phenomenon of pediatric burn injuries in early childhood (0–6 years) from a biopsychosocial perspective, including medical, parental, and family environmental factors regarding the child's health outcomes. The current study was therefore designed to target parents of preschool children who had sustained an unintentional burn injury in order to capture their subjective experiences and perceptions during the hospital stay period. A descriptive qualitative approach was adopted, based on ontological, philosophical, and epistemological principles applied to health research, in order to obtain a more comprehensive understanding and an accurate description of the participant's experience and the meanings they attribute to the phenomenon under study (Bradshaw et al., 2017). Furthermore, this approach is considered the most appropriate when little is known about a particular topic (Neergaard et al., 2009), and the goal is to gather information to serve as an empirical basis for informing public policy and developing future evidence-based interventions (Sandelowski, 2000).

Research Team

M.S. (male) is a clinical and health psychologist and a PhD student in Applied Psychology, working on his doctoral thesis on this topic, with training in qualitative methods. A.F. (female) is also a

clinical and health psychologist and a PhD student in Applied Psychology with training in qualitative methods. M.G. (female) has been a graduate hospital assistant in pediatric surgery since 2014 and is responsible for the Pediatric Burns Unit at the hospital. M.G.P. (female) is an associate professor with habilitation, a clinical and health psychologist/psychotherapist, with three decades of experience in supervising and conducting qualitative and quantitative research on chronic illness and health promotion.

Setting

The Pediatric Surgery Department, part of the Autonomous Management Unit of Women and Children (UAG MC), provides surgical care to pediatric patients up to 18 years with different medical conditions and needs (e.g., congenital anomalies, injuries, oncological problems) and supports neonatal/pediatric intermediate and intensive care units. The department has 18 inpatient beds (maximum two patients per room) and includes a recent Pediatric Burns Unit with five individual rooms and its operating room.

Since 2021, a playroom (i.e., Ronald McDonald Playroom) has been available for pediatric patients and their parents, with many play resources/activities and seven distinct areas (e.g., recreational, social, and multi-sensory relaxation area). The establishment of the Ronald McDonald Playroom, based on a family-centered care model, aims to promote the emotional well-being of both families and children during the inpatient phase. Only one of the parents/legal guardians may be with the child during hospital stay without (visiting hours) restrictions.

Participants and Procedure

Eligible participants were parents/legal guardians who met the following inclusion criteria: (a) 18 years or older; (b) Have a child aged between one month and six years who recently sustained an unintentional burn injury that required hospital admission; (c) Accompany the child during hospital stay and subsequent treatment. Exclusion criteria comprised insufficient language proficiency to complete the study protocol, psychiatric or oncological diagnosis in the child's medical records, and/or the suspicion that the burn injury was the result of abuse or neglect.

Potential eligible parents were identified, addressed, and invited to participate in the current study by a specialist pediatric surgeon (M.G.) during clinical rounds in the Pediatric Surgery Department of a referral hospital in the Northern region of Portugal. Recent national data indicate that 43.9% of burn admissions (the vast majority) were recorded in the northern region of mainland Portugal (Santos et al., 2019), which justifies the decision to carry out this study in this geographical area.

All parents who agreed to take part in this study were informed by M.S. of the aims of the study, confidentiality, anonymity, and its voluntary nature. Thereafter, the parents/legal guardians gave

written informed consent for their and their child's participation.

Data collection took place between March 2021 and May 2023, and the study protocol was implemented by M.S. during the child's stay in the hospital's Pediatric Surgery Department that ranged between one and seventeen days ($M = 6.26$, $SD = 3.09$) after the occurrence of the burn event. After completing part A of the study protocol, which included sociodemographic and clinical questionnaires (e.g., gender, age, how the burn event occurred), parents filled out a "logbook" with 10 open-ended questions (part B) to gather qualitative data and returned it prior to the child's discharge. Parents were asked to reflect and honestly write about their experience and their child's experience during the hospital stay to help benefit other children and their families to have a better experience, in the future. The questions included in the logbook were developed by our multidisciplinary research team (i.e., specialists in clinical and health psychology, pediatric trauma, and pediatric surgery) and covered many key issues (e.g., perceived needs and adjustment difficulties) supported by the available burn-specific literature on the topic (e.g., Lernevall et al., 2020, 2021), in order to capture the subjective experiences and perspectives of parents regarding the hospital stay period. Thus, the following open-ended questions were presented: (i) *During the hospital stay, I think my child felt...*; (ii) *During my child's hospital stay, I felt...*; (iii) *In my opinion, the most positive situation for my child during the hospital stay was...*; (iv) *In my opinion, the most negative situation for my child during the hospital stay was...*; (v) *My biggest concern about the future is that my child...*; (vi) *The fact that my child was hospitalized during the COVID-19 pandemic left me...*; (vii) *The main difficulties I experienced during my child's hospital stay were...*; (viii) *The main difficulties my child experienced during the hospital stay were...*; (ix) *I think my child would feel better in hospital if...*; (x) *If I could leave a message to other parents who might find themselves in this situation in the future, I would say...* A blank box was also added for other relevant comments, reflections, and/or recommendations. The study protocol (parts A and B) took around 30 min to complete. The child's clinical data were recorded by the specialist pediatric surgeon (M.G.), who had no role in data collection, analysis, and interpretation.

Ethics

This study was carried out following the guidelines of the Declaration of Helsinki [40] and was approved by the Ethics Committee for Research in Social and Human Sciences of the Ethics Council of the University of Minho (CEICSH 020/2020) and the Ethics Committee of the hospital involved (CE 429/20).

Data Analysis

Qualitative data were duly anonymized (to ensure confidentiality), imported into QSR

International's NVivo 10 software, and then analyzed in the same order as it was carried out, using content analysis (Bardin, 2022), aligned with the post-positivist paradigm in which the authors are positioned (Ponterotto, 2005). Bardin (2022) established the following sequential steps for the proper organization and data analysis: pre-analysis, exploration of data, and treatment of the results (including inference and interpretation). After carefully reading the participants' records and an overview of the data, two trained researchers/coders (M.S. and A.F.) independently organized/mapped the relevant information and highlighted the key points to identify codes. The codes that emerged from the data were identified, and any differences were resolved after discussion and consensus, resulting in a draft codebook. An experienced researcher and supervisor (M.G.P.) reviewed, discussed, and helped refine the codes to obtain a final codebook. Themes and sub-themes were independently selected, following an iterative inductive process, and differences were again discussed and resolved through consensus. To strengthen the trustworthiness and consistency of the findings, Goodell et al. (2016) recommendations (e.g., practice applying the codebook together and compare and discuss the coding process) were followed. The data were then analyzed, reorganized, and interpreted. M.S. coded all the data, and A.F. coded approximately 35% (16 records) independently. Inter-rater agreement, using the Kappa Statistic, was .82, which is considered almost perfect (Landis & Koch, 1977). Data saturation was reached with 46 participants, as no new information emerged during the coding process, and informational redundancy was verified (Saunders et al., 2018). Finally, descriptive statistics were performed to describe the sociodemographic and clinical characteristics of the participants, using IBM SPSS Statistics (Statistical Package for the Social Sciences) version 29.

Results

Participants Characteristics

Forty-six parents (38 mothers), with an average age of 33.54 years (SD = 5.82), of forty- six burn-injured children (18 girls), aged between eight months and six years (M = 2.28, SD = 1.52) took part in this qualitative study (Tables 2.1 and 2.2). The majority of children (78.3%) had never been hospitalized before. Of the burn injuries that occurred at home, the majority were in the kitchen (69.6%) and the living room (15.2%). The number of burn regions sustained ranged from 1 to 5 (M = 2.28, SD = 1.11), with the upper limbs (forearm, hands, and arm, 39.1%, 37%, and 28.3%, respectively) and the face (23.9%), being the most affected areas. All children received pain treatment, and among the planned skin grafts, synthetic skin grafts (52.2%) and partial skin grafts (32.6%) were the most common.

[Table 2.1]

[Table 2.2]

Themes

Five key themes emerged from the qualitative analysis: (1) Diving into the crisis of the child burn injury; (2) Being together and in good hands; (3) Becoming aware of an uncertain future; (4) Enhancing supportive care and environment; (5) Finding ways to guide parents. All themes except one (i.e., enhancing supportive care and environment) represented 93.48% or more ($n \geq 43$) of the total cases. Table 2.3 provides an overview of the themes and sub-themes (generated within the themes), as well as sub-themes distribution (frequency) and representative quotes (in quotation marks) from the parents' records.

[Table 2.3]

Diving into the Crisis of the Child Burn Injury

Hospital stay forces parents to confront the seriousness of their child's burn injury and raises new and unexpected challenges that threaten the adjustment of both parents and patients. Within this theme, five sub-themes were identified: negative trauma responses, facing medical procedures, changes in the child's functioning, COVID-19 stressors, and unmet needs.

Negative Trauma Responses

Thirty-seven parents experienced at least one maladaptive reaction during the inpatient phase, as well as negative psychological, cognitive, emotional, and physical responses (e.g., self/other blame attribution, impotence, physical and emotional exhaustion), which encompassed normative and potentially adaptive affective responses to their child's burn injury (e.g., worries, negative mood). Most of these parents reported feeling "distressed", "exhausted", "sad", "worried", "anxious", and "guilty". In addition, intrusive memories related to the burn event were mentioned as a factor exacerbating their distress and maladjustment: "*I felt very bad. Distressed, worried, completely exhausted! I can't sleep, because even if I close my eyes, everything is very fresh in my memory. Sometimes I find myself acting as if I were there at that moment (when the accident occurred). I can't think about anything else and being locked up in here doesn't help.*" (mother of a three-year-old boy). In fact, the parents who witnessed the burn accident reacted more negatively to the whole process and described a greater variety of traumatic reactions (e.g., avoidance), and for one of them, this situation reactivated similar traumatic memories: "*(...) it makes me relive what I've been through because I also got burned with hot milk around this time.*" (mother of a two-year-old boy). Also, in the early stages of hospital stay, burn-injured children displayed negative psychological and emotional reactions, mainly due to the "unfamiliar environment" and seeing "strange people". This whole new environment initially caused "fear", "anger", "restlessness", and a "feeling of being trapped" in many patients, which dissipated

over time: "*My son felt very trapped because he was used to playing outdoors, with the animals, with his brother and cousin, getting fresh air, and that really affected him. (...) then he adapted to the hospital and the people, but at first, it was very difficult to calm him down! He was very restless and scared*." (mother of a one-year-old boy).

Facing Medical Procedures

Thirty-four parents described medical procedures as a traumatic experience, both for the children and for themselves. Spending long days in the hospital and witnessing the child's suffering due to invasive and painful treatments was considered "one of the most devastating experiences" for parents during this phase and "completely traumatizing for the children". One mother even stressed that: "*The most difficult time was the dressing changes*." (mother of one-year-old boy).

Dressing changes were the procedure most often mentioned as "the most negative aspect" and the main factor contributing to the child's "pain". For example: "*He never seemed to have any pain or discomfort, only when it was time to change the dressings*." (mother of a one-month-old boy). Less recurrently, the "incision to place the catheter" was also mentioned as "painful" and "traumatic" for the child. Furthermore, some parents explained that any element the child associated with taking medication or treatments (e.g., the operating room; conditioned stimulus) was enough for them to become reactive and start crying (conditioned response): "*(...) whenever someone approached her, she would start crying because she thought they were going to change her bandages or force her to take medication*." (mother of a one-year-old girl).

Changes in the Child's Functioning

More than half of the parents reported that observing differences in their child's baseline functioning (compared to the period before sustaining a burn injury) was a source of distress. In addition to the significant changes in the child's routines, this situation has led to some developmental setbacks and impaired functionality. Limitations to a child's mobility were the difficulties most emphasized by parents. For example: "*He can't even walk because he has to be stuck to this machine. If only I could walk with him a little bit, that would be better...*" (mother of a two-year-old boy); and "*(...) It hurts me a lot to see him wanting to crawl and not being able to*." (father of a one-year-old boy). Other important changes in health-related domains of the child's functioning were also reported, including appetite (e.g., loss of appetite, refusal to eat), skin (e.g., itching), and sleep problems (e.g., could not sleep a whole night, nightmares). Specifically, one mother attempted to describe the content of the nightmares: "*It seems like he dreams about what's going on during the dressing changes and wakes up scared*." (mother of a two-year-old boy). As a result of these changes, the child's autonomy was compromised,

making them even more dependent on their caregivers and increasing the parents' burden: "*(...) he can't go out because of the catheter in his foot. I have to be dedicated to him at all times because he is completely dependent on me; he already was, but now he is even more so*." (father of a one-year-old boy).

COVID-19 Stressors

Despite this study covering different waves of the COVID-19 pandemic, the impact of COVID-19 seemed to be relatively minor for most parents. Nevertheless, parents' answers were divided into two different groups regarding COVID-19-related stressors at a time when (a) restrictions were more severe and (b) restrictions were relaxed or lifted. Regarding the first group, parents expressed "concern" and "fear" since a positive test would mean delaying planned treatments: "*(...) because the first test (of the child) was inconclusive and that delayed the whole process. Consequently, he couldn't receive the care he should have been receiving*." (mother of a one-year-old boy). Notwithstanding, parents considered that the major obstacle during this period was social restrictions. On one hand, visits were also limited, burdening the caregiver who accompanied the child: "*I have to carry all this on my own because I can't exchange with my husband, or receive visits from my family*" (mother of a two-year-old girl); on the other hand, carrying out tests entailed more costs: "*(...) for visits to take place, a test has to be carried out which, after four tests, is very expensive*." (mother of a five-year-old girl). To get around these constraints, parents resorted to technology (e.g., video calls); however, they stated that nothing replaces physical contact at such a critical time: "*I am always on video call, but it is not the same. I need to feel them, touch them (nuclear family members)...*" (mother of a two-year-old boy). As for the last group, parents reported minimal impact, although they had to wear masks. Interestingly, for some parents, COVID-19 has increased their "sense of safety and security" in the hospital: "*(...) because there is more attention to everything and things are cleaner.*" (mother of a one-year-old boy). In general, although at an early stage, COVID-19-related stressors contributed to increased difficulties in the treatment and adaptation process due to protocol issues and social restrictions, respectively; of the thirty-three parents who identified a negative influence of the pandemic during hospital stay, the majority described it as a minimal to a small influence: "*I am so focused on other things that this completely passes me by. In a way, it gets in the way a little, because I can't be with my other two kids, but this whole situation and what it entails is already so bad that COVID is the least of our problems*." (mother of a one-year-old boy).

Unmet Needs

Thirty-eight parents shared common unmet needs (their own and those of their children) covering various dimensions, including psychosocial, emotional, and physical needs. Regarding parents' unmet

needs, lack of support from the hospital staff was the most frequently reported issue, followed by the lack of family/social support. Also, some parents reported difficulties in meeting their child's needs due to a lack of support from the hospital staff (e.g., having to carry the child all the time and having no one to support them, bathing the child, feeding the child). Most parents felt "neglected" and believed that the hospital staff should have given them more support and resources to cope with the different challenges involved in the inpatient phase (e.g., informational) in order to reduce their discomfort and burden. Several parents even mentioned they had lost their identity and felt reduced to "the child's companion": "*I am just the mother. I don't have a name here, I am just my daughter's legal guardian. She is the patient. That is how they treat me*." (mother of a one-year-old girl). For some parents, these attitudes remained evident in many circumstances, namely "having to sleep in a recliner chair", which was described as "extremely uncomfortable". One mother also added: "*I feel that there is a huge lack of support and humanization of care. Here we are treated only as "the parents". My son is completely dependent, he is only one year old, and they do not help me to go out to buy food. My immune system has fallen, and I am breastfeeding, which is a risk for me and my son. This system is not at all "friendly" to us (parents). It is unthinkable to sleep in this armchair for nights on end with a child on your lap*." (mother of a one-year-old boy). Most parents pointed out that sleeping in a recliner chair affected their sleep and their physical and psychological well-being. Parents also identified a lack of opportunities for self-care. For example, some parents also stressed that they needed more time for themselves and more autonomy (e.g., going outside). These aspects were more relevant for parents with some physical conditions, such as pregnancy or chronic illness: "*I am pregnant and I sleep in a recliner chair, which is not comfortable at all! It does not allow me to sleep well and causes me a lot of back pain*." (mother of a two-year-old boy). Regarding children's needs, parents identified needs related to homesickness and family. For example: "*(...) he really missed playing with his cousins and friends, especially missing his mother and grandparents. Basically, homesickness*." (father of a three-year-old boy).

Being Together and in Good Hands

The crisis imposed a "break from reality", which was an opportunity to strengthen parent-child ties, making them a unit capable of facing this challenge together. At the same time, trust in the healthcare team and the medical treatment received, as well as being engaged throughout the process, seemed to have been key factors in mitigating the side effects of the initial shock. Two sub-themes were identified: child's well-being and recovery and quality of healthcare and environment.

Child's Well-Being and Recovery

Thirty-four parents pointed out that objectively monitoring their child's recovery was a critical

factor in feeling better and more confident, suggesting that as their child improved, the parents also improved. For these parents, the child's recovery was closely linked to the well-being of both of them, particularly the child: "*(...) when they removed the catheter from one of his hands. He was very happy, he even said 'We are about to go home'*." (mother of a two-year-old boy). Thus, more than half of the parents mentioned that "the most positive aspect" of this process was the "child's observable recovery", regardless of whether it was progressive or minimal: "*When my daughter was able to eat again, it was one of the happiest days of my life*." (mother of a ten-month-old girl). Therefore, parents considered that their presence and participation in all the procedures was important in maintaining the child's well-being, which overall was described as positive: "*My son is adjusting well and, as he recovers, his mood and social interaction improve a lot, especially with the other children (pediatric inpatients) (...) Being here with me helped him feel more secure*." (mother of an eight-month-old boy).

Quality of Healthcare and Environment

Parents seemed to have gradually adapted to the hospital environment, accepting and integrating the whole event, as a result of the combination of several protective factors they attributed essentially to the quality of the healthcare, including the resources and activities to distract/entertain (e.g., clown doctors) their children, and the possibility of interacting with other parents of patients with the same/similar medical conditions. More than half of parents considered that the healthcare team provided all the necessary care for their child's well-being and recovery: "*My son was always very well cared for and embraced by everyone. All the staff, nurses, doctors, and assistants, are caring and attentive to the children. They are in good hands*!" (mother of a six-year-old boy). Of the thirty-five parents who identified issues within this subtheme, the majority mentioned the "playroom" as the aspect most appreciated by their children: "*(...) Everything is new in the playroom, it is full of toys. She gets excited and wants to touch everything! She just wants to be there*." (mother of a one-year-old girl).

Regarding parents, sharing experiences with other parents helped to assimilate the whole experience and minimize the feeling that it only happened to them: "*Listening to other parents' stories was important for me to realize that this did not just happen to me. Also, those who have been here longer have helped me deal with it all*!" (father of a three-year-old girl).

Becoming Aware of an Uncertain Future

As the child recovers, other questions usually arise related to the post-discharge phase, namely the short- and long-term effects of the burn injury. Within this theme, two sub-themes were identified: ongoing suffering of the child and (potential) permanent scaring, and concerns about being blamed and that a burn might happen again.

Ongoing Suffering of the Child and (Potential) Permanent Scarring

Forty-one parents expressed concern that their children would experience some kind of physical or psychological sequelae as a result of the burn injury. Most parents reported concerns about the wound healing process, with some parents emphasizing their "fear of permanent visible scars". Less frequently, parents also highlighted potential functional constraints that could condition the child's normative (physical) development. A mother who also sustained a burn injury in childhood pointed out the following: "*I know what he will suffer later at school, in social groups, and other contexts, because I went through the same thing*." (mother of a two-year-old boy). In fact, the return to kindergarten and/or the community was anticipated by some parents as potentially threatening to their children. For example: "*When he goes back to kindergarten, how will the other children react? I am afraid they will ask him what happened to his face or bully him*." (mother of a three-year-old boy). Other parents mentioned that they were afraid that there would be "episodes of bullying" and "social exclusion". In addition, they fear that the child will develop traumatic reactions or other maladaptive psychological outcomes, including "low self-esteem" and "denial of the situation". For some parents, the challenge was dealing with uncertainty: "*(...) Everything is open, he may not have any physical marks if the skin grafts go well, but the psychological ones, I don't know... this uncertainty destroys me*." (father of a one-year-old boy).

Concerns about Being Blamed and That a Burn Might Happen Again

Six parents reported being worried that their children would blame them in the future. Interestingly, these parents were the same ones who reported feelings of guilt and expressed perceptions of being judged by others. For example: "*(...) I am afraid that he will blame me or think that this was intentional*." (mother of a two-year-old boy). In addition, a few parents stated that their biggest concern about the future was that their child would suffer a burn injury again. For example: "*(...) the possibility of my son being burned again*." (mother of a one-year-old boy). These parents were aware that this type of accident was unpredictable and uncontrollable, showing threatening risk perceptions: "*(...) If this happened at home, under our supervision, it could happen anywhere, at any time*." (mother of a two-year-old girl).

Enhancing Supportive Care and Environment

Thirty-five parents considered that there were controllable factors that could promote a better inpatient experience, and they intersected with some of the needs and difficulties they listed. These factors included strengthening support and adapting the care plan, as well as the improvement of hospital facilities. The remaining parents, who reported being generally satisfied with the hospital's services and facilities, did not mention any aspects for improvement.

Strengthening Support and Adapting the Care Plan

As parents were an essential part of the child's recovery, given that their children were in a situation of increased vulnerability (due to their clinical condition, but above all due to their stage of development, which makes them more dependent on their parents), more than half of the parents expected to find a more supportive and humanized service, responsive to their needs and difficulties. Among the several suggestions, most parents focused on increasing the number and frequency of visits, followed by the need to receive more support in caring for the child (e.g., help with meals), as well as for themselves to be able to "get back on their feet". For example: "*It was essential for me and my son that they let the godparents and grandparents in.*" (mother of a six-year-old boy); and "*Not having support took away a lot of my energy to look after him and if I was well, he would be better off, because I would be able to devote more of myself to him.*" (mother of a one-year-old boy). Some parents mentioned that they had never been asked about their emotions or how they were feeling and claimed to be unaware of the existence of psychological services: "*I felt very bad and was never asked if I needed psychological support. I don't even know if there are psychologists here. I think they should improve the services in this area.*" (mother of an eight-month-old boy). Furthermore, few parents reported that it would be important to adjust the feeding schedule to each child's routine to help them adapt: "*(...) adjusting meal schedules for young children. They bring lunch at 1 pm and dinner at 6:30 pm, and of course he finds it strange.*" (mother of a two-year-old boy).

Improvement of Hospital Facilities

Eight parents suggested several improvements over the existing hospital facilities, related mostly to the comfort of those accompanying the child, such as sleeping close to/in the same room as the child in "decent conditions" (sleeping in a bed) while also wishing for a single room to ensure their/their family (visitors) "privacy" (not sharing with other patients). For example: "*Everything is at the service of the child, but they forget the parents. It is important to invest in our comfort, for example, that all the rooms have bathrooms, single rooms, etc.*" (mother of a four-year-old girl). Two parents also stressed that it would be important to "better equip the social area" and "re-evaluate the cleaning conditions".

Finding Ways to Guide Parents

Reflecting on their experience, most parents tried to outline a set of strategies and advice to guide other parents who might experience this situation in the future. Within this theme, three sub-themes were identified: maintaining a positive mindset and activating coping resources, recognizing parental distress and promoting child's well-being, and raising awareness.

Maintaining a Positive Mindset and Activating Coping Resources

More than half of the parents mentioned the importance of maintaining a positive mindset and activating coping resources (including support resources) in order to self-regulate, stabilize, and ultimately benefit from a more adaptive inpatient experience. These parents listed a set of strategies that involved self-regulation and self-soothing functioning, "hope", "reliance", "faith", and "resilience". Regarding resilience, one mother even emphasized that "*This experience made me realize that I am more resilient than I thought.*" (mother of a three-year-old boy). Curiously, there were paradoxical reports from parents when it came to counteracting feelings of guilt. For example: "*It feels strange to say this since I am not doing it, but try not to blame yourself.*" (mother of a one-year-old girl). In this line, other parents highlighted that "*Don't feel guilty. This is the first thing you should do. Express your feelings without fear, it relieves you.*" (father of a one-year-old boy). Six parents mentioned it was important to seek out and use all available types of support (e.g., informational, social, family) to minimize the effects of distress, better understand the process and subsequent phases (e.g., how they can help the child recover faster), and overall promote a better adjustment to the whole experience. For example: "*Seek all the help you need at the hospital, there are many alternatives available.*" (mother of a five-year-old boy). Family support was the most mentioned type of support: "*Seek the support of your family. That is the greatest support you can receive*." (mother of a one-year-old boy). For a few parents, the development of a sense of cohesion with the child and the hospital staff is also crucial to dealing positively with this challenge: "*Together we really win. You have to trust the medical team. Trust and unity give us peace of mind and a good mood to get through this stage*." (mother of a six-year-old boy). Even though few parents experienced the hospital stay as a "hard" and "long-lasting" process, "*A day here feels like several days*." (mother of a ten-month-old girl), they encourage other parents to "give it time" as recovery takes time.

Recognizing Parental Distress and Promoting Child's Well-Being

Of the nine parents who reflected on the importance of recognizing their distress, the majority reported that their children were well-adapted most of the time, although they experienced multiple indicators of distress. For example: "*Indeed, we are the ones who suffer the most, they may not even remember what happened. For us, it is a (psychological) scar for life*." (mother of a one-year-old boy). For some parents, recognizing their symptoms is a key to normalize parents' emotional states and raise awareness among healthcare providers for the need to develop a targeted care system, helping parents be fully active in their child's therapeutic plan, particularly in maintaining care at all stages of treatment (e.g., post-discharge): "*Validate your distress, it is normal given the situation. Nobody likes to see their children in this situation*." (mother of a six-year-old girl). In addition, twelve parents focused on the child's well-being. These parents emphasized the child's need to have them physically and psychologically

available to meet all their needs and ensure their well-being. In addition to the dependency issues justified by the child's stage of development, children tend to be influenced by their parents' emotional states and behaviors (e.g., mimicking facial expressions), which leads these parents to assume that they have to "stay strong" for their children. One father even mentioned: "*Stay strong to help the child get through the situation. They feel everything we feel and depend on us a lot!*" (father of a one-year-old boy). "Our love helps them to recover" and "devoting full attention to their behavior and needs" were some of the examples most often mentioned by parents. Furthermore, one mother highlighted the importance of the parent's support: "*Do your best for your children. They need to feel that they have the support of their parents and family.*" (mother of a one-year-old boy).

Raising Awareness

Some parents reported not having enough information about the type of accident that happened to their child (e.g., prevalence and incidence, burn mechanisms), which posed several threats to their initial adjustment and their ability to respond effectively: "*When the accident happened, I found myself at a loss. Did I make the burn worse? I didn't know about it or how to proceed*." (mother of a one-year-old girl). Thus, nine parents believe that raising awareness of burn injuries is fundamental to prevent, minimize, and adaptively manage the impact of the burn event. "Accidents happen" and "it is not in our control" were the most frequent answers. For these parents, accepting the uncontrollable and unpredictable nature of the accident is imperative: "*One minute costs a life! One minute costs a life! This can happen at any time and all it takes is an instant! And there is nothing we can do about it*." (mother of a two-year-old boy).

Summary of the Results and Goals for Intervention

A graphical map of the main findings was designed to facilitate readers' understanding and help guide future clinical practices and health promotion (Figure 2.1).

[Figure 2.1]

Discussion

The present study describes the qualitative findings of the parents' perceptions and experiences regarding their burn-injured children aged between eight months and six years, during the hospital stay period. This qualitative study provides a deeper understanding of how parents and their children adjusted to the inpatient phase from the parents' perspective and raises several implications for healthcare research and clinical practice. Parents face a highly adverse situation triggered by a primary stressor (burn event) preceded by a secondary one (dealing with the hospital experience). In addition, they are responsible for a child who, due to their age/stage of development and (critical) medical condition, is

even more dependent on them. For these reasons, parents are plunged into a crisis marked by several threats to their psychological adjustment. The main findings of the current study revealed that parents were significantly burdened and distressed during the inpatient phase. Parents who witnessed the burn accident experienced intense negative emotional and psychological responses, such as psychological morbidity and feelings of guilt. These responses were also reported by McGarry et al. (2015), suggesting that witnessing the burn event is a potentially traumatic experience, but due to the initial shock, parents tend to suppress their emotions. A qualitative study by Ravindran et al. (2013) found similar results and highlighted that the hospital stay period was described as traumatic by all the participants and that the parental emotional and physical distress was directly related to the experience of watching their child suffer. According to the authors, parents also neglected their own needs (e.g., restricting their emotional expression with healthcare professionals) in order to focus exclusively on meeting their child's needs (Ravindran et al., 2013). In fact, recent evidence suggests that being responsive to the child's needs is a crucial task underlying the parental role during burn wound care (Egberts, de Jong, et al., 2018). Thus, as expected, parents put their children's needs before their own, although they perceive less severe maladaptive emotional and psychological reactions in their child compared to their own. Furthermore, parents seem to minimize and disguise what they are feeling, trying to show that they are "still strong" and capable of promoting their children's physical and psychological well-being. Karahan et al. (2023) found similar results in a qualitative study focused exclusively on the experiences of mothers in a pediatric burn intensive care unit and emphasized the importance of using adaptive coping strategies during this period. In addition to difficulties in emotional expression and regulation, these parents have intrusive memories of the burn accident, which threatens their psychological adjustment. In a qualitative study focused on parents' memories and appraisals, within three to six months post-burn, parents revealed intrusive memories regarding the burn injury and subsequent procedures (e.g., first aid), including visual and auditory memories (Egberts et al., 2019). An unexpected finding in the present study was the reactivated traumatic memories of a mother who had also sustained a burn injury in her childhood. Therefore, future studies should consider parents' past traumatic experiences.

In this study, facing medical procedures was threatening and highly traumatic for both parents and children, mainly dressing changes. Witnessing the child's procedural suffering and pain was a source of significant parental distress. McGarry et al. (2015) corroborated and highlighted that the traumatic procedural reactions persist for up to six months post-burn, suggesting that some parents will relive the experience again, given the need to maintain post-discharge care (e.g., removing dressings in the bath). Egberts, de Jong, et al. (2018) found similar results, but also noticed that these reactions during wound

treatment decreased over time. In addition, a quantitative study found that invasive medical procedures were a significant predictor of parental PTSS over time (De Young et al., 2014). In a qualitative study on parental experiences during the child's wound care, parental pre-procedure emotional states appeared to be a key factor in their participation in treatment (Egberts, de Jong, et al., 2018). Parental emotional reactions should be considered, as recent evidence has shown that parents' psychological adjustment (e.g., acute symptoms of distress) during the first dressing change impacts the child's prognosis and clinical outcomes, such as delayed re-epithelialization (e.g., Brown et al., 2019). Despite that, our findings regarding parents' perceptions of medical procedures also contradict the results reported in a previous qualitative study (Egberts et al., 2019). According to Egberts et al. (2019), the medical procedures were not perceived as very threatening to parents since they were positively linked to the child's recovery. In the present study, the results suggest that, although the parents recognized the importance of the treatments for the child's recovery, they considered the treatment very threatening. Further research is needed to clarify these contradictory results in order to better understand the distressing nature of medical procedures and their implications on parents' perceptions.

Another source of distress found was the observable changes in the child's functioning, including mobility, appetite, skin, and sleep problems. A quantitative study found a positive association between parental distress and health-related problems (i.e., greater parental distress was associated with greater health-related problems), such as sleep problems and post-burn pruritus, in children under four years of age (Stewart et al., 2019). Changes in children's functioning (e.g., mobility) and appearance have been associated with later social problems (e.g., bullying episodes and low social competence) (Bakker et al., 2013), and most parents, when revisiting their experience in the hospital (e.g., when talking with researchers), were able to identify these specific burn-related outcomes (Egberts et al., 2019), which suggests that this is an important target for intervention. This distress interacts with the parents' most recurrent concern about the future, particularly the child experiencing physical or psychological sequelae as a result of the burn injury. These findings were consistent with previous qualitative studies (e.g., Brown et al., 2020; Lernevall et al., 2023; McGarry et al., 2015). For example, Brown et al. (2020) found that parents reported significant concerns regarding potential child physical sequelae (e.g., permanent scarring), and McGarry et al. (2015) found that when the child returned to the community, dealing with the public stigma related to visible scars, was a challenging experience for parents. Regardless of the child's age, most parents' concerns were linked to scars and their implications (e.g., social problems) (Lernevall et al., 2023). The development of scars has an uncontrollable and unpredictable nature, which produces parents' feelings of helplessness (McGarry et al., 2015). Moreover, a study focusing on the

burden of pediatric burns concluded that parents of pediatric burn survivors with visible scars had more difficulty coping with the physical sequelae of burn injuries than parents of survivors with hidden scars (Rimmer et al., 2015). Thus, these concerns about an uncertain future must be addressed and discussed by the healthcare team with the parents, as suggested by other authors (e.g., Lernevall et al., 2023). In fact, parent-healthcare provider communication, a central component of family-centered care, is essential to increase satisfaction with the care pro- vided and improve overall outcomes for both parents and children, particularly during the child's medical procedures (Brown et al., 2020), as well as to prepare and negotiate the transition from the inpatient phase to post-discharge phase (e.g., home care) (Andrews et al., 2018). According to Brown et al. (2020), healthcare providers should be prepared for parents' emotional disclosures (e.g., distress) and communicate efficiently by providing parents with clear information about prevention, the steps of medical procedures, pain management, prognosis, and healing process, in order to relieve parental distress rather than contribute to parental uncertainty and concern.

For parents, the child's recovery was the most positive part of the whole experience. De Young et al. (2014) also suggested that, as the child improves, parents will get better, especially since distressing medical procedures (which decrease in number as the child recovers) and child distress were considered potential risk factors for parental maladjustment. Furthermore, our findings showed that the child's physical and psychological well-being was effectively ensured due to the quality of the healthcare and the hospital environment. Previous qualitative research was consistent with these findings, showing that the majority of parents reported having confidence in the healthcare team and satisfaction with the care provided to their children (Andrews et al., 2018; Egberts et al., 2019).

An original finding, in the present study, was the parent's feelings of neglect during the hospital stay, reported as a loss of one's identity, being reduced to "the child's companion". Future qualitative studies should explore the role of feelings of neglect during the hospital stay period and identify potential factors that may contribute to their development in order to better understand and satisfy parents' needs.

Furthermore, in the present study, none of the parents received psychological support, and some parents were unaware of the hospital's psychological services/resources. These findings, coupled with the unmet needs identified by parents (e.g., lack of support and opportunities for self-care), which is in line with previous qualitative studies (e.g., Karahan et al., 2023; Lernevall et al., 2021), raise an important contribution to healthcare research, in this area, underlining the need for parents' psychological support and screening. The Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress (Price et al., 2016) provides a useful framework to guide psychosocial assessment and

intervention for both pediatric patients and families, considering subjective responses/appraisals and offering specific intervention goals for each medical phase (i.e., peri-trauma, acute medical care, and ongoing care or discharge from care). According to this model, psychosocial screening and trauma-informed care should be provided at hospital admission (Price et al., 2016). In addition, regarding parents' maladjustment outcomes, a recent study highlighted the pressing need to include caregivers in the burn survivors' care plan starting at hospital admission (Hsu, 2023).

The results of the present study support the need to develop and implement an inte- grated care plan geared toward the needs and suggestions (e.g., enhancing supportive care and environment) listed by parents of burn-injured children. In fact, pediatric burn centers must have a defined and adequate strategy to receive and support parents, preparing them for the post-discharge period (Lernevall et al., 2021). In addition, healthcare provision should include a specialized multidisciplinary team in pediatric burns to improve clinical outcomes (Bakker et al., 2013). The results within the theme "finding ways to guide parents" are also relevant for informing future family-centered intervention programs to improve parent and child outcomes. An integrated family-centered care approach is paramount within the context of pediatric burn injuries (Egberts et al., 2019; Wickens et al., 2024). Mohammadzadeh et al. (2023) also encouraged the adoption of a family-centered empowerment model, given its role in promoting the quality of life of pediatric burn patients and reducing parental stress. A longitudinal qualitative study focusing on the psychosocial trajectories of parents of critically injured children highlighted the importance of early intervention and ongoing care, given the complex needs of these families and the persistence of parental distress, over time (Foster et al., 2019). To ensure consistency and optimize the quality of the delivery of integrated healthcare to these families, the authors recommend a family support healthcare coordinator (Foster et al., 2019). In this line, understanding and addressing parents' healthcare needs and emotional and psychosocial adjustment difficulties is imperative to improve the health and psychological outcomes of both parents and burn-injured children. Therefore, multidisciplinary healthcare teams, including clinical and health psychologists, are crucial, and an empirical literature review found promising results regarding these practices within pediatric burn injury care (Bakker et al., 2013). Moreover, a recent case report in the field of burn care highlighted the roles and several benefits of mental health professionals in integrated care when families are involved (e.g., routine psychosocial screening) (Cartwright & Pounds-Cornish, 2023).

According to our graphical map (Figure 2.1), integrated care is paramount with intervention programs, including self-regulation training, active coping strategies, parent-healthcare provider communication, and family empowerment, in order to promote more adaptive outcomes and improve

overall parents' and children's quality of life.

Despite the strengths of this study, some limitations must be acknowledged. First, parents' experiences were limited to a single hospital, and the majority of participants were mothers (82.6%), limiting the generalization of the results. Second, logbook weaknesses: although the open-ended questions captured a wide variety of information, some parents were very short in their answers. Finally, the present study did not consider the socio- economic and ethnic status of the parents, which may have an impact on the results.

Future studies should include a balanced number of fathers and mothers, explore the views of healthcare providers, employ a mixed-method design, and control the effect of potential confounders (e.g., socio-economic variables).

Conclusion

This is the first qualitative study that addressed and explored the perceptions and experiences of Portuguese parents during the hospital stay of preschool children who had sustained an unintentional burn injury. Our qualitative findings showed that these parents were significantly burdened and distressed during this phase and considered that this process was typically more traumatic and challenging for them than for their children. In addition to raising several important clinical implications (e.g., establishing targeted goals for intervention), this study also adds new original data about the parents' emotional and psychosocial adjustment and healthcare needs, such as the fact that most of these parents feel neglected (i.e., reduced to the role of the child's companion) during the inpatient experience, and helped clarify previous contradictory findings regarding the perceived traumatic and distressing impact of medical procedures (e.g., dressing changes was the most negative aspect of the whole experience). Taken together, the qualitative findings suggest that there is a pressing need for integrated care in the field of pediatric burn injuries. In addition, parents should be screened early and included in the treatment care plans starting at the child's hospital admission, in order to improve their adjustment, prevent the development of clinical traumatic symptoms, and also provide vital resources and strategies for the later stages of care (e.g., post-discharge care).

Finally, the present findings may be considered a first step to inform the development of family-centered intervention programs within integrated healthcare delivery.

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Table 2.1

Parents' sociodemographic and clinical characteristics (n = 46)

Parents' characteristics	*n* (%)	Mean (*SD*)	Range
Age	46	33.54 (5.82)	22 - 47
Gender			
Men	8 (17.4)		
Women	38 (82.6)		
Residential area			
Urban	30 (65.2)		
Rural	16 (34.8)		
Marital status			
Single	6 (13.0)		
Married	20 (43.5)		
Living with partner	19 (41.3)		
Divorced or separated	1 (2.2)		
Education			
With higher education	34 (73.9)		
Without higher education	12 (26.1)		
Employment status			
Inactive	15 (32.6)		
Active	31 (67.4)		
Chronic illness			
No	35 (76.1)		
Yes	11 (23.9)		
Medication			
No	33 (71.7)		
Yes	13 (28.3)		
Witnessed the burn event			
No	21 (45.7)		
Yes	25 (54.3)		

Table 2.2

Children's sociodemographic and clinical characteristics (n = 46)

Children's Characteristics	*n* (%)	Mean (*SD*)	Range
Age (in years)	46	2.28 (1.52)	0.67 - 6
Gender			
Boys	28 (60.9)		
Girls	18 (39.1)		
Number of siblings	27	1.44 (0.80)	1 - 4
Enrollment in preschool			
No	21 (45.7)		
Yes	25 (54.3)		
Pre-existing medical conditions			
No	45 (97.8)		
Yes	1 (2.2)		
Place where the burn occurred			
At home	44 (95.7)		
Outside the home	2 (4.3)		
Mechanism of burn			
Scald	34 (73.9)		
Contact	4 (8.7)		
Flame	3 (6.5)		
Friction	2 (4.3)		
Other (e.g., chemical)	3 (6.5)		
Number of burn regions sustained			
Single	13 (28.3)		
Multiple	33 (71.7)		
Burn depth			
Superficial partial-thickness (2nd degree)	6 (13.0)		
Deep partial-thickness (2nd degree)	31 (67.4)		
Full-thickness (3rd degree)	9 (19.6)		
Visible burns [a]			
No	22 (47.8)		

Children's Characteristics	*n* (%)	Mean (*SD*)	Range
Yes	24 (52.2)		
Edema			
No	13 (28.3)		
Yes: Local edema	33 (71.7)		
Edema texture			
Soft edema	31 (67.4)		
Hard edema	2 (4.3)		
Skin graft			
No	7 (15.2)		
Planned	39 (84.8)		
Hospital length of stay			
Less than 2 weeks	8 (17.4)		
2 weeks or more	38 (82.6)		
Days since burn injury	46	6.26 (3.09)	1 - 17
%TBSA	46	4.71 (3.10)	1 - 13

Note. %TBSA = percentage of the total body surface area burned; [a] Burn injuries affecting the hands, neck, face, and/or head.

Table 2.3

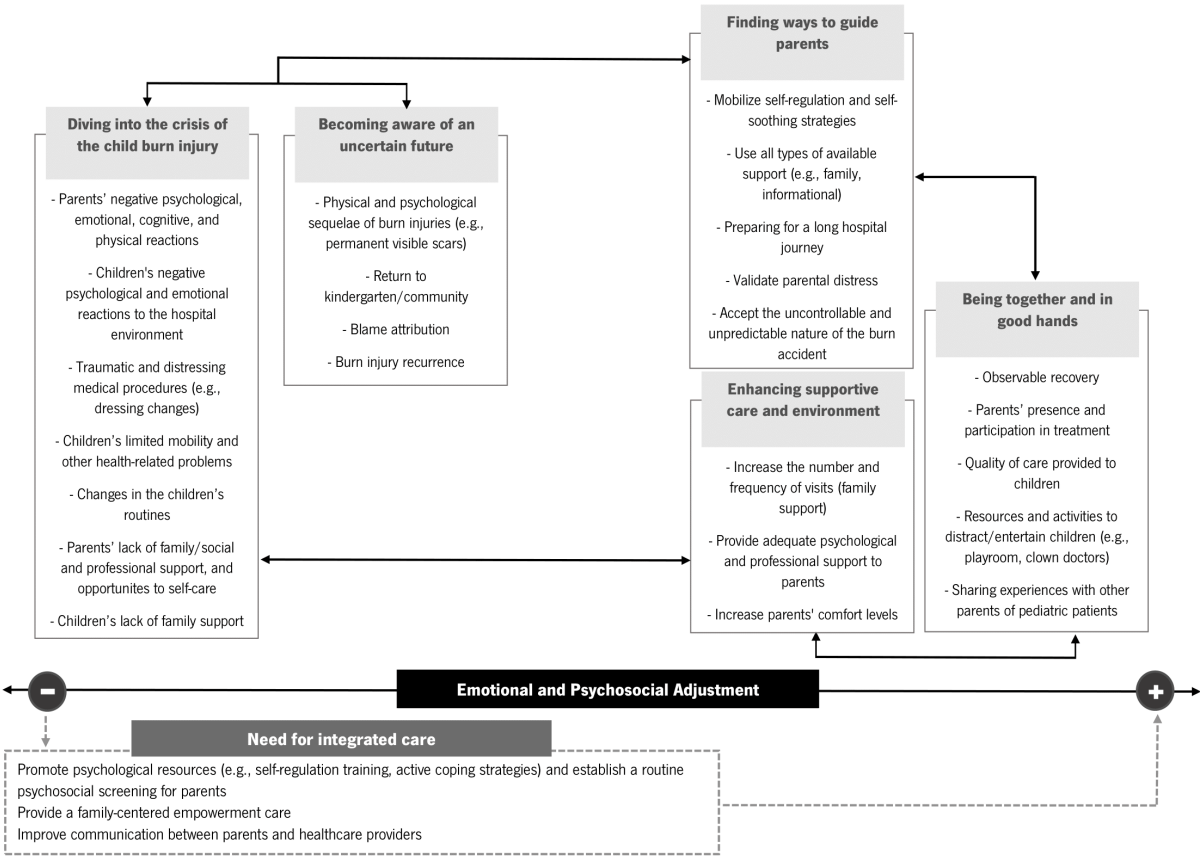
Themes, sub-themes, and representative quotes from the participants' records

Themes	Sub-Themes (*n*, %)	Examples
Diving into the crisis of the child burn injury	Negative trauma responses (44, 95.65%)	"*I feel very bad (...) I feel that they look at us like we're guilty*." (mother of a two-year-old boy)
	Facing medical procedures (34, 73.91%)	"*It was very distressing to see my daughter screaming in pain during the dressing change...*" (mother of a ten-month-old girl)
	Changes in the child's functioning (27, 58.70%)	"*Because of the bandages on his hands, he can't do some of the activities he is used to, such as eating, playing with other children...*" (mother of a one-year-old boy)
	COVID-19 stressors (33, 71.73%)	"*(...) a bit apprehensive, afraid that he might get COVID again because that slows down the whole process*." (mother of a five-year-old boy)
	Unmet needs (38, 82.61%)	"*I miss my family and the support they could give me, for example, here I don't have anyone to help me feed my daughter. (...) It is in these situations that we see that we're just the child's companions...*" (mother of a nine-month-old girl)
Being together and in good hands	Child's well-being and recovery (34, 73.91%)	"*The day my daughter (with a facial burn) opened her eyes again was a victory*." (father of a ten-month-old girl)
	Quality of healthcare and environment (35, 76.09%)	*"The medical team made me feel confident (...) The people here in the hospital talk a lot about the experience they've had/are having, and that helped me a lot to take it all in."* (mother of a one-year-old boy)

Themes	Sub-Themes (*n*, %)	Examples
Becoming aware of an uncertain future	Ongoing suffering of the child and (potential) permanent scarring (41, 89.13%)	"*I am afraid there will be some rejection from him or his classmates or even bullying episodes. I hope he doesn't have any physical or emotional marks*." (mother of a six-year-old boy)
	Concerns about being blamed and that a burn might happen again (8, 17.39%)	"*(...) that my daughter blames me when she looks at the scars*." (mother of a one-year-old girl)
Enhancing supportive care and environment	Strengthening support and adapting the care plan (29, 63.04%)	"*The food should be more appropriate for children of this age, and we would have more support in this regard, such as helping to feed them, distracting them while they eat, etc*." (father of a three-year-old boy)
	Improvement of hospital facilities (8, 17.39%)	"*We should only have single rooms so that families can have their privacy and feel at ease*." (mother of an 11-month-old boy)
Finding ways to guide parents	Maintaining a positive mindset and activating coping resources (41, 89.13%)	"*Have hope that better days will come*." (mother of a one-year-old girl)
	Recognizing parental distress and promoting child's well-being (21, 45.65%)	"*This turns out to be more difficult for us than for them*." (mother of a three-year-old boy)
	Raising awareness (9, 19.57%)	"*People should talk more about this issue of burns, because it happens a lot, especially in children, and you don't hear about it*." (mother of a one-year-old boy)

Figure 2.1

Graphical map of the main results



Note. Theme boxes closer to one of the poles of emotional and psychosocial adjustment represent more adaptive (+) or more maladaptive adjustment (–). Bold arrows indicate the interaction between themes. Dotted-line box reflects the role of healthcare providers.

CAPÍTULO 3:

Longitudinal Changes on Burn Scar and Health-Related Quality of Life in Pediatric Burn Patients: The Mediating Role of Family Functioning

[Manuscrito submetido para publicação]

Abstract

Burn injuries are a leading cause of preventable childhood trauma that threatens family functioning and well-being. This study aimed to analyze changes over time in parental psychosocial and family factors, and child's health-related quality of life (HRQoL) outcomes, as well as the mediating role of family functioning. A total of one hundred parents and their preschool-aged children were included. Data were collected at four different assessment moments: during the hospital stay (T0), one month (T1), three months (T2), and six months (T3) post-discharge. Parental coping and distress symptoms (anxiety, depression, and traumatic stress), family functioning, and the child's burn scar quality and HRQoL were assessed. The results showed significant changes in all variables. In general, parental distress symptoms decreased over time, parental coping significantly increased from T1 to T2, and family functioning significantly decreased when compared to T0. The child's burn scar quality and HRQoL improved over time. In addition, family functioning fully mediated the relationship between parental distress and burn scar quality. The results suggested the importance of family functioning in the relationship between parental psychosocial adjustment and child's physical recovery. The implementation of an integrated care approach, including family-centered empowerment care and routine psychosocial screening for parents, is highly recommended.

Keywords: burn injuries, children, health-related quality of life, scar quality, parental distress, family functioning

Introduction

Burn injuries are the fifth most common cause of non-fatal childhood trauma and, although most pediatric burns are preventable (e.g., scald burns), they are often underestimated and remain a major public health concern worldwide (Nassar et al., 2023; World Health Organization, 2023). The lack of community and parental awareness of burn injury prevention (e.g., potential household hazards) and burn-related knowledge (e.g., first aid procedures) contributes to a high incidence of unintentional burn injuries, predominantly in early childhood (Moore et al., 2022; Nassar et al., 2023; Price et al., 2021; Tupetz et al., 2020; van Balen et al., 2023). In Portugal, children under the age of five account for a fifth of all cases, with scalds (e.g., due to hot liquids) being the most common burn mechanism (Santos et al., 2016, 2019). This type of serious physical injury has well-known physical, psychological, social, economic, and family consequences (Bakker et al., 2013; Woolard et al., 2021), causing a significant impact on health-related quality of life (HRQoL) of pediatric burn survivors (Bakker et al., 2013; Landolt et al., 2002; Pan et al., 2015; Patterson et al., 2023; Spronk et al., 2018, 2023). Scarring has been described as one of the most adverse consequences of burn injuries (Spronk et al., 2021). Hypertrophic scars are highly prevalent after severe pediatric burns (Lonie et al., 2017), and have complex long-term implications (e.g., lower self-esteem; Bakker et al., 2013). Cubison et al. (2006) suggest that burn injuries that heal in less than 21 days have a better prognosis (e.g., lower risk of hypertrophic scar formation). However, the healing time depends on burn severity (i.e., total body surface area [TBSA] and burn depth), which in turn is considered a strong predictor of HRQoL in pediatric patients in a recent systematic review (Spronk et al., 2018). Previous studies found that burn scar outcome was linked to HRQoL in burn patients (Koljonen et al., 2013; Maskell et al., 2013); however, its impact is not completely clear (Lonie et al., 2017). In addition, a recent study found that burn scar outcome fully mediated the relationship between burn severity and HRQoL, suggesting that burn scar status plays a key role in determining HRQoL more than burn severity (Oh & Boo, 2017). Despite these findings, there is a significant lack of evidence regarding long-term burn scar quality in children (Spronk et al., 2021), and the influencing factors on burn scar changes over time (Tyack et al., 2015).

Previous qualitative findings showed that parents of preschool-aged children, during the inpatient phase, were significantly distressed and worried about the short- and long-term sequelae of the burn injury (e.g., permanent and visible scars; Santos et al., 2024). Along with the aforementioned literature gaps, the qualitative findings highlighted the importance of a longitudinal quantitative assessment of child health-related outcomes considering parental distress symptoms, parental coping, and family functioning, given the influential role of parental and family psychosocial factors in child recovery, as

described in a growing body of literature (Bakker et al., 2013; Egberts et al., 2016; Hall et al., 2006; Landolt et al., 2002; Nassar et al., 2023; Odar et al., 2013; Öster et al., 2014; Phillips & Rumsey, 2008). In this line, Landolt et al. (2002) found that better family functioning predicted a better HRQoL in school-aged burn survivors. Despite that, a longitudinal study by Ryan et al. (2015) suggests family functioning seems to worsen following burns and, in cases of severe injuries, can remain low for up to three years post-burn. In addition, Odar et al. (2013) highlighted that family-related pre-trauma factors (e.g., level of familial stress, psychiatric illness) should be taken into account, given their significant association with parental traumatic stress symptoms, which in turn are significantly related to poor children's psychosocial adjustment (Bakker et al., 2013; Brown et al., 2019a; De Young et al., 2014; Woolard et al., 2021), physical symptoms (e.g., post-burn pruritus; Stewart et al., 2019) and overall quality of life (Townsend et al., 2023). Regarding coping, few studies have explored the role of parental coping following pediatric burn injuries (e.g., Brown et al., 2019a), but it is known that there is a negative relationship with parents' anxiety and depressive symptoms (Tyack & Ziviani, 2003), and the promotion of active problem-solving coping may be beneficial in reducing parental distress (Tully et al., 2022).

Most studies reported that the HRQoL outcomes of pediatric survivors improved over time (Koljonen et al., 2013; Rashaan et al., 2019; Spronk et al., 2018, 2023) and parents' distress symptoms tended to decrease (De Young et al., 2014; Egberts et al., 2020; Phillips & Rumsey, 2008). Nevertheless, more robust evidence is needed regarding the evolution of HRQoL over time (Patterson et al., 2023), especially in preschool-aged patients, who remain underrepresented in the literature, despite the high incidence of burn injuries in this age group (e.g., Santos et al., 2016, 2019). Furthermore, to the best of our knowledge, only one study found a significant association between parental distress and re-epithelialization (Brown et al., 2019b) and, although the importance of family dynamics is unquestionable for the pediatric population (Landolt et al., 2002; Nassar et al., 2023), no study has examined the role of family functioning in the relationship between parental distress and HRQoL outcomes in pediatric burn patients. Also, a recent systematic review focusing on physical and psychosocial outcomes in pediatric burn patients underlined the need for further research into family functioning to elucidate their role in the recovery process (Patel et al., 2021).

To address these gaps and help inform future public health policies and evidence-based family-centered interventions, the current study aims to: (1) examine changes in parental distress (i.e., parents' anxiety, depressive and traumatic stress symptoms), parental coping, family functioning, and child's burn scar quality and HRQoL over time; and (2) explore the mediating role of family functioning in the relationship between parental distress symptoms and child's burn scar quality. In this line, this study

was theoretically based on the Conceptual Model of Burn Scar HRQoL proposed by Simons et al. (2016), which provides a comprehensive understanding of the direct and indirect effects of a set of factors on burn-specific HRQoL outcomes over time. According to this conceptual framework, there is one proximal factor (i.e., burn-related symptoms, such as physical and sensory) and seven distal factors (i.e., emotional functioning, physical functioning, cognitive functioning, social functioning, burn scar interventions, and environment and individual characteristics) that have a significant (direct and/or indirect) impact on burn scar HRQoL, which in turn affects the overall quality of life of both adult and pediatric burn survivors (Simons et al., 2016). In the present study, only specific environmental characteristics (i.e., parental coping), emotional functioning (i.e., parental distress symptoms), social functioning (i.e., family functioning), and outcomes (i.e., burn scar and HRQoL) were considered. Therefore, it is expected that over time, parents will show a decrease in family functioning, greater parental coping, and lower anxiety, depression, and traumatic stress symptoms, while children will show better burn scar quality and HRQoL. Finally, family functioning will play a mediating role in the relationship between parental distress symptoms and child's burn scar quality.

Method

Study Design and Participants

The current study, with a longitudinal design, is part of a larger research project on pediatric burn injuries in early childhood (0-6 years), in which each study addresses specific research questions and provides unique insights into the psychosocial and familial impact of the traumatic event (burn injury), and the child's health-related outcomes (e.g., Santos et al., 2024). In this study, family functioning, parents' anxiety, depressive and traumatic stress symptoms, and the child's HRQoL were assessed at four different assessment moments: during the hospital stay (baseline assessment – T0), one month (T1), three months (T2) and six months (T3) after the hospital discharge. Parental coping and the child's burn scar quality were assessed at T1, T2, and T3. Eligible participants were parents/legal guardians (aged ≥ 18 years) of preschool-aged children (aged one month to six years) recently admitted to the hospital due to an unintentional burn injury, and who accompanied the child throughout the medical care process (including inpatient and outpatient phases of treatment). Participants were excluded from the study if: (a) they presented insufficient language proficiency to complete the questionnaires; (b) there was a suspicion that the burn injury was intentional (e.g., caused by neglect or abuse); and (c) the child had a psychiatric illness or an oncological diagnosis (as recorded in the child's medical records).

A total of 100 participants fulfilled the inclusion criteria and were recruited at T0 within 20 days post-burn (M = 6.83, SD = 3.44), during clinical rounds, by a specialist pediatric surgeon in charge of the Pediatric Burns Unit (part of the Pediatric Surgery Department) of a reference hospital in the Northern region of Portugal. All parents/legal guardians who agreed to participate in this research provided written informed consent. Of the 100 parents who were assessed at T0, more than 90% completed the T1 and T2 assessments (96% and 93%, respectively), and 77% completed the T3 assessment (see Figure 3.1).

[Figure 3.1]

Measures

Sociodemographic and clinical questionnaire

This questionnaire was developed for the purposes of this research and includes 10 items to assess parents' sociodemographic and clinical variables (e.g., age, gender, diagnosis of chronic illness, medication), and 15 items regarding the child's sociodemographic and burn injury characteristics (e.g., number of siblings, mechanisms of burn injury, place where the burn event occurred). The child's clinical data (e.g., burn depth, edema, number of surgeries, type of skin graft) was recorded by the specialist pediatric surgeon and included a scale to measure the burn scar index, the Vancouver Scar Scale (VSS; Baryza & Baryza, 1995), which is widely used in medical settings to evaluate scar properties within burn care research (Brusselaers et al., 2010). The VSS assesses four scar parameters: pigmentation, pliability, height, and vascularity. The total score ranges from 0 to 13, with higher scores indicating worse scar quality.

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Portuguese version by Pais-Ribeiro et al., 2007)

This self-report questionnaire consists of 14 items, equally divided into two subscales: anxiety (7 items) and depression (7 items). Respondents (parents) are asked to indicate how they felt in the last week on a four-point Likert scale (0-3). The score for each subscale ranges from 0 to 21, with higher scores indicating greater psychological morbidity. In the Portuguese version, Cronbach's alpha was .76 and .81 for anxiety and depression, respectively. In this study, both Cronbach's alpha and McDonald's omega were .85 for the anxiety subscale and .77 for the depression subscale.

Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997; Portuguese version by Pereira & Figueiredo, 2008)

This self-report instrument assesses traumatic stress symptoms and consists of 22 items divided into three subscales, namely intrusion (8 items), avoidance (8 items), and hyperarousal (6 items). Parents are asked to indicate how distressed they felt in the last week following their child's burn injury

(the traumatic event), on a five-point Likert scale ranging from 0 (not at all) to 4 (extremely) for each item. The total scale score ranges from 0 to 12, with higher scores indicating greater traumatic stress symptoms. In this study, only the total scale score was used. Cronbach's alpha was .90 in the Portuguese version, and in the present study, both Cronbach's alpha and McDonald's omega were .94.

Family Assessment Device – General Functioning (FAD-GF; Epstein et al., 1983; Portuguese version by Almeida et al., 2020)

The FAD-GF is a single validated scale from the Family Assessment Device, composed of 12 items, which assesses the general functioning of the family. Items are rated on a four-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). Higher scores indicate worse family functioning. Cronbach's alpha was .79 in the Portuguese version and, in this sample, Cronbach's alpha was .84, and McDonald's omega was .83.

Coping Health Inventory for Parents (CHIP; McCubbin et al., 1983; Portuguese version by Almeida & Pereira, 2016)

This self-report instrument assesses the coping strategies used by parents of children with critical or chronic conditions in their daily lives. It consists of 44 items divided into three core components: (I) maintaining family integration, cooperation, and optimism (16 items); (II) maintaining social support, self-esteem, and psychological stability (19 items); and (III) understanding the medical situation (9 items); which are scored on a four-point Likert scale ranging from 0 (not helpful) to 3 (extremely helpful). Higher scores indicate greater parental coping. In this study, only the total scale was used. In the Portuguese version, Cronbach's alpha was .89, and in the present study, Cronbach's alpha and McDonald's omega were .91 and .92, respectively.

TNO-AZL Preschool Children Quality of Life Questionnaire (TAPQoL; Fekkes et al., 2000; Portuguese version by Ferraz et al., 2024)

This instrument assesses the perceptions of parents (direct informants) about the HRQoL of their children (aged 0-6 years) through 43 items divided into 12 subscales (in the original version). The Portuguese version is composed of 11 subscales, four of which (i.e., problem behavior, anxiety, positive mood and liveliness, and social functioning) are scored on a three-point Likert scale ranging from 1 (never) to 3 (often). For the remaining subscales (i.e., stomach, lung, skin and sleep problems, appetite, communication, and motor functioning), each item consists of two parts. The first part assesses the frequency of a specific symptom/limitation on a three-point Likert scale (1-3), identical to the previous four subscales; and the last part assesses the impact of that symptom/limitation on the child's well-being, using a four-point Likert scale ranging from 1 (fine) to 4 (bad). The social and motor functioning

and communication subscales only apply to children aged ≥ 18 months. Higher scores indicate better HRQoL. The TAPQoL was validated in a Portuguese pediatric clinical sample that included burn patients and showed good internal consistency with Cronbach's alpha and McDonald's omega of .83 for the total scale. In this study, only the total scale was used with a Cronbach's alpha and McDonald's omega of .81 and .78, respectively.

Procedure

The study protocol was approved by the Ethics Committee for Research in Social and Human Sciences of the Ethics Council of the University of Minho (Ref. CEICSH 020/2020; approval on April 8, 2020), and by the Ethics Committee for Health (Ref. CE 429/20; approval on December 10, 2020) of a major public hospital in the Northern region of mainland Portugal, where the data was collected. Data collection was conducted between March 2021 and November 2023, in the hospital's Pediatric Surgery Department. During the inpatient phase, participants who met the inclusion criteria were informed by the researcher responsible for implementing the study protocol about the purpose of the study and other relevant information regarding their participation (e.g., data confidentiality, voluntary nature). One, three, and six months after the hospital discharge, the same day of the outpatient appointments, the parents filled out the questionnaires online using a secure survey platform: Qualtrics^{XM} (April 2021 to November 2023). All study procedures followed the recommendations of the Declaration of Helsinki (World Medical Association, 2013).

Statistical Analyses

Data analysis was performed using R Statistical Computing Environment (R Development Core Team, 2023). In order to examine changes in parental distress symptoms (i.e., anxiety, depressive, and traumatic stress symptoms) and coping, family functioning, and child's health-related outcomes (i.e., burn scar and HRQoL) over time, linear mixed models were used. The model included two dichotomous variables (i.e., parents' education and child's pre-existing medical condition) as confounding variables, and was fitted using maximum likelihood estimation to determine the point estimates for the regression coefficients, with standard error based on standard asymptotic theory (Bates et al., 2015). Mediation analyses were also conducted to examine the mediator role of family functioning in the relationship between parental distress symptoms (i.e., anxiety, depressive, and traumatic stress symptoms) and burn scar quality through the mediation package for R (Tingley et al., 2014). The estimates of the direct and indirect effects were based on 5,000 bootstrap samples, with the corresponding 95% confidence intervals (CI) of these bootstrap estimates (Hayes & Preacher, 2013). The indirect effect was considered significant if the 95% CI did not include zero. Descriptive statistics were performed to describe the categorical

(frequencies and percentages) and continuous variables (means and standard deviations) of the sample, using IBM SPSS Statistics (Statistical Package for the Social Sciences) version 29.

Results

Sample characteristics

This study included one hundred parents (87 mothers), with an average age of 33.56 years (*SD* = 5.52) and their respective children (65 boys) aged between two months and six years (*M* = 2.30, *SD* = 1.62). Tables 3.1 and 3.2 show the sociodemographic and clinical characteristics of the parents and children, respectively, at the four assessment moments. Before the burn event, most of the children (54%) were enrolled in preschool and 79% had never been hospitalized. Most of the burn injuries occurred at home (94%), predominantly in the kitchen (65%) and the living room (16%). The number of burn regions sustained ranged from 1 to 5 (*M* = 2.12, *SD* = 1.11), with the forearm (35%), hands (34%), arm (23%) and anterior trunk (23%) being the most affected body zones. At the baseline assessment, the majority of patients (79%) had local edema, 91% of which had a soft texture, and all received pain treatment. The total number of surgeries ranged from 0 to 6 (*M* = 0.83, *SD* = 1.16). Table 3.3 shows the scores of parental distress symptoms and coping, family functioning, and child's health-related outcomes at the four assessment moments.

[Table 3.1]

[Table 3.2]

[Table 3.3]

Changes over time

Controlling for parents' education and child's pre-existing medical condition, significant differences were found (Table 3.4 and Figure 3.2). Parents' anxiety, depressive and traumatic stress symptoms significantly decreased from T0 to T1 (β = -2.42, p < .001; β = -2.02, p < .001; β = -2.24, p < .001; respectively), from T0 to T2 (β = -3.12, p < .001; β = -2.86, p < .001; β = -3.04, p < .001; respectively) and from T0 to T3 (β = -3.60, p < .001; β = -2.64, p < .001; β = -2.99, p < .001; respectively). Parents' traumatic stress and depressive symptoms also decreased significantly from T1 to T2 (β = -0.81, p < .001; β = -0.84, p < .01; respectively), as well as traumatic stress and anxiety symptoms from T1 to T3 (β = -0.75, p < .001; β = -1.18, p < .01; respectively). Family functioning scores significantly increased from T0 to T1 (β = 0.15, p < .001), from T0 to T2 (β = 0.12, p < .01), and from T0 to T3 (β = 0.12, p < .01), indicating that compared to the baseline assessment (hospital stay), family functioning decreased. Parental coping significantly increased from T1 to T2 (β = 2.88, p < .05). Regarding the child's health-related outcomes, burn scar scores significantly decreased from T1 to T2 (β

= -0.43, $p < .01$), from T1 to T3 (β = -1.08, $p < .01$), and from T2 to T3 (β = -0.65, $p < .01$), which indicates an improvement in burn scar quality over time. In addition, the child's HRQoL significantly increased from T0 to T3 (β = 1.91, $p < .05$), from T1 to T2 (β = 1.94, $p < .05$), and from T1 to T3 (β = 2.57, $p < .01$).

[Table 3.4]

[Figure 3.2]

Mediator effects

The results showed that family functioning fully mediated the relationship between parental distress symptoms and the child's burn scar quality (Table 3.5). The indirect effects of parents' anxiety (β = -0.01, 95% CI [-0.03, 0.00], $p < .01$), depressive (β = -0.02, 95% CI [-0.04, 0.00], $p < .01$), and traumatic stress symptoms (β = -0.02, 95% CI [-0.05, 0.00], $p < .05$) on the child's burn scar outcome were significantly mediated by family functioning. The direct effects of parents' anxiety (β = 0.04, 95% CI [-0.01, 0.09], $p = .10$), depressive (β = 0.06, 95% CI [-0.00, 0.11], $p = .06$), and traumatic stress symptoms (β = -0.08, 95% CI [-0.02, 0.19], $p = .13$) on the child's burn scar quality were not significant.

[Table 3.5]

Discussion

This study analyzed longitudinal changes in parental distress symptoms (anxiety, depression, and traumatic stress symptoms), parental coping, family functioning, and child's burn scar quality and HRQoL, as well as the mediating role of family functioning in the relationship between parental distress symptoms and child's burn scar quality.

Regarding the first goal, the results were in line with our hypothesis. Parents' anxiety, depressive, and traumatic stress symptoms significantly decreased from T0 to T1, T2, and T3, and traumatic stress along with depressive and anxiety symptoms significantly decreased from T1 to T2 and from T1 to T3, respectively. The results were also consistent with previous longitudinal studies that assessed differences in parental distress symptoms (De Young et al., 2014; Egberts et al., 2020). For example, a study that used the same measures of distress as the present study found that parents' depressive and traumatic stress symptoms decreased significantly from one to 18 months post-burn (Egberts et al., 2020). De Young et al. (2014) suggested that, for most parents, traumatic stress symptoms tend to subside within six months post-burn. In addition, a recent study found that the level of parental distress shortly after the burn event was a significant predictor of later distress (Parrish et al., 2019), which underlines the importance of early psychosocial screening. Previous qualitative findings (Santos et al., 2024) support the present quantitative results, suggesting that the hospital stay is an extremely challenging and

distressing phase for these parents and is, therefore, the best moment to start the intervention and prevent the risk of long-term serious psychosocial consequences (e.g., posttraumatic stress disorder; PTSD). During this phase, potential secondary stressors that threaten their emotional and psychosocial adjustment should be taken into account, such as invasive and traumatic medical procedures, dealing with uncertainty about the future, and overall lack of support (Santos et al., 2024). Moreover, parental coping significantly increased from T1 to T2, which may help to understand the decrease in parental distress symptoms after hospital discharge. This result seems to suggest that returning to daily life and the comfort of home, unlocks a set of adaptive coping mechanisms that were compromised during the hospital stay and which may have a protective effect on parental adjustment (e.g., concentrating on hobbies). Brown et al. (2019b) highlighted that parental coping, especially during wound care, is an important target for intervention. In fact, less active coping strategies can lead to an increased parents' vulnerability to long-term maladjustment (Tully et al., 2022). In the present study, parental coping was not assessed at T0 since some CHIP items are not adapted to parents of inpatient children (e.g., "purchase gifts for myself and family", "invest time in my job", "go out with my spouse"). Future studies with a longitudinal design and using another parental coping measure should assess the coping resources of parents, starting from hospital admission, in order to elucidate their mechanisms and role in parents' psychosocial adjustment. Research is also needed on parental post-traumatic growth following pediatric burns, which is often associated with active coping strategies (Woolard et al., 2021), in order to obtain a more comprehensive picture of the phenomenon.

In line with previous studies (e.g., Koljonen et al., 2013; Spronk et al., 2018), the results showed that the child's HRQoL outcomes improved over time, especially the quality of the burn scar, which improved significantly from T1 to T2 and T3, and from T2 to T3, while the child's HRQoL increased significantly from T0 to T3 and from T1 to T2. A recent study focused on long-term HRQoL in pediatric burn survivors found that 76% of the sample had no significant long-term disturbances within seven years post-burn (Spronk et al., 2023). In addition, Oh and Boo (2017) suggested that better scar quality allowed patients to better adapt and cope with potentially related physical and psychosocial problems, resulting in better HRQoL. Nevertheless, the results of the present study should be interpreted taking into account specific burn injury characteristics, for example, %TBSA, which was ≤ 15% (M = 4.40, SD = 2.92) in this sample (N = 100); since healing time changes according to injury severity (Cubison et al., 2006; Lonie et al., 2017). Providing parents with the knowledge of the child's HRQoL outcomes improvements within six months post-burn, may help reduce their concerns about child recovery during the hospital stay (e.g., fear of permanent and visible scars), thereby promoting better psychosocial outcomes over time. This is

particularly relevant since there is evidence that the psychosocial adjustment of parents and children is closely linked (Brown et al., 2019a; De Young et al., 2014; Woolard et al., 2021), which in turn has a bidirectional effect on patients' HRQoL outcomes (Simons et al., 2016).

Family functioning scores significantly increased from T0 to T1, T2, and T3, suggesting that family functioning decreased when compared to T0, and remained stable from T1 onwards. Although this result was expected and consistent with previous research (Ryan et al., 2015; Sveen et al., 2014), remains an interesting finding since family functioning was the only variable under study that decreased compared to T0. The length of hospital stay in this sample (N = 100: 77% ≥ two weeks) may have influenced these results. The more serious the burn, the longer the hospital stay and the greater the need for follow-up care. Indeed, a recent qualitative study showed that parents returned home without the necessary skills to maintain adequate post-discharge care (Lernevall et al., 2023). Post-discharge care involves the need for the family to readjust, being highly challenging (Öster et al., 2014), and may even result in divorce (Bakker et al., 2013). In addition, a study found that parents of preschool-aged burn patients reported more family disruptions than parents of older patients (Sveen et al., 2014). Given the contribution of family functioning to the child's HRQoL (e.g., Landolt et al., 2002), family needs and demands post-discharge must be anticipated and discussed, and adaptive resources and strategies should be made available by health professionals even during the hospital stay, in order to promote better family functioning afterward, as suggested in other studies (e.g., Lernevall et al., 2023; Santos et al., 2024).

Finally, the results showed that family functioning fully mediated the relationship between parental distress symptoms (anxiety, depressive, and traumatic stress symptoms) and the child's burn scar quality. This surprising finding showed that low parental anxiety, depressive, and traumatic stress symptoms predicted better burn scar quality through better family functioning. Thus, family functioning is the underlying mechanism or process by which parents' anxiety, depressive, and traumatic stress symptoms predict the child's burn scar outcome after hospital discharge. Although Sveen et al. (2014) concluded that the impact of family variables on children's HRQoL outcomes was modest, increasing evidence has shown that family functioning (pre- and post-burn) has a key role during the child's recovery process (Bakker et al., 2013; Enlow et al., 2019; Hall et al., 2006; Patel et al., 2021; Odar et al., 2013). Furthermore, there is evidence that poor family functioning significantly predicted greater parental distress, such as anxiety and depressive symptoms (Phillips & Rumsey, 2008). Family functioning has also been associated with parents' resilience following pediatric burn injuries (Tully et al., 2022), which suggests that promoting family functioning increases parental resilience, which in turn plays a protective

role against distress symptoms (Quezada et al., 2016). According to the Conceptual Model of Burn Scar HRQoL (Simons et al., 2016), caregivers are faced with several family challenges resulting from the demands of scar management interventions post-discharge, such as increased family conflicts. Also, a study by Hall et al. (2006) found that increased conflict between parents and children in aftercare played a mediating role in the relationship between parents' acute anxiety and traumatic stress symptoms. Thus, the present findings highlight the importance of adopting family-centered empowerment practices from hospital admission onwards, to promote better HRQoL outcomes for the child and also to mitigate the impact of parental distress on the child's burn scar outcome at later stages of care. Further research (e.g., mixed methods studies) is recommended to gain an in-depth understanding of the family functioning (e.g., cohesion, resilience, disruption) following pediatric burn injuries, especially in aftercare, in order to help the development of evidence-based interventions that are sensitive and responsive to specific family needs.

Limitations

Despite the strengths of the current study (e.g., original findings, four assessment moments), results should be interpreted with caution, due to some limitations that must be addressed. First of all, the small sample size and the fact that the data was collected in a single hospital. However, a recent systematic review focusing on the HRQoL of pediatric burn patients reported that of the 27 studies included, 20 had a sample size of fewer than 200 participants and, of these 20 studies, nine had fewer than 70 participants (Spronk et al., 2018), suggesting that, in the pediatric population, sample sizes are generally low. In addition, data collection was carried out in the only Pediatric Burns Unit in the Northern region of Portugal, as recent national data indicates that this is the region with the highest incidence of pediatric cases (Santos et al., 2019). Second, parent-proxy reports were used to assess the child's HRQoL. Nevertheless, due to the age range of this pediatric population (0-6 years), the parents' perception is the only way to measure the child's HRQoL over time (Ferraz et al., 2024). Previous studies comparing children's self-reports (older than 8 years) with parent reports (both parents) of HRQoL have shown that there is a perfect match in most cases (e.g., Pan et al., 2015), which suggests that parents are valid informants of the child's HRQoL. Parents' education and the child's pre-existing medical condition were also controlled for in the analyses to allow for more precise conclusions. Parents' socio-economic and ethnic status were not considered in this study. Finally, the loss of 23% of the participants from baseline (T0) to the last follow-up assessment (T3), may also limit the generalizability of the results. Future studies with a longitudinal design should include larger sample sizes and longer follow-up

assessments (e.g., 12 months, 18 months), controlling for the socio-economic and ethnic status of the parents.

Conclusion

Overall, the results of the current study showed improvements in the parents' psychosocial adjustment (i.e., parental coping and distress symptoms) and the child's HRQoL outcomes over time, except for family functioning, which decreased significantly when compared to the baseline assessment. This is the first longitudinal study that examined the mediating role of family functioning in the relationship between parents' anxiety, depressive and traumatic stress symptoms, and the child's burn scar quality, suggesting that family functioning plays a major role in the relationship between parental distress and burn scar outcomes. Taken together, these findings highlight the importance of offering supportive family interventions following the burn event. Future longitudinal studies are recommended to determine causal relationships between the variables under study.

Implications for clinical practice

Addressing and understanding parental psychosocial and family variables is paramount in pediatric burn care, especially when preparing the scar treatment plan. Therefore, health professionals should be aware that parental distress can affect the quality of the child's burn scar after hospital discharge, so contributing to more optimal HRQoL outcomes in preschool-aged patients may involve fostering family functioning. The results of this study support previous qualitative findings (Santos et al., 2024) and highlight that the hospital stay (the most demanding phase) is an opportunity and the best moment to intervene. The time parents spend in the hospital can be maximized in this sense, providing them with knowledge, resources, and strategies (e.g., emotional regulation training, active problem-solving coping) which, in later stages of treatment, may lead to a better child's recovery and parental psychosocial adjustment. The implementation of an integrated care approach, including family-centered empowerment care and routine psychosocial screening for parents, is highly recommended.

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Table 3.1

Parents' sociodemographic and clinical characteristics at T0, T1, T2, and T3

		T0 (*N* = 100)	T1 (*N* = 96)	T2 (*N* = 93)	T3 (*N* = 77)
Categorical variables		*n* (%)	*n* (%)	*n* (%)	*n* (%)
Gender					
Men		13 (13.0)	13 (13.5)	13 (14.0)	11 (14.3)
Women		87 (87.0)	83 (86.5)	80 (86.0)	66 (85.7)
Residential area					
Urban		59 (59.0)	56 (58.3)	54 (58.1)	45 (58.4)
Rural		41 (41.0)	40 (41.7)	39 (41.9)	32 (41.6)
Marital status					
Single		17 (17.0)	14 (14.6)	13 (14.0)	9 (11.7)
Married		47 (47.0)	47 (49.0)	47 (50.5)	42 (54.5)
Living with partner		34 (34.0)	33 (34.4)	31 (33.3)	25 (32.5)
Divorced or separated		2 (2.0)	2 (2.1)	2 (2.2)	1 (1.3)
Education					
With higher education		25 (25.0)	24 (25.0)	24 (25.8)	21 (27.3)
Without higher education		75 (25.0)	72 (75.0)	69 (74.2)	56 (72.7)
Employment status					
Inactive		37 (37.0)	34 (35.4)	32 (34.4)	25 (32.5)
Active		63 (63.0)	62 (64.6)	61 (65.6)	52 (67.5)
Chronic illness					
No		78 (78.0)	74 (77.1)	71 (76.3)	59 (76.6)
Yes		22 (22.0)	22 (22.9)	22 (23.7)	18 (23.4)
Medication					
No		73 (73.0)	69 (71.9)	71 (76.3)	54 (70.1)
Yes		27 (27.0)	27 (28.1)	22 (23.7)	18 (23.4)
Witnessed the burn event					
No		48 (48.0)	47 (49.0)	45 (48.4)	35 (45.5)
Yes		52 (52.0)	49 (51.0)	48 (51.6)	42 (54.5)
Continuous variables	Min-Max	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Age	22-47	33.56 (5.52)	33.60 (5.45)	33.78 (5.41)	33.97(5.47)

Table 3.2

Childs' sociodemographic and clinical characteristics at T0, T1, T2, and T3

Categorical variables	T0 (*N* = 100) *n* (%)	T1 (*N* = 96) *n* (%)	T2 (*N* = 93) *n* (%)	T3 (*N* = 77) *n* (%)
Gender				
Boys	65 (65.0)	62 (64.6)	59 (63.4)	47 (61.0)
Girls	35 (35.0)	34 (35.4)	34 (36.6)	30 (39.0)
Pre-existing medical condition				
No	97 (97.0)	94 (97.9)	91 (97.8)	77 (100)
Yes	3 (3.0)	2 (2.1)	2 (2.2)	0 (0)
Place where the burn occurred				
At home	94 (94.0)	90 (93.8)	87 (93.5)	72 (93.5)
Outside the home	6 (6.0)	6 (6.3)	6 (6.5)	5 (6.5)
Mechanism of burn				
Scald	75 (75.0)	71 (74.0)	69 (74.2)	57 (74.0)
Contact	16 (16.0)	16 (16.7)	15 (16.1)	12 (15.6)
Flame	4 (4.0)	4 (4.2)	4 (4.3)	4 (5.2)
Friction	2 (2.0)	2 (2.1)	2 (2.2)	2 (2.6)
Other (e.g., chemical)	3 (3.0)	3 (3.1)	3 (3.2)	2 (2.6)
No. of burn regions sustained				
Single	37 (37.0)	36 (37.5)	35 (37.6)	30 (39.0)
Multiple	63 (63.0)	60 (62.5)	58 (62.4)	47 (61.0)
Burn depth				
Superficial partial-thickness	13 (13.0)	13 (13.5)	13 (14.0)	9 (11.7)
Deep partial-thickness	64 (64.0)	61 (63.5)	59 (63.4)	50 (64.9)
Full-thickness	23 (23.0)	22 (22.9)	21 (22.6)	18 (23.4)
Visible burns [a]				
No	47 (47.0)	44 (45.8)	42 (45.2)	36 (46.8)

Yes		53 (53.0)	52 (54.2)	51 (54.8)	41 (53.2)
Hospital length of stay					
< 2 weeks		23 (23.0)	23 (24.0)	23 (24.7)	19 (24.7)
≥ 2 weeks		77 (77.0)	73 (76.0)	70 (75.3)	58 (75.3)
Continuous variables	Min-Max	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Age (in years)	0.17-6	2.30 (1.62)	2.31 (1.64)	2.35 (1.65)	2.41 (1.74)
%TBSA	1-15	4.40 (2.92)	4.37 (2.94)	4.38 (2.98)	4.23 (2.75)

Note. %TBSA = percentage of the total body surface area burned; [a] Reflects burn injuries affecting the hands, neck, face, and/or head.

Table 3.3

Parental distress symptoms and coping, family functioning, and child's health-related outcomes at T0, T1, T2, and T3

		T0 (*N* = 100)	T1 (*N* = 96)	T2 (*N* = 93)	T3 (*N* = 77)
Parents/family variables	Min-Max	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Anxiety symptoms	0-21	10.37 (4.87)	7.96 (4.93)	7.37 (4.81)	6.90 (5.11)
Depressive symptoms	0-21	7.42 (4.29)	5.40 (3.74)	4.61 (3.66)	4.84 (3.60)
Traumatic stress symptoms	0-11	5.68 (2.78)	3.47 (2.31)	2.72 (2.03)	2.78 (2.09)
Family functioning	1-4	1.54 (0.45)	1.66 (0.43)	1.63 (0.41)	1.59 (0.45)
Parental Coping	44-132	-	107.63 (14.18)	110.49 (14.58)	108.99 (15.53)
Child's health-related variables	Min-Max	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Burn scar	0-9	-	4.26 (2.21)	3.80 (2.26)	3.34 (2.49)
HRQoL	41-100	86.67 (8.26)	85.90 (10.67)	87.65 (9.63)	88.50 (9.18)

Table 3.4

Regression coefficient estimates of the linear mixed-effects model for parental distress symptoms and coping, family functioning, and child's health-related outcomes

Response variable	Anxiety	Depression	Traumatic stress	Family functioning	Parental coping	Burn scar	HRQoL
Fixed effects	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Intercept	10.37 (0.56)***	7.57 (0.44)***	5.75 (0.27)***	1.52 (0.05)***	109.04 (1.75)***	4.30 (0.28)***	87.73 (1.02)***
T1	-2.42 (0.41)***	-2.02 (0.41)***	-2.24 (0.20)***	0.15 (0.04)***	–	–	-0.66 (0.80)
T2	-3.12 (0.42)***	-2.86 (0.44)***	-3.04 (0.20)***	0.12 (0.04)**	2.88 (1.27)*	-0.43 (0.13)***	1.13 (0.81)
T3	-3.60 (0.44)***	-2.64 (0.46)***	-2.99 (0.21)***	0.12 (0.04)**	1.87 (1.36)	-1.08 (0.13)***	1.91 (0.86)*
Education	0.33 (0.99)	-0.32 (0.75)	-0.15 (0.47)	0.00 (0.09)	-6.45 (3.16)*	-0.02 (0.53)	-2.87 (1.76)
PMC	-2.59 (2.64)	-2.13 (2.01)	-0.89 (1.26)	0.57 (0.24)*	9.27 (9.86)	-1.58 (1.62)	1.39 (5.44)

Note. β = Estimate; SE = Standard error; PMC = Child's pre-existing medical condition: 0 = no, 1 = yes; Education = Parents' education: 0 = without higher education, 1 = with higher education; * $p < .05$, ** $p < .01$, *** $p < .001$

Table 3.5

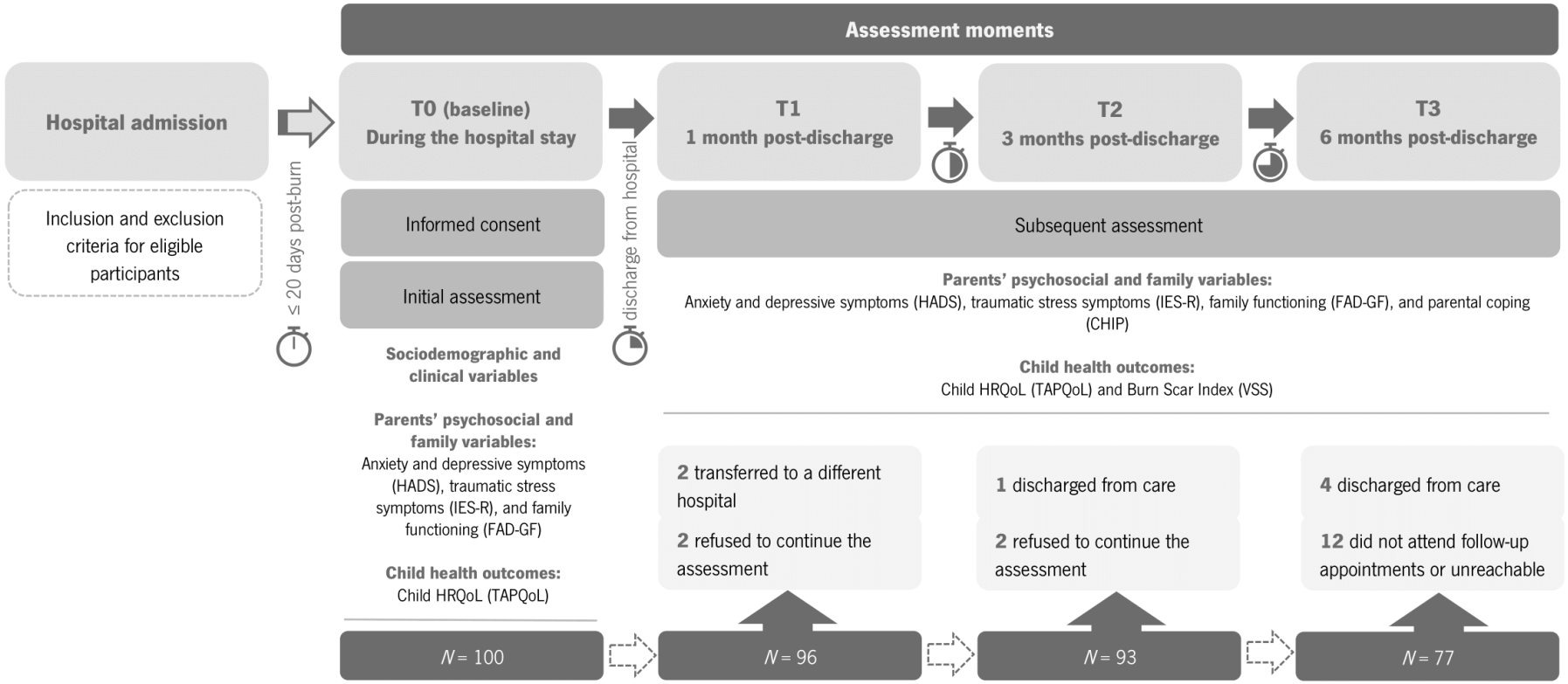
Effects of the mediation model of family functioning in the relationship between parental distress symptoms and child's burn scar quality

Predictor	Mediator	Outcome	β	*p*	95% CI	
					LL	HL
Parents' traumatic stress symptoms	Family functioning	Burn scar	-0.021	.02	-0.049	0.000
Parents' traumatic stress symptoms	Family functioning	-	0.034	<.001	0.008	0.059
-	Family functioning	Burn scar	-0.624	<.001	-1.1	-0.13
Parents' anxiety symptoms	Family functioning	Burn scar	-0.014	.007	-0.028	0.000
Parents' anxiety symptoms	Family functioning	-	0.021	.001	0.009	0.030
-	Family functioning	Burn scar	-0.679	.009	-1.181	-0.177
Parents' depressive symptoms	Family functioning	Burn scar	-0.019	.007	-0.038	0.000
Parents' depressive symptoms	Family functioning	-	0.027	<.001	0.014	0.041
-	Family functioning	Burn scar	-0.691	.007	-1.190	-0.190

Note. β = Estimate; *p* = P-value; 95% CI = 95% Confidence interval; LL = Lower limit; HL = Higher limit

Figure 3.1

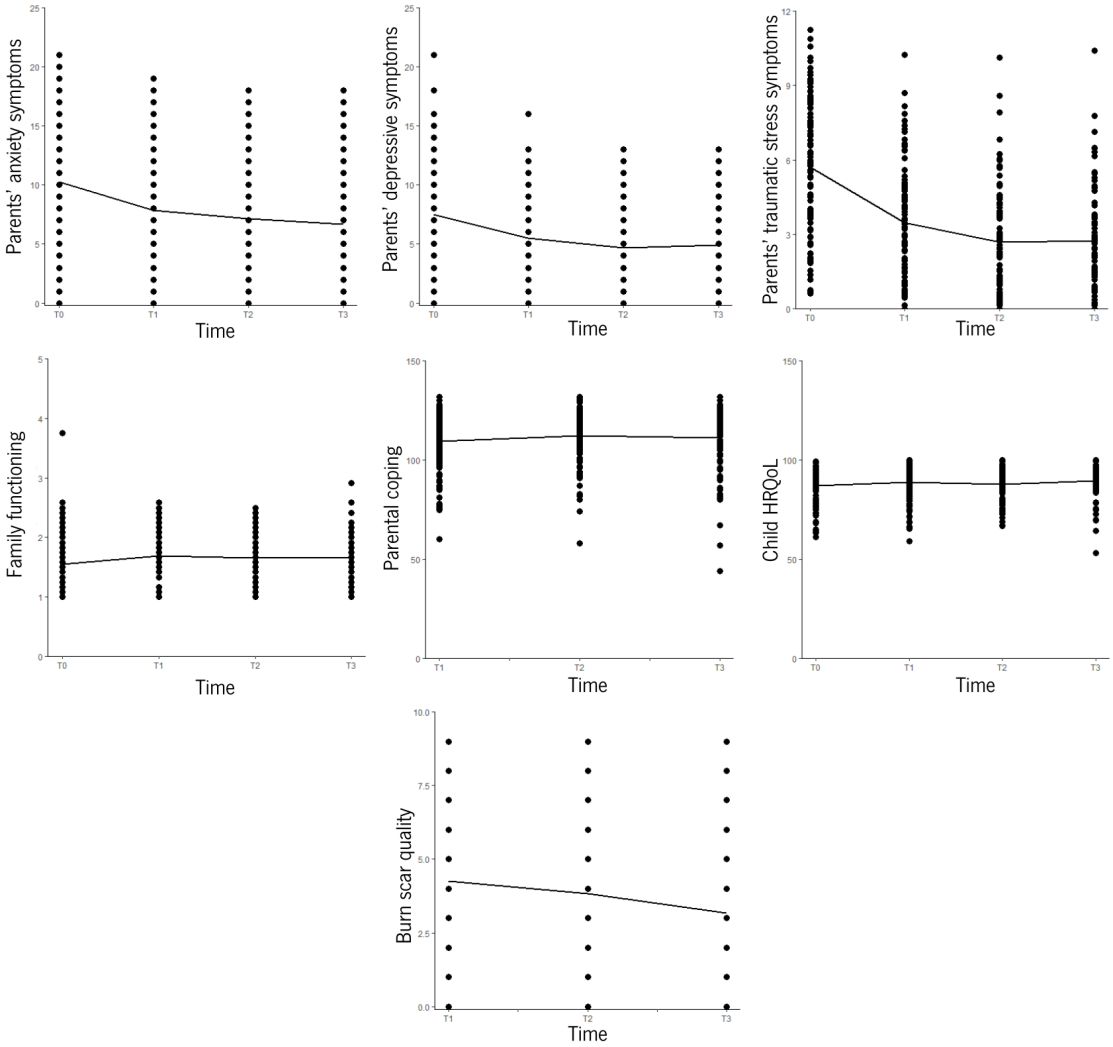
Visual representation of the study design and sample



Note. HADS = Hospital Anxiety and Depression Scale; IES-R = Impact of Event Scale-Revised; FAD-GF = Family Assessment Device – General Functioning; CHIP = Coping Health Inventory for Parents; TAPQoL = TNO-AZL Preschool Children Quality of Life Questionnaire; VSS = Vancouver Scar Scale.

Figure 3.2

Graphical representation of changes over time



CONCLUSÃO

De uma forma integrada, o presente trabalho procurou compreender o impacto das lesões por queimaduras na pele em idade pediátrica no funcionamento psicossocial e familiar, e nos resultados de saúde das crianças até seis meses após a alta hospitalar, com especial enfâse na idade pré-escolar (dos zero aos seis anos), atendendo à elevada incidência de lesões por queimaduras não intencionais nesta faixa etária, mundialmente (Emond et al., 2016; Kemp et al., 2014; WHO, 2023), e pelo facto de representarem 20% do total de casos em Portugal (Santos et al., 2019). A adoção de uma lente biopsicossocial sustentada empiricamente (inclusão de variáveis sociodemográficas e clínicas dos pais e das crianças, variáveis psicossociais dos pais e familiares, e de variáveis relacionadas com a saúde da criança), bem como de uma dimensão qualitativa e quantitativa longitudinal, foram imperiosas para uma leitura mais integrativa e elucidativa das implicações multifatoriais, dinâmicas e relacionais (entre pais e filhos) decorrentes deste evento potencialmente traumático ao longo de várias fases clinicamente relevantes (i.e., durante o internamento hospitalar, um mês, três e seis meses após a alta hospitalar).

Mais concretamente, a revisão sistemática da literatura descrita no capítulo 1, que teve como foco a análise de fatores e/ou preditores de *distress* parental na sequência de lesões por queimaduras não intencionais em idade pediátrica, bem como das suas consequências (para os próprios e para as crianças), permitiu identificar cinco categorias *major* de fatores/preditores e duas categorias ao nível das consequências do *distress* parental. Por um lado, constatou-se que variáveis sociodemográficas, em particular a idade da criança (idade mais precoce aquando do evento), variáveis psicológicas e psicossociais dos pais (e.g., estratégias de *coping* parental menos adaptativas, reduzido suporte social) e das crianças (e.g., sintomas de stress traumático, menor resiliência), variáveis familiares (e.g., funcionamento familiar mais pobre), e variáveis relacionadas com a queimadura (e.g., maior gravidade e profundidade da queimadura, maior número de procedimentos médicos invasivos), podem ajudar a explicar ou contribuir, separadas ou conjuntamente, para os sintomas de *distress* dos pais. Por outro lado, verificou-se que o *distress* dos pais pode despoletar consequências psicológicas para os próprios como a persistência e/ou desenvolvimento de sintomas de *distress* a longo-prazo (e.g., 18 meses após a queimadura), sendo os níveis de *distress* iniciais um forte preditor de *distress* posterior, e para as crianças (e.g., sintomas de stress traumático); bem como para uma menor perceção da qualidade dos cuidados prestados e para os resultados de saúde e funcionais da criança, nomeadamente dor pré e durante os tratamentos, atraso no processo de reepitelização da ferida, prurido, problemas de sono e comportamentais, e menor qualidade de vida percebida. Verificou-se ainda que as mães parecem ser um grupo particularmente vulnerável quando comparadas aos pais, dado reportarem mais sintomas iniciais de culpa e de ira/raiva, e mais sintomas de stress traumático e de depressão, sobretudo nos três

primeiros meses após a lesão por queimadura dos seus filhos. Além disso, parece observar-se uma tendência decrescente dos sintomas de *distress* dos pais ao longo do tempo, em particular no período de seis meses após a lesão. De um modo geral, concluiu-se que os pais apresentam uma marcada vulnerabilidade emocional e psicossocial, embora desempenhem um papel protagonista na adaptação psicossocial e recuperação da criança. As primeiras semanas após a lesão, o que inclui o internamento hospitalar e os procedimentos médicos (mais invasivos) relacionados, destacam-se como um período crítico para o desenvolvimento significativo de *distress* psicológico nos pais, o que, por sua vez, afeta os resultados das crianças durante esse período e nas fases posteriores dos cuidados, tornando-se emergente a necessidade de monitorizá-los e incluí-los precocemente no plano de cuidados da criança, como preconizado por evidências recentes (e.g., Hsu, 2023; Patterson et al., 2023). Contudo, para uma efetiva concretização desse objetivo, implica conhecer, mais aprofundadamente, as perspetivas destes pais durante fases críticas da trajetória da condição clínica (e.g., internamento), de modo a identificar idiossincrasias e necessidades específicas para orientar o foco da avaliação e intervenção. As abordagens qualitativas são, por definição, as mais adequadas para responder a essas questões, sobretudo quando o conhecimento relativo a um determinado fenómeno é reduzido (Neergaard et al., 2009) e procura-se fornecer uma base empírica para informar futuras práticas e planos estratégicos (e.g., Sandelowski, 2000).

Com efeito, informados pelo conhecimento adquirido a partir do capítulo 1 e considerando a escassez de estudos qualitativos que refletissem as perceções e experiências destes pais durante um dos momentos mais críticos da fase de tratamento, o internamento hospitalar (e.g., Brown et al., 2020; Karahan et al., 2023; Lernevall et al., 2021; McGarry et al., 2015; Rimmer et al., 2015), o estudo qualitativo apresentado no capítulo 2 realçou a necessidade premente da adoção de uma abordagem integrada nos cuidados de saúde. Durante esse período, os pais de crianças vítimas de lesões por queimaduras na pele em idade pré-escolar, revelaram estar significativamente sobrecarregados e com *distress*. A necessidade de internamento obrigou-os a confrontarem-se com a gravidade do cenário e desencadeou um conjunto de *stressores* adicionais, inesperados e desafiantes, que comprometeram o seu ajustamento emocional e psicossocial. Apesar de considerarem que as crianças estavam a receber cuidados de qualidade e estarem globalmente satisfeitos com as respostas providenciadas pelo hospital, para a maioria destes pais, o mesmo não aconteceu em relação a eles, sentindo-se negligenciados e reduzidos ao papel de "acompanhantes da criança". Entre as diferentes necessidades não atendidas partilhadas pelos pais, a falta de suporte profissional foi a mais relatada, que se refletiu em dificuldades acrescidas na satisfação das necessidades exigidas por uma criança internada e em diminutas

oportunidades para o autocuidado. Por sua vez, os tratamentos, em particular as mudanças dos pensos cirúrgicos, foram considerados traumáticos, provocando reações adversas, tanto nas crianças como nos pais, que os classificaram como a "parte mais negativa" de todo o processo. Em contrapartida, a COVID-19 pareceu ter pouca relevância neste contexto, sobretudo nas fases mais tardias, quando as medidas se tornaram menos restritivas ou foram levantadas. Nas fases iniciais, as restrições sociais potenciadas pela situação pandémica interligavam-se com a falta de suporte familiar reportado, sendo identificadas como um dos maiores obstáculos dessa fase. De facto, as restrições das visitas foram um dos aspetos que estes pais sugeriram que fosse revisto, dada a importância de se sentirem apoiados neste processo e para promover um ambiente menos ameaçador e, por conseguinte, mais familiar, para a criança. Além disso, observar a recuperação da criança, de uma forma objetiva (e.g., a criança voltar a abrir os olhos depois de uma lesão por queimadura facial), foi descrito como a "parte mais positiva" da experiência, constatando-se que à medida que a criança recupera, os pais também melhoram o seu funcionamento psicossocial, possivelmente por ser um indicador de que a criança está mais próxima de ter alta e não corre risco de vida. Todavia, o futuro não deixa de ser incerto para estes pais e as preocupações relacionadas com possíveis sequelas psicológicas e/ou físicas decursivas das lesões, como potenciais cicatrizes permanentes e/ou visíveis, permaneceram como as mais perturbadoras. Nestes casos, o acompanhamento psicológico podia ter um papel diferencial, embora alguns pais tivessem referido que nunca lhes tivesse sido questionado sobre as suas emoções, desconhecendo a existência de respostas (apoio psicológico) nesse sentido. Este aspeto, alinhado com as demais sugestões elencadas pelos mesmos (e.g., aumentar os seus níveis de conforto), devem ser sinalizados aquando do desenho de futuras intervenções devidamente orientadas, tendo em vista a promoção de uma melhor adaptação emocional e psicossocial dos pais, conhecidas as evidências entre o ajustamento dos pais e o dos filhos, como sugerido pelos resultados do capítulo anterior. Além disso, as mensagens que estes pais deixam a outros pais que possam vivenciar esta situação no futuro, podem indicar importantes alvos da intervenção que não foram diretamente reportados, nomeadamente a validação dos seus sentimentos e a promoção de recursos e estratégias de *coping* ativo (e.g., resolução de problemas, estratégias de regulação e expressão emocionais), incluindo o suporte profissional, informacional e social/familiar. Não obstante, a melhoria da comunicação entre os profissionais de saúde e estes pais é fundamental no decurso desta experiência e pode facilitar a identificação precoce de potenciais dificuldades nas fases de cuidados posteriores (pós-alta), a fim de promover estratégias para uma manutenção efetiva dos cuidados futuramente prestados em casa pelos próprios. À semelhança do capítulo anterior, concluiu-se que a inclusão destes pais no plano de cuidados da criança nesta fase seria crucial e a orientação da

intervenção para os mesmos (e.g., práticas centradas na família), podem contribuir para uma experiência mais adaptativa e para a melhoria dos resultados das crianças. Uma abordagem integrada nos cuidados de saúde, com uma equipa multidisciplinar que inclua, entre outros, psicólogos clínicos e da saúde, poderá ser a chave para mitigar as dificuldades emocionais e psicossociais experienciadas, sendo a fase do internamento hospitalar uma oportunidade para começar e dirigir as futuras intervenções.

Acumulando o conhecimento do capítulo 1, que revelou que poucos estudos analisaram a influência dos sintomas dos pais nos resultados de saúde das crianças, com o conhecimento do capítulo 2, que demonstrou que o internamento hospitalar é um potencial *stressor* secundário ao evento principal que conduz a *distress* adicional e a um conjunto de preocupações exacerbadas com um futuro incerto, como o medo do desenvolvimento de cicatrizes permanentes e visíveis, o estudo quantitativo longitudinal apresentado no capítulo 3, visou analisar ao longo de quatro momentos temporais diferentes (i.e., internamento hospitalar [T0], um mês [T1], três [T2] e seis meses [T3] após a alta) fatores psicossociais dos pais e familiares, e a qualidade da cicatriz e QVRS das crianças, bem como o papel mediador do funcionamento familiar na relação entre os sintomas de *distress* parental e a qualidade da cicatriz. Foi possível observar que existiram mudanças significativas em todas as variáveis e confirmar os resultados qualitativos em relação aos níveis elevados de *distress* (sintomas de ansiedade, depressão e stress traumático) no T0. De um modo geral, os sintomas de *distress* decresceram ao longo do tempo (confirmando uma das conclusões do estudo de revisão sistemática), o *coping* parental aumentou significativamente de T1 para T2, e o funcionamento familiar decresceu significativamente quando comparado ao T0, mantendo-se estável posteriormente. Este último resultado, consistente com estudos anteriores (e.g., Ryan et al., 2015; Sveen et al., 2014), sublinha a necessidade de considerarmos variáveis familiares neste processo, podendo ser explicado pelas dificuldades que as famílias enfrentam no pós-alta relativas às exigências promovidas pela manutenção dos cuidados com a criança em ambiente doméstico/familiar que implicam uma readaptação das suas dinâmicas (Öster et al., 2014). A par disso, verificou-se que a qualidade da cicatriz aumentou significativamente a partir do T1, em todos os momentos, e a QVRS melhorou ao longo do tempo, embora não se tenha observado uma mudança significativa em todos os momentos. Globalmente, os resultados permitem concluir que parece existir uma melhoria e, subsequente, estabilidade, ao nível do *coping* parental e da QVRS. As mudanças mais acentuadas verificaram-se para a qualidade da cicatriz e para os sintomas de *distress*. Com efeito, concluiu-se que, de facto, o T0 é uma fase particularmente desafiante, pelo que constitui o melhor momento para iniciar a intervenção. Além disso, verificou-se um efeito de mediação total do funcionamento familiar na relação entre os sintomas de *distress* e a qualidade da cicatriz na criança, o

que reforça a importância da família no pós-alta e enfatiza a necessidade da adoção de um modelo baseado na promoção de competências familiares.

Limitações e Investigações Futuras

Os estudos espelhados nos diferentes capítulos apresentam limitações que podem comprometer a interpretação dos resultados, abrindo, no entanto, portas para investigações futuras. No estudo de revisão sistemática da literatura do capítulo 1, apenas nove dos estudos incluídos obtiveram a pontuação máxima da escala qualitativa da medida de avaliação metodológica utilizada. A maioria dos estudos incluídos (63.16%) tinham um *design* transversal, impossibilitando inferências causais e a clara determinação de papéis preditivos. Verificou-se ainda uma grande heterogeneidade das caraterísticas das amostras entre estudos (e.g., estudos exclusivamente focados nas mães) e nos instrumentos utilizados para medir o *distress* parental, bem como a escassez de medidas validadas e específicas para a avaliação dos sentimentos de culpa (um dos construtos operacionalizados como potencial sintoma de *distress*), o que dificulta a comparação entre resultados e a condução de uma meta-análise. Além disso, o limite da janela temporal da revisão foi até 18 de novembro de 2021, e sendo que este tópico tem vindo a despertar o interesse da comunidade científica nos últimos anos, existem estudos posteriores que não foram incluídos na análise formal, embora tenham sido utilizados para discutir os resultados encontrados. Assim, estudos futuros deverão focar-se na validação de medidas apropriadas para a avaliação dos sentimentos de culpa dos pais, alargar o tamanho da amostra e adotar um *design* longitudinal. É ainda recomendada uma revisão sistemática no tema focada exclusivamente em estudos qualitativos, para colmatar potenciais aspetos que as medidas de autorrelato utilizadas nos estudos quantitativos não conseguem captar (e.g., perceções subjetivas).

No estudo relativo ao capítulo 2, devido à sua natureza qualitativa, seria importante incluir um número mais equilibrado de mães e pais, de modo a não limitar a generalização dos resultados. As perspetivas dos profissionais de saúde podem também acrescentar valor aos resultados encontrados, sendo pertinente o cruzamento das diferentes informações para informar de um modo mais compreensivo as futuras práticas neste contexto. A realização de uma entrevista semiestruturada em alternativa ao caderno de registos pode ser importante, dado que algumas das respostas foram muito diretas e pouco claras. Estudos multicêntricos são igualmente recomendados, visto que neste estudo apenas um hospital foi considerado. Esta limitação, bem como o facto de não se ter considerado variáveis socioeconómicas e étnico-raciais (potenciais variáveis de controlo) cruzam-se com algumas das limitações do estudo inerente ao último capítulo. Aliás, existem relações documentadas entre o estatuto socioeconómico e sintomas depressivos nas mães (El Hamaoui et al., 2006), bem como em relação à

etnia (minoritária) e sintomas de *distress* nos pais (e.g., Parrish et al., 2019; Stewart et al., 2019; Suurmond et al., 2020). A nível metodológico, o estudo relativo ao capítulo 3, apresenta uma amostra reduzida (100 participantes no T0) e uma perda de 23% para o último momento da avaliação (T3). Por fim, recorre-se exclusivamente à perceção dos pais para avaliar a QVRS da criança, embora estudos que comparem as respostas entre pais e filhos nesta população, tenham encontrado correspondências similares entre ambos (Pan et al., 2015). Estudos futuros com *design* longitudinal devem incluir amostras maiores e mais momentos temporais (e.g., 12 meses, 18 meses), de modo a acrescentar uma perspetiva a longo-prazo dos resultados, controlando variáveis socioeconómicas e étnico-raciais.

Implicações Teóricas e para a Investigação

O Modelo Integrativo de Stress Traumático Pediátrico (*The Integrative [Trajectory] Model of Pediatric Medical Traumatic Stress;* Kazak et al., 2006; Price et al., 2016) forneceu um racional teórico crucial para a compreensão, enquadramento empírico, e formulação de hipóteses de trabalho/questões de investigação, preponderantemente para os estudos dos capítulos 1 e 2, revelando ter um importante valor heurístico e aplicação em múltiplas condições médicas em idade pediátrica com potencial traumático (e.g., lesões físicas, doenças oncológicas), alinhando-se com as especificidades das diferentes fases agudas dos cuidados. A consideração de uma dimensão familiar ao longo da trajetória da condição clínica, possibilita esclarecer as relações ao nível do funcionamento psicossocial dos pais e das crianças, bem como enfatiza a sua preponderância para a recuperação e adaptação funcional aos tratamentos das mesmas. Compreender a natureza destes eventos de saúde em idades precoces, partindo de uma perspetiva familiar torna-se, de facto, imperativo para o delineamento de intervenções dirigidas e devidamente responsivas a necessidades individuais e familiares (Price et al., 2016). Nesta sequência, a avaliação precoce constitui uma das primeiras etapas para que este processo se traduza em resultados efetivos, o que implica conhecer, teoricamente, quais os instrumentos que se encontram disponíveis, validados e são apropriados para esse efeito. No estudo do capítulo 1, observou-se que existe uma multiplicidade de instrumentos de avaliação dos sintomas psicológicos dos pais sugestivos de *distress*, sendo que as medidas mais comumente utilizadas são fidedignas e podem ser incorporadas em futuros protocolos de avaliação, de forma a contribuir para o rastreio e monitorização de sintomas potencialmente desadaptativos, visando uma minimização do risco de desenvolvimento de quadros psicopatológicos (e.g., perturbação de stress pós-traumático) ou de sintomatologia severa em fases posteriores, orientando o foco da intervenção. Assim, investigações futuras que tenham como objetivo compreender o funcionamento psicossocial nesta díade (família/pais-criança) e explorar a bidirecionalidade entre os sintomas dos pais e o dos filhos, podem ter como base conceptual o Modelo

Integrativo de Stress Traumático Pediátrico *(The Integrative [Trajectory] Model of Pediatric Medical Traumatic Stress;* Kazak et al., 2006; Price et al., 2016). Recomenda-se ainda que estudos futuros com *design* longitudinal avaliem o papel da variável incerteza, visto que nenhum dos estudos incluídos na revisão sistemática considerou este indicador de *distress,* tendo em consideração que as perceções em relação ao futuro (e.g., sequelas físicas) são classificadas como ameaçadoras (e.g., McGarry et al., 2015). Além disso, mais estudos longitudinais são necessários para determinar relações causais entre variáveis psicossociais individuais/familiares e a qualidade de vida da criança, dada a escassez de estudos focados neste tema. A necessidade de transição para uma orientação mais centrada em fatores protetores (e não só de risco) também pode ter especial utilidade para a intervenção nestes contextos, na medida em que permitirá maximizar esses recursos e promover estratégias de *coping* ativo transferíveis ao longo da trajetória das lesões por queimaduras. Assim, estudos futuros deverão explorar o papel de variáveis no âmbito da Psicologia Positiva em contextos de saúde, como a gratidão e a espiritualidade, entre outras. Através dos resultados obtidos no estudo qualitativo referido no capítulo 2, futuras investigações de natureza descritiva também podem ser relevantes, por exemplo, para avaliar mais aprofundadamente, na perspetiva dos pais, os fatores que estão subjacentes e contribuem para a presença/desenvolvimento das suas perceções de que estão a ser negligenciados durante o período de internamento hospitalar, e para elucidar sobre o caráter traumático de determinados tratamentos (e.g., mudança dos pensos cirúrgicos), sobretudo no regresso a casa e procedimentos médicos subsequentes. Esses dados seriam importantes no desenho de intervenções futuras, no sentido de responder às necessidades desta população, quer ao nível da saúde mental, quer da promoção do seu bem-estar, físico e psicológico (e.g., autocuidado).

Por sua vez, o Modelo Conceptual de QVRS (*Conceptual Model of Burn Scar Health-Related Quality of Life;* Simons et al., 2016), que esteve na base da fundamentação teórica para as análises do estudo quantitativo longitudinal do capítulo 3, demonstrou ser apropriado para testar os efeitos diretos e indiretos entre os fatores distais de funcionamento (e.g., funcionamento social/familiar, funcionamento emocional) ao longo do tempo, pelo que estudos futuros deverão examinar os efeitos diretos e indiretos de outros domínios do funcionamento (e.g., funcionamento cognitivo) e de determinadas características do ambiente (onde os autores originais consideram que se insere o *coping* parental) na relação entre o funcionamento emocional dos pais e resultados da cicatriz da criança. A par disso, devem também testar o papel da QVRS como variável resultado. Neste capítulo, outras implicações para a investigação, de acordo com os resultados obtidos, referem-se à necessidade de estudos longitudinais futuros utilizarem instrumentos de avaliação do *coping* parental mais apropriados e que possam ser implementados ainda

durante o internamento hospitalar, de modo a explanar o seu papel e quais os mecanismos de *coping* que mais contribuem para um melhor ajustamento psicossocial, bem como analisar a importância de variáveis associadas ao crescimento pós-traumático.

Implicações para a Prática

No seu conjunto, os estudos apresentados ao longo dos capítulos 1, 2 e 3, ressaltam a importância da avaliação psicossocial precoce (e consequente monitorização) destes pais e das intervenções centradas na família, não só para diretamente diminuir o risco do desenvolvimento e/ou persistência de sintomas de *distress* significativos ao longo do tempo, mas também, para, indiretamente, contribuir para uma melhor recuperação e ajustamento da criança, dada a sua fase do desenvolvimento e dependência subjacente. A inclusão destes pais desde a admissão hospitalar no plano terapêutico da criança pode assumir um papel diferencial e possibilitar a transição de um paradigma remediativo, para um paradigma preventivo e integrado.

Mais concretamente, no capítulo 1 destaca-se a importância da inclusão de uma equipa multidisciplinar (e.g., psicólogos clínicos e da saúde), o desenvolvimento e aplicação de um protocolo de avaliação *standard*, e a adotação de um modelo de cuidados informados pelo trauma, de modo a cobrir todas as necessidades em termos de saúde mental destes pais, preparando-os para a fase do pós-alta. O mapeamento dos diferentes fatores/preditores e consequências do *distress* parental tendo por base o Modelo Integrativo de Stress Traumático Pediátrico (*The Integrative [Trajectory] Model of Pediatric Medical Traumatic Stress;* Kazak et al., 2006; Price et al., 2016), incluindo a fase pré-trauma, pode ser útil para identificar em cada uma das diferentes fases, quais os focos da intervenção e as variáveis potencialmente explicativas (e.g., fatores de risco) das dificuldades experienciadas em termos de *distress.* No estudo do capítulo 2, fornece-se um mapa gráfico que permite situar, baseado nas perspetivas dos próprios pais, diferentes circunstâncias experienciadas que podem conduzir a uma maior perceção de dificuldades emocionais e psicossociais. Recomenda-se que as intervenções se foquem na promoção de recursos psicológicos (e.g., treino de autorregulação, estratégias de *coping* ativo) e na implementação de um protocolo de rotina para avaliar o ajustamento destes pais. Além disso, os profissionais de saúde devem ter conhecimento das ameaças ao ajustamento parental e melhorar a comunicação, de modo a debater, negociar e fornecer recursos específicos para as fases posteriores de cuidados. A adoção de um modelo centrado na família e no empoderamento das suas competências, como sugerido por Mohammadzadeh et al. (2023), pode ser fundamental para a adequada manutenção dos progressos da criança.

Por último, decorrente do conhecimento do estudo apresentado no capítulo 3, é importante dotar os profissionais de saúde que trabalham junto desta população, sobre o papel de variáveis de ajustamento psicossocial dos pais e familiares, sobretudo aquando do delineamento do plano de tratamento das cicatrizes. Dado o papel mediador do funcionamento familiar, intervenções focadas na promoção de competências familiares (abarcando os desafios às dinâmicas familiares pré-existentes e exigências subjacentes à manutenção dos cuidados em ambiente familiar) são fortemente recomendadas para melhorar a qualidade da cicatriz das crianças, devendo ser enquadradas num plano de cuidados integrado a começar desde o internamento hospitalar, que demonstrou ser o melhor momento para (começar a) intervir. O tempo que os pais passam no internamento pode ser rentabilizado nesse sentido, escudando-os de competências-chave como o treino de regulação emocional e de resolução de problemas. De um modo geral, estas conclusões (re)afirmam a importância que os profissionais de saúde mental podem ter neste contexto, corroborando com a literatura internacional no tema (Cartwright & Pounds-Cornish, 2023; Potter et al., 2023). De facto, uma revisão sistemática recente focada nas intervenções psicossociais aplicadas ao contexto das lesões por queimaduras em idade pediátrica, destacou que, devido ao acentuado risco de potenciais sequelas psicossociais nesta população e respetivas famílias, intervenções implementadas precocemente a este nível têm um impacto positivo na recuperação geral das crianças, designadamente na redução da dor e dos sintomas de ansiedade na fase aguda dos cuidados, por exemplo, antes ou durante determinados tratamentos (e.g., mudança de pensos, fisioterapia), por meio de diferentes técnicas relacionadas como as técnicas de distração com ou sem recurso à realidade virtual (Hornsby et al., 2020). Verificou-se ainda que a terapia cognitivo-comportamental e o aconselhamento psicológico parental apresentaram resultados promissores, embora os autores sublinhem a necessidade de mais investigação para determinar de forma robusta a eficácia destas intervenções em faixas etárias específicas (Hornsby et al., 2020). Um dos ingredientes para que estas intervenções sejam bem-sucedidas consiste no treino dos profissionais que as implementam (Cartwright & Pounds-Cornish, 2023).

Implicações para o Treino dos Profissionais

De acordo com recomendações internacionais (e.g., British Burn Association, 2018), a adoção de uma abordagem integrada nos cuidados de saúde, composta por equipas multidisciplinares (e.g., cirurgiões pediátricos, psicólogos clínicos e da saúde, enfermeiros especialistas), é fundamental, porém implica que toda a equipa envolvida receba formação em diferentes domínios, devidamente adaptada às suas funções e competências técnicas, nomeadamente na área da psicologia (e.g., cuidados psicológicos básicos), tendo em vista um célere reconhecimento de potenciais indicadores de respostas

desadaptativas e de *distress* por qualquer um dos profissionais destas equipas, de modo a permitir um encaminhamento eficaz para um outro nível de cuidados complementares (neste caso e se necessário, a nível da prestação de suporte/apoio psicológico). Esta estrutura de cuidados, por níveis, adequados às distintas necessidades apresentadas pelos pacientes e pelas suas famílias, que passam a ser vistos de uma forma holística, requer uma prática reflexiva com frequência regular, que deverá ser dinamizada pelos membros da equipa dedicados a este nível específico de cuidados (i.e., cuidados psicossociais; Cartwright & Pounds-Cornish, 2023). Deste modo, dotar os profissionais destas equipas de recursos e competências técnicas e transversais, é um dos primeiros passos para a efetiva implementação desta abordagem integrada, que privilegia práticas baseadas na evidência. Segundo Wisely et al. (2007), neste domínio de cuidados centrados no funcionamento psicossocial, existem três subníveis que as equipas deverão ter em consideração para uma adequada intervenção, designadamente: (1) competências gerais de apoio e de escuta ativa; (2) competências de normalização dos sintomas, comunicação relacionada com a ansiedade e estratégias de controlo/gestão da dor; e (3) capacidade de avaliação do risco, formulação e trabalho colaborativo com as equipas. Os psicólogos clínicos e da saúde podem ter um papel determinante neste nível e facultar importantes contributos na prestação dos cuidados de saúde integrados a familiares e pacientes que sofreram lesões por queimaduras, nomeadamente por estarem aptos para realizar avaliações de caráter psicossocial (rastreio e monitorização; intervenção mais indireta) e por dominarem um conjunto de técnicas que pode ajudar estas populações a lidarem com as dificuldades emocionais e psicossociais encontradas (intervenção mais direta) através da psicoeducação e da intervenção psicológica (e.g., Cartwright & Pounds-Cornish, 2023; Wisely et al., 2007). Investigações recentes têm demonstrado que a integração de psicólogos clínicos e da saúde nas unidades de tratamento especializado para as lesões por queimaduras é valiosa, dadas as necessidades a este nível reportadas pelos pacientes e pelas suas famílias (Potter et al., 2023). Num contexto pediátrico, a relevância ainda é mais imperativa, pela dependência subjacente à fase de desenvolvimento em que as crianças se encontram. Nesta sequência, as equipas multidisciplinares inseridas neste modelo de cuidados, devem reunir regularmente e partilhar *insights* sobre um conjunto de necessidades complexas (e.g., físicas, emocionais, sociais) que pacientes pediátricos e as suas famílias apresentam, e que só poderão ser satisfeitas, num todo, se forem abarcadas por uma perspetiva biopsicossocial e integrada. A educação interprofissional para a prática colaborativa nestes contextos é fortemente recomendada para a promoção e manutenção de práticas de qualidade em saúde.

Impacto Societal

Os estudos inerentes aos capítulos 2 e 3, apresentam estudos pioneiros em Portugal, conduzidos na recente e primeira unidade pediátrica de queimados da região Norte, onde existe uma acentuada prevalência do fenómeno em idade pré-escolar (Santos et al., 2019). Os resultados encontrados podem constituir uma oportunidade para reforçar as práticas/informar os cuidados de saúde e podem ser empiricamente utilizados para o desenvolvimento de futuros programas de intervenção que tenham como foco os cuidadores primários destas crianças como via para a melhoria dos resultados de saúde das mesmas ao longo do tempo. Além disso, os objetivos destes estudos estão alinhados com o objetivo 3 da Agenda 2030 das Nações Unidas para o Desenvolvimento Sustentável, em particular a meta 3.2, na medida em que informa e visa contribuir para a redução das taxas de mortalidade de crianças em idades precoces do desenvolvimento (menores de cinco anos), promovendo uma adaptação funcional ao tratamento e contribuindo para a melhoria da qualidade de vida desta população, o que, por sua vez, permitirá uma melhor recuperação e integração no pós-alta ao nível das múltiplas esferas de vida da criança (e.g., social, familiar, escolar). O presente trabalho pode ainda desempenhar um papel diferencial para sensibilizar para a prevenção das lesões por queimaduras na pele nesta faixa etária, uma vez que carateriza a amostra de uma forma global, incluindo características específicas da lesão (e.g., mecanismo de queimadura, profundidade, local onde ocorreu o acidente) e características sociodemográficas dos pais (e.g., idade, educação), fornecendo uma base empírica que encoraja o delineamento e necessidade de implementação de planos estratégicos ativos a nível comunitário focados na prevenção, como por exemplo, a educação para a identificação e minimização de potenciais riscos domésticos. A criação de condições facilitadoras para a transição de um paradigma remediativo para preventivo através da operacionalização desses planos, poderá ser crucial para a redução dos custos públicos associados, que no caso de Portugal, estão acima da média europeia, conforme mencionado anteriormente.

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