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Parental Distress in Childhood Acute Lymphoblastic Leukemia: A Systematic Review of the Literature

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The present study is a systematic review of factors and consequences of parental distress following their children's acute lymphoblastic leukemia (ALL) diagnosis. PubMed, Web of Science, and APA PsycInfo databases were searched. Twenty-eight papers were included, with only three longitudinal studies. Fifteen studies explored factors of parental distress, including sociodemographic, psychosocial, psychological, family, health, and ALL-specific variables. Correlations were found between social support, illness cognitions, coping strategies, and parental distress, as well as contradictory results regarding sociodemographic variables. Family cohesion and the overall impact of illness were associated with parental distress. Resilience factors contributed negatively to parental distress symptoms, and perceived caregiver strain and negative child's emotional functioning contributed positively. Thirteen papers explored the consequences of parental distress, including psychological, family, health, and social/education factors. Distress was correlated with care burden and contributed to family strain, child's symptom burden, and parental protective behavior. Significant correlations were found between parental distress, at diagnosis, and further adjustment of parents and children. Most papers reported correlations between parental distress and psychological condition and quality of life; few studies reported no association. Correlations between maternal depression and child's participation in education and social life were found. Differences on distress were found regarding parents' gender, age, children's group risk, and treatment phases. Longitudinal studies are needed to better understand the phenomenon and its consequences. Future interventions should address parents' mental health needs in an early and ongoing assessment in order to promote healthier outcomes.

Keywords: parental distress, childhood acute lymphoblastic leukemia, psychological adjustment, quality of life, family

Supplemental materials: https://doi.org/10.1037/fam0001113.supp

Acute lymphoblastic leukemia (ALL) is the most common form of childhood malignancy and accounts for 75% of all leukemia cases in children and teens, with a peak in the incidence for children 2–5 years old (American Cancer Society, 2023a).

Although the overall survival rates for pediatric ALL exceed 90% (American Cancer Society, 2023b), pediatric cancer has been described as a life-changing experience for parents (Sultan et al., 2016). The diagnosis of a life-threatening illness, the intense and lengthy treatment, and the disruption of family relationships and routines may impact parental psychological well-being and quality of life (QoL) (Long & Marsland, 2011). Parents have reported feeling emotionally and physically drained (van Warmerdam et al., 2019) and are at risk for psychological distress (Bakula et al., 2019). Indeed, the stress faced by parents can be extensive and seem to lead to considerable distress during the first year of diagnosis and treatment (Schepers et al., 2018). The prevalence of distress is higher in these parents when compared to noncancer controls, and higher in mothers when compared with fathers (Pai et al., 2007). However, although some studies have found persistent clinically elevated levels of distress in a subset of parents (e.g., Pai et al., 2007), other studies have shown decreased distress over time (e.g., Wakefield et al., 2011).

As a result of increased attention to the impact of cancer on patients and families, distress was recognized as the sixth vital sign in 2004 (Bultz & Carlson, 2005) defined as a multifactorial unpleasant experience of a psychological, physical, social, and/or spiritual nature that can affect the ability to cope with the experience of having cancer, its treatment, and symptoms, impacting one's thinking, feeling, and acting (National Comprehensive Cancer Network, 2020). Therefore, parental distress may refer to the degree

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Preliminary results of this review were presented at CHPC 2022: XVI. International Conference on Health Psychology and Cancer. A summary table of included articles, the quality assessment scores of the included studies, and the search strategy are available in the supplemental material.

The study's protocol was registered on Prospero on December 27, 2021, number CRD42021289485; see https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021289485.

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parents are affected intrapersonally (Duchovic et al., 2009), through a wide range of symptoms/feelings such as vulnerability, sadness, fear (NCCN, 2020), worry, guilt (Duchovic et al., 2009), uncertainty, anxiety, depression, traumatic stress, and psychological health (Sultan et al., 2016). As a result, parental distress can be measured across a wide range of domains such as anxiety, depression, traumatic stress, general distress, and mental QoL subscales (Sultan et al., 2016).

According to the literature, parental distress is an important factor to evaluate in the context of childhood cancer, having implications for parents themselves and their children. This phenomenon may compromise the parents' ability to cope with stressors affecting their health (Sultan et al., 2016) and is significantly correlated with children's distress and psychological health (Bakula et al., 2019), with high levels of parental distress being associated with low QOL, in children (Bakula et al., 2020).

To our knowledge, five systematic reviews on parental distress in the context of childhood cancer have been published (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016), with two studies focused on psychological late effects (Ljungman et al., 2014; Wakefield et al., 2011). Numerous risk factors of parental distress have been reported. Sociodemographic factors such as low socioeconomic status, unemployment, and being a mother have been associated with parental distress (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011). Furthermore, parent's psychological factors, like previous conditions and internal resources (e.g., anxiety, depression, coping, resilience), as well as family factors (e.g., family conflict, family functioning) also seem to influence parental distress (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011). In addition, factors related to the illness such as time since diagnosis, treatment phases, and the number of hospitalizations were identified as contributing to parental distress (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Ljungman et al., 2014; Sultan et al., 2016; Wakefield et al., 2011). Also, children-related factors such as behavior problems were associated with parental distress (Klassen et al., 2007), as well as important stressful family events (e.g., divorce) prior to the diagnosis (Sultan et al., 2016). To date, only one systematic review has explored the consequences of parental distress and focused on psychological adjustment in parents and children (Sultan et al., 2016).

Nevertheless, despite the researchers' efforts in describing the nature of parental distress in childhood cancer, prior reviews had some restrictions, either because of the heterogeneity of the cancer types and treatment variables, the lack of precise analysis of bias (e.g., Klassen et al., 2007) or substantial literature on consequences of parental distress focused on children.

Because ALL is the most common type of childhood cancer (American Cancer Society, 2023a), the treatment lasts for 2–3 years (American Cancer Society, 2023c), and the overall survival rates are greater than 90% (American Cancer Society, 2023b), an assessment of parental distress predictors/factors and consequences related specifically to ALL is needed to understand and reduce morbidities associated with this diagnosis and treatment. In fact, parents are involved in the entire therapeutic process, playing a critical role in the children's adjustment to illness (Benedetto et al., 2022), therefore, they should be one of the targets of intervention. Thus, seeking to lower parents' distress by identifying associated factors and consequences may consequently be an important component to inform future family centered psychosocial interventions to improve care in pediatric ALL. In the first instance, a systematic review of the current evidence is needed to examine the scope and nature of parental distress in childhood ALL.

The present review has two objectives: (a) to synthesize the existing evidence on factors/predictors of distress in parents of children diagnosed with ALL and (b) to synthesize the existing evidence on the consequences of parental distress in parents themselves and children. If available, the authors will include studies with subgroup differences between sociodemographic variables (e.g., gender, age), time since diagnosis/treatment phases, and risk groups in which the children are stratified (e.g., standard, medium, high). Risk groups are based on prognostic factors and are used to plan treatment and its intensity.

Method

Eligibility Criteria

The present systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Eligibility criteria were informed using the PICO guidelines. The study's protocol was registered on Prospero on December 27, 2021, number CRD42021289485; see [https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021289485]. The determination of the sample size, all data exclusions (if any), all manipulations, and all measures are described below.

Studies eligible for inclusion presented the following criteria: (a) studies that include parents of children diagnosed with ALL (≤18 years at diagnosis) undergoing treatment and posttreatment (survivorship); (b) studies that include measures of parental distress in this population (consistent with the definition given in the introduction); and (c) human cross-sectional and longitudinal observational studies. Thus, distress may be assessed by several measures, including questionnaires of general distress/mixed psychological symptoms (e.g., SCL-90, BSI), anxiety (e.g., STAI, HAM-A), depression (e.g., BDI, HAM-D), stress (e.g., PSS, PSI), traumatic stress (e.g., IES-R, PTSS), psychiatric conditions (e.g., PTSD), and mental health/QoL (e.g., GHQ, SF). Exclusion criteria were (a) studies with parents of children with ALL during end-of-life or palliative care since the distress experienced during these situations was presumed to be different from that experienced during treatment and posttreatment; (b) review articles (i.e., systematic reviews and meta-analyses), qualitative studies, case reports, book chapters, commentaries, dissertations, animal studies, and gray literature.

Information Sources and Search Process

PubMed, Web of Science, and PsychINFo databases were searched for papers published since inception to 2021. Only studies in English and Spanish were included. The search strategy included MeSH terms for parents, for distress, for childhood acute lymphoblastic leukemia, and for pediatric context (see supplemental material 1).

Study Selection and Data Collection Process

After removing duplicates through ZOTERO, a reference management software to manage bibliographic data, titles, and abstracts were independently reviewed by two researchers for eligibility. The selected papers for full-text analysis were reviewed by the same two

independent researchers. In situations of disagreement, they were resolved through discussion between the two reviewers. Since no discrepancies remained regarding eligibility between the two reviewers, no discussion was performed with a third reviewer. As recommended by PRISMA, the interrater agreement was calculated. Cohen's kappa coefficient indicated strong agreement ($k = .94$).

Methodological Quality Analysis

The quality of the studies was assessed using National Heart, Lung, and Blood Institute (NHLBI) Quality Assessment Tools for Observational Cohort and Cross-Sectional Studies. The tools are specific to different study designs and tested for possible flaws in the study methods or implementation. The quality tool includes 14 items that were designed to help the author focus on the key concepts for evaluating the internal validity of a study. Each item is rated as yes, no, not applicable, or not reported, with the final quality, rated as poor, fair, or good. This evaluation was performed by the same independent researchers and situations of disagreement were resolved through discussion between the two reviewers.

Results

Main Findings

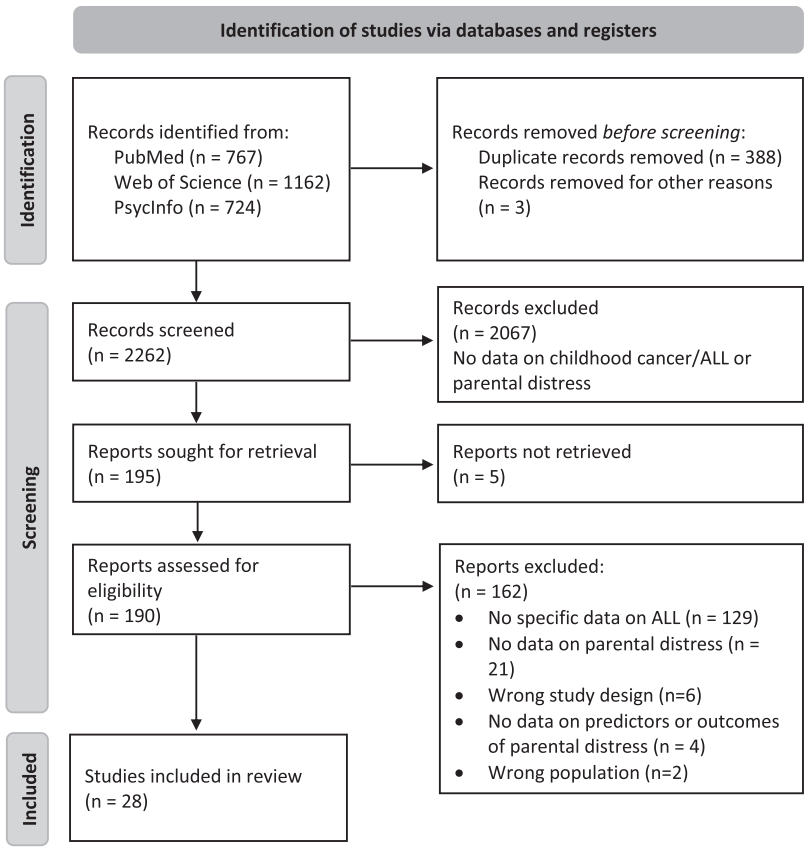
A total of 2,653 articles was identified from the database searches. After exporting the articles to Zotero, duplicates ($n = 388$) and retracted articles ($n = 3$) were eliminated, and 2,262 were evaluated based on title and abstract. The full text of 195 articles was reviewed, of which five were not retrieved and 162 did not meet the inclusion criteria. Twenty-eight articles were eligible for inclusion. The authors also reviewed the reference lists of all eligible articles and no additional articles were identified. A PRISMA flow diagram showing how articles were selected for review is represented in Figure 1.

Characteristics of the Studies

There has been an increased number of studies published on this specific topic with 10 studies published until 2010 and 18 published after 2010. Ten studies were conducted in Europe, nine in America, seven in Asia, and two in Africa. Only three studies were longitudinal (Barrera et al., 2012; Magni et al., 1983, 1988), with the last one published in 2012; the majority (25) were cross-sectional. The sample size across the studies ranged from 25 (Magni et al., 1983) to 213 (Huang et al., 2018) participants, with three studies exclusively with mothers (Bhattacharya et al., 2016; Khazaeli et al., 2021; Matthews et al., 2014). Of the 25 studies that include mothers and fathers, 19 included more mothers, four included the same number of mothers and fathers (Burns et al., 2018; Magni et al., 1986; Sharan et al., 1995, 1999), and two did not report the sample by gender (Rao et al., 1992; Sherief et al., 2015).

Figure 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses Flow Diagram of the Study Selection Process



The time of assessment ranged considerably between studies. According to the longitudinal studies, two were related to the first year of treatment (Magni et al., 1983, 1988), and one was conducted from the pre-stem cell transplantation (SCT) to 2 years post-SCT (Barrera et al., 2012). In the cross-sectional studies, two were related to the diagnostic phase (Magni et al., 1986; Ruccione et al., 1991), six were related to the initial/intermediate phases of treatment (i.e., the first year of treatment) (Iqbal & Siddiqui, 2002; Khazaeli et al., 2021; Sharan et al., 1995, 1999; Sint Nicolaas et al., 2016; Wang et al., 2017), and four were related to a later phase-maintenance (Daniel et al., 2018; Matthews et al., 2014; Rensen et al., 2020; Sherief et al., 2015). Two studies were related to any stage of active treatment (Irwanto et al., 2020; Jankowska-Polańska et al., 2020), and one was conducted from the initial treatment phases until maintenance (Steur et al., 2020). In addition, two studies were conducted from 6 months postdiagnosis to more than 12 months postdiagnosis (Bhattacharya et al., 2016) and 18 months postdiagnosis (Rao et al., 1992). Five studies were related to survivorship, 4–12 years postdiagnosis (Eilertsen et al., 2016) and more than 5 years postdiagnosis (Burns et al., 2018; Huang et al., 2018; Liu et al., 2018; Malpert et al., 2015). Two studies were conducted from diagnosis to survivorship (off-therapy for at least 1 year) (Brown et al., 1992) and to relapse (Khalifa et al., 2014); and one was conducted during active treatment and off-therapy (Vance et al., 2001).

Regarding the use of instruments, 24 different measures were used to assess overall distress/psychological symptoms, mental health and mental QoL, stress symptoms, anxiety, depression, and both anxiety and depression disorders. The most used measures of parental distress included the Beck depression inventory (BDI) in five studies, followed by the Brief Symptom Inventory (BSI), in four studies, and the Symptom Checklist–90 (SCL-90), state-trait anxiety inventory (STAI) and General Health Questionnaire (GHQ), each used in three studies (see supplemental material 2).

Quality Assessment

The methodological quality of the studies was rated according to the NHLBI assessment tool (see supplemental material 3). This tool did not focus on a "fatal flaw," but rather on flaws that could compromise the study's reported results or the study's ability to accurately assess an association between exposure and outcome. Thus, most of the studies were of good quality (16), 10 were of fair quality, and two were of poor quality.

Study Findings

Regarding study results, 15 studies found potential predictors/factors, 13 found potential consequences of parental distress, and 11 papers reported subgroup differences (comparing groups of sociodemographic and illness-related variables; see supplemental material 2). Taken together, the factors and consequences of parental distress were represented in a model that systematizes the main results of this review (Figure 2).

Factors of Parental Distress

Sociodemographic, psychosocial, psychological, family, health, and ALL-specific variables were found as factors of parental distress. Unfortunately, none of the three longitudinal studies explored predictors of parental distress (Barrera et al., 2012; Magni et al., 1983, 1988) although some cross-sectional studies found several related factors.

Sociodemographic Variables. Six studies explored sociodemographic variables associated with parental distress. Two studies found associations between female gender and unemployment/unskilled, and depressive disorder after the first remission (Sharan et al., 1995, 1999); one study found that lower education and professional levels were associated with more anxiety, depression, and posttraumatic stress symptoms in the maintenance phase (1-year postdiagnosis; Khalifa et al., 2014). However, no associations were found between parents' socioeconomic status, education (Iqbal & Siddiqui, 2002; Khazaeli et al., 2021), age (Iqbal & Siddiqui, 2002; Khazaeli et al., 2021; Magni et al., 1983), occupation and gender (Iqbal & Siddiqui, 2002), and parental distress symptoms throughout the first year of treatment.

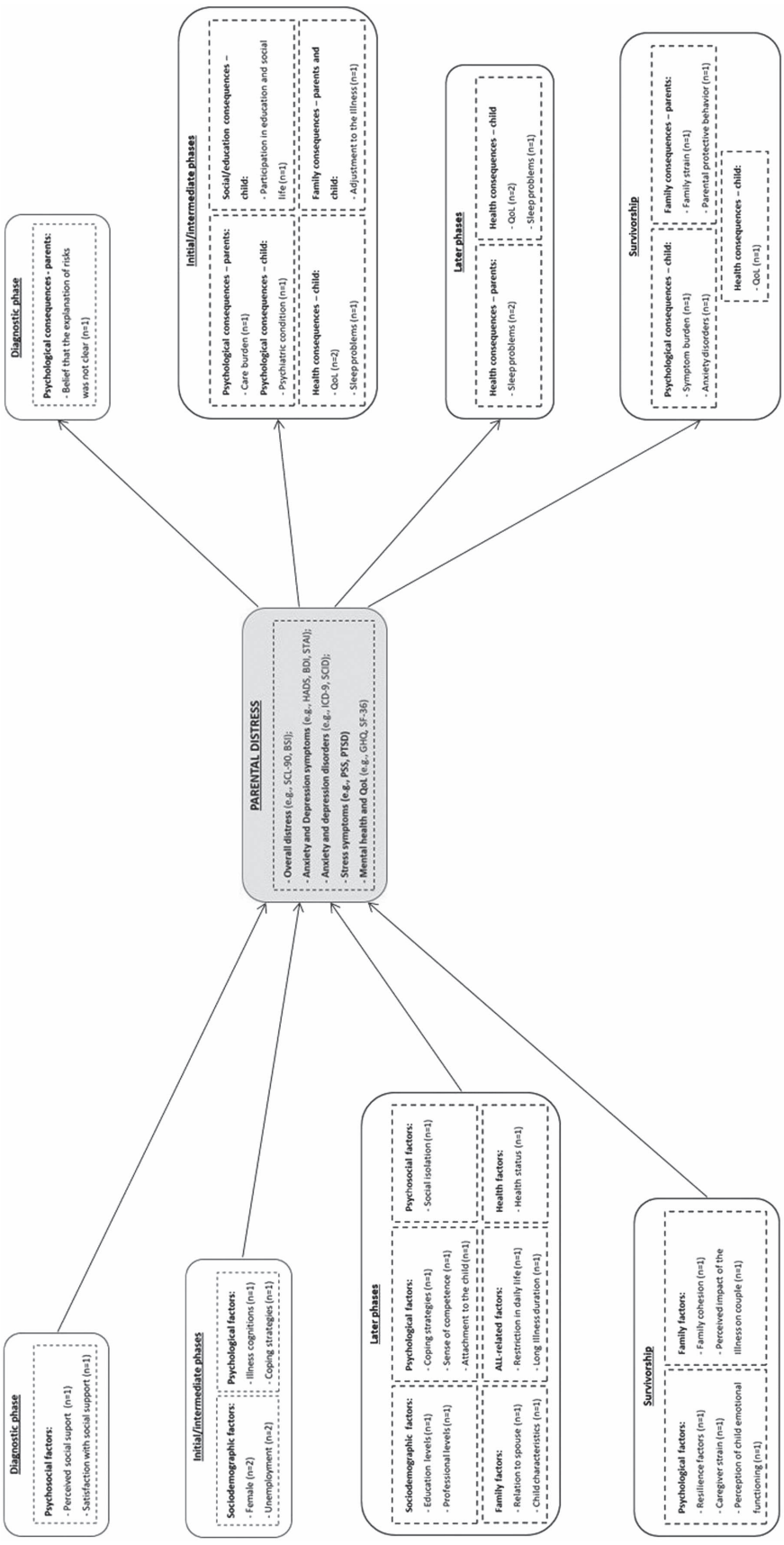
Psychosocial Variables. Two studies analyzed the relationship between psychosocial variables and parental distress. The perceived social support and the satisfaction with the available social support were negatively associated with depression and anxiety symptoms at diagnosis (Magni et al., 1986). Later in treatment, high social isolation was associated with parenting stress (Sherief et al., 2015).

Psychological Variables. Five studies included potential psychological factors of parental distress. From the first month postdiagnosis, parental illness cognitions of helplessness were associated with higher distress levels while cognitions of acceptance, the opposite, was observed (Sint Nicolaas et al., 2016). Also, during the first year of treatment, mothers' use of coping strategies Pattern I (maintaining family integration, cooperation, and optimism), Pattern II, (maintaining social support, self-esteem, and psychological stability), and Pattern III, (understanding the medical situation) were negatively associated with anxiety symptoms. In sharp contrast, no coping patterns were associated with depression levels (Bhattacharya et al., 2016). Parents' low sense of competence and poor attachment to their children, in the maintenance phase, were associated with higher parenting stress (Sherief et al., 2015). Also, mothers' resilience factors (i.e., good self-image, social competence, family cohesion, and ability to plan their future) were associated with and contributed to lower distress levels, in survivorship (Eilertsen et al., 2016). Perceived caregiver strain and parents' negative perception of the survivor's emotional functioning contributed significantly to emotional distress symptoms (Malpert et al., 2015).

Family Variables. Four studies investigated family variables associated with parental distress. In the maintenance phase, the lack of support from the other spouse was associated with high levels of parenting stress. Also, some characteristics displayed by children (i.e., high distraction and demanding, negative reinforcement, lower levels of mood, acceptability, and adaptability) were associated with high parenting stress levels and depression symptoms (Sherief et al., 2015). Low family cohesion in survivorship was associated with parental distress (Huang et al., 2018). Interestingly, also in survivorship, the perceived positive impact of illness on the couple was positively associated with anxiety symptoms in mothers and depression and somatization symptoms in fathers. On the other hand, the perceived positive impact of illness on the couple's intimacy was negatively associated with depressive symptoms in mothers (Burns et al., 2018).

Figure 2

Model of Representation of the Factors and Consequences of Parental Distress Found in This Review, With the Number of Studies That Explore Each Variable, in the Different Stages



ALL-Related Variables. Three studies examined the associations between ALL-specific variables and parental distress. During the maintenance phase, parents' perception of restrictions in their daily life impacted by the child's illness was associated with high parenting stress (Sherief et al., 2015). The same study found that illness duration was positively associated with parenting stress (Sherief et al., 2015), while a recent study found no significant associations with mothers' depression symptoms, more than 2 months postdiagnosis (Khazaeli et al., 2021). No correlation was found between the child's prognosis group and anxiety symptoms at diagnosis (Ruccione et al., 1991).

Health Variables. One study found that parents' poor health was associated with higher parenting stress (Sherief et al., 2015).

Consequences of Parental Distress

Several studies focused on the consequences of parental distress on children and parents themselves, including only one longitudinal study (Magni et al., 1988). There were psychological, family, health, and social/educational consequences.

Psychological Variables. Five studies investigated the psychological consequences of parental distress in parents and children. Regarding parents' consequences, two studies were identified. Anxiety symptoms at diagnosis were associated with a decreased likelihood of believing that treatment risks had been explained clearly (Ruccione et al., 1991). Anxiety and depression symptoms and poor mental health were associated with high levels of parental care burden at the initial stages of treatment, with anxiety contributing to the burden (Wang et al., 2017). Three studies pertained to children's consequences of parental distress found an association with the child's psychiatric condition, after the first remission (Sharan et al., 1995). In survivorship, parental distress contributed to the child's burden symptoms (i.e., perceived abnormal physical, emotional, and cognitive symptoms; Huang et al., 2018), being associated with survivors' anxiety disorders reported by the parents, but not by the survivors (Liu et al., 2018).

Family Variables. Two studies explored family consequences of parental distress. The distress of survivors' parents contributed to family strain and parental protective behavior (Huang et al., 2018). In addition, a longitudinal study (Magni et al., 1988) found that anxiety and depression symptoms in parents at diagnosis were negatively associated with their later adjustment to the child's illness, but only mothers' symptoms were associated with the later child's adjustment.

Health Variables. Two studies examined sleep consequences of parental distress in parents themselves. Daniel et al. (2018) reported that, during the maintenance phase, parent stress was associated with worse parents' sleep quality. Similarly, Matthews et al. (2014) found that perceived stress, anxiety, and depression symptoms were positively associated with insomnia severity in mothers and perceived stress with the number of maternal awakenings. Five studies explored health consequences (i.e., sleep and QoL) of parental distress in children. Similar to parents, distress was associated with child sleep problems, after induction therapy (Steur et al., 2020). During active treatment, parents' anxiety (Irwanto et al., 2020), and depression symptoms (Irwanto et al., 2020; Vance et al., 2001) were associated with poorer child's QoL (Irwanto et al., 2020; Vance et al., 2001). The more parents reported illness stressors, the worse they reported their child's QoL; but no association was found with the child's QoL self-reports (Vance et al., 2001). In addition, parental distress was also associated with poor QoL of survivors (Huang et al., 2018; Vance et al., 2001). Two studies found no associations between parents' perceived stress and child's Qol (Irwanto et al., 2020; Jankowska-Polańska et al., 2020).

Social/Education Variables. One study found that maternal depression was negatively associated with child participation in education and social life, for more than 2 months postdiagnosis (Khazaeli et al., 2021).

Subgroup Differences

Only one longitudinal study was reported regarding ALL-related variables (Barrera et al., 2012).

Sociodemographic Variables. Eight studies explored differences between mothers and fathers, with four studies reporting more distress levels (Khalifa et al., 2014), neuroticism (Rao et al., 1992), symptoms of anxiety (Khalifa et al., 2014; Ruccione et al., 1991), depression (Khalifa et al., 2014; Rao et al., 1992; Sharan et al., 1995), and posttraumatic stress (Khalifa et al., 2014) in mothers, from diagnosis to survivorship; and one reporting greater depression symptoms in fathers in survivorship (Burns et al., 2018). Four studies found no gender differences in depression disorders in the beginning of treatment (Iqbal & Siddiqui, 2002), anxiety, and somatization symptoms at survivorship (Burns et al., 2018), nor global distress at diagnosis, maintenance phase, and survivorship (Burns et al., 2018; Magni et al., 1983, 1986). One study explored age differences and found that older fathers reported more depression symptoms than younger ones during treatment (Barrera et al., 2012), while another study found no significant association between age and symptoms of depression and anxiety, at diagnosis and maintenance phase (Magni et al., 1983).

ALL-Related Variables. Four studies explored differences between time since diagnosis/treatment phases and one explored differences between the children's risk groups. Parental distress symptoms were higher at diagnosis and in the beginning of treatment compared to later phases and off-therapy (Brown et al., 1992; Khalifa et al., 2014). Interestingly, in the maintenance, mothers and fathers revealed significantly more overanxious and major depressive disorders, respectively, than at diagnosis and off-therapy (Brown et al., 1992). Also, in the maintenance phase, parents revealed lower anxiety and depression symptoms compared to parents of relapsed children (Khalifa et al., 2014). One longitudinal study found that mothers reported higher distress before SCT compared with 2 years post-SCT (Barrera et al., 2012). In contrast, no differences in distress levels were found comparing parents of children at diagnosis and 8 months postdiagnosis (Magni et al., 1983). Concerning the risk groups, distress levels were found to be higher in parents of children in the medium-risk (MR) group than in the standard-risk (SR) group (Rensen et al., 2020).

Discussion

This systematic review aimed to identify the factors/predictors and consequences of parental distress related to childhood ALL, detailing the consequences for parents and children. To the best of our knowledge, this is the first systematic review investigating these effects related specifically to the most common form of childhood malignancy. After a careful analysis of the 28 included studies, it

seems that there are some risk factors among the parents that may increase the likelihood of them experiencing distress, as well as some protective factors. Moreover, some consequential implications of parental distress are possible for parents themselves and their children. We identified six categories of factors of parental distress: sociodemographic, psychosocial, psychological, family, health, and ALL-related variables; four categories of consequences: psychological, family, health, and social/educational variables; and two categories of subgroup differences: sociodemographic and ALL-related variables.

Factors and Subgroup Differences

The most probable factors associated with distress found in this systematic review were being a mother and being unemployed/unskilled (Sharan et al., 1995, 1999). Other vulnerability sociodemographic factors were identified, such as having low education and professional levels (Khalifa et al., 2014). However, contradictory evidence was found which may be attributed to different sample sizes, treatment phases, and measurement tools. This overall pattern is consistent with previous literature reviews on childhood cancer not only at diagnosis, but during treatment and survivorship (e.g., Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011). In addition, despite the contradictory evidence identified in this review regarding distress in mothers and fathers, mothers tended to report more distress symptoms, from diagnosis to survivorship (Khalifa et al., 2014; Rao et al., 1992; Ruccione et al., 1991; Sharan et al., 1995). This is corroborated by previous systematic reviews on childhood cancer and could be explained by the caregiving role and responsibility, usually performed by mothers (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011). Contrarily, one study found more depression symptoms in fathers of survivors, highlighting the possibility of decreased mother's distress over the course of the treatment so that the exacerbated distress toward fathers is not visible years later (Burns et al., 2018). Additionally, inconsistent results were found regarding parents' age differences in distress symptoms, in accordance with the only previous review that explored these differences (Sultan et al., 2016). Thus, the question remains whether mothers require specific attention over fathers (Jantien Vrijmoet-Wiersma et al., 2008), and particularly over older fathers.

According to previous research (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Ljungman et al., 2014; Sultan et al., 2016), psychosocial protective and risk factors were found. In this review, perceived social support and satisfaction with the available support were found to be protective factors at diagnosis (Magni et al., 1986), while high social isolation was described as a risk factor for parental distress, later in treatment (Sherief et al., 2015). Indeed, receiving social support can improve life satisfaction and reduce parental stress (Melguizo-Garín et al., 2019) and the satisfaction with that support may have an alleviating effect on psychological distress (Harper et al., 2016).

Associations between psychological factors such as mother's coping strategies, resilience and caregiver strain, and the development of distress due to childhood cancer have been identified previously (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011). In this review, similar results were found, with coping strategies (Bhattacharya et al., 2016) and resilience factors (Eilertsen et al., 2016) acting as protective factors, during treatment and in survivorship, respectively; and caregiver strain (i.e., the difficulties associated with caring for a child) being a risk factor in survivorship (Malpert et al., 2015).

In addition, original findings regarding psychological factors were explored. Parental illness cognitions were associated with distress, with parents with more helplessness cognitions and fewer acceptance cognitions reporting worse psychological well-being (Sint Nicolaas et al., 2016). According to Bilani et al. (2019), feelings of helplessness and lower acceptance contributed to the presence of pathological, health-related anxieties, which can be explained by the cognitive–behavioral model. Besides illness cognitions, a low sense of competence, poor attachment to the child (Sherief et al., 2015), and negative perceptions of the child's emotional functioning (Malpert et al., 2015) were also original findings associated with distress symptoms. Indeed, feeling competent in the role of caregiver has previously been reported to lower the risk of distress, as demands for caregiving increase (Teo et al., 2020). One explanation might be that parents who feel confident in their ability to manage their child care may feel more in control of the situation, and therefore, experience less distress. Also, based on evidence that parental attachment patterns can influence parenting stress (Rholes et al., 2006), parents who were poorly attached to their children, i.e., with no emotional closeness to the child, reported high levels of stress associated with parenting, in this review (Sherief et al., 2015). Interestingly, the negative perception of the child's emotional functioning contributed to parental distress symptoms in survivorship (Malpert et al., 2015). Although the literature has reported that parental emotional distress symptoms may influence perceptions and reporting of child's emotional functioning (Malpert et al., 2015), it is reasonable to assume that the parents' perception of the child's suffering has an impact on the parents themselves and, consequently, on the child's functioning (Pöder et al., 2010).

Family risk factors of parental distress were also found. There is substantial research showing that lack of support from another spouse (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Ljungman et al., 2014), low family cohesion (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016; Wakefield et al., 2011), and certain child's characteristics (Klassen et al., 2007) were associated with parental distress. Although, child's characteristics identified in this review were different from those identified in previous reviews. Here, characteristics such high distraction (i.e., behaviors that are consistent with attention-deficit/hyperactivity disorder), high demanding (i.e., described as unreasonable, impatient, and needy), negative reinforcement (i.e., little reinforcing for the parents to be with the child and their interaction does not produce positive feelings), low mood levels (i.e., symptoms associated with depression), low acceptability (i.e., child's physical/intellectual/emotional adjustment is not what the parents expected to be), and low adaptability (i.e., lacking the ability to adapt to changes in their physical/social environment) (Abidin & Ona, 1995) were identified as risk factors for parental distress (Sherief et al., 2015). Another original finding was that the perceived positive impact of illness on the couple's intimacy was negatively associated with distress in mothers. Surprisingly, the positive perception that the illness brought the couple closer and strengthened their relationship was found to be a risk factor for parental distress (Burns et al., 2018). As expected, recalling positive

changes in the couple relationship during the child's treatment should lead to less distress, which makes the risk factor being counterintuitive, and easily explained by the nature of the study since it was a cohort recall. Indeed, most of the parents revealed their relationship was strengthened as a result of their child's illness (Ljungman et al., 2014).

Some findings reported in this review regarding ALL-related variables also resonate with the available literature. Despite the contradictory evidence identified in this review and previous literature (e.g., Jantien Vrijmoet-Wiersma et al., 2008) regarding the association between illness duration and parental distress symptoms, some studies suggest that this is an important influencing factor of parental distress (Klassen et al., 2007; Sultan et al., 2016). In fact, a recent study identified a shorter time since ALL diagnosis as a predictive factor of distress (Rensen et al., 2022). Moreover, although this review offered a portrait of parental distress in ALL as being more elevated at early stages when compared to later stages and off-therapy (Brown et al., 1992; Khalifa et al., 2014), reviews including mixed cancer types have found persistent clinically elevated levels of distress in a subset of parents throughout their child's treatment and postdiagnosis years (e.g., Jantien Vrijmoet-Wiersma et al., 2008). In addition, in line with existing literature (Sultan et al., 2016), there is a decrease in maternal distress symptoms in the 2 years after SCT, and it suggests that the elevated levels pre-SCT were primarily due to the medical crisis (Barrera et al., 2012). In fact, much of the psychological distress experienced by parents after their child's diagnosis of leukemia occurred during invasive procedures (Willingham Piersol et al., 2008). Moreover, as expected, elevated levels of distress were found in parents of relapsed children (Khalifa et al., 2014). This vulnerability factor has already been described in the literature (e.g., Sultan et al., 2016) and is seen as a "second blow" that made parents more vulnerable to experiencing distress (Sultan et al., 2016). Interestingly, contrary to previous literature (Klassen et al., 2007; Sultan et al., 2016), no association was found between the child's prognosis group and distress symptoms in this review (Ruccione et al., 1991). However, an original finding emerged regarding distress in different risk groups. Distress symptoms were found to be higher in parents of children in the MR group than in parents of children in the SR group, which can be clearly explained by the higher treatment intensity, occurrence of clinical complications, and prognostic estimates of the MR (Rensen et al., 2020). Another original finding was that the degree to which parents feel their freedom has been restricted by the child, due to the caregiver's role, was identified as a risk factor for parental distress (Sherief et al., 2015). Indeed, parents with high restrictions feel frequently frustrated in their attempts to maintain their own identity and often report that their children's demands control and dominated them (Abidin & Ona, 1995).

Finally, parents' poor health was identified as a risk factor, with parents' perception that their physical health is deteriorating, being associated with distress symptoms (Sherief et al., 2015). According to the literature, caregiver's physical health seems to be an aspect of the caregiving process that has received less research attention (Klassen et al., 2007).

Consequences

The most reported consequence of parental distress for parents, in this review, was sleep problems, particularly worse parents' sleep quality (Daniel et al., 2018), mother's insomnia severity and number of maternal awakenings, during treatment (Matthews et al., 2014). This is in line with a report by Rensen et al. (2022) that identified distress as a perpetuating factor of sleep problems years after diagnosis. However, despite the fact that previous studies have identified distress as a predictive factor of sleep problems (e.g., Seixas et al., 2015), it is also true that sleep disruption may lead to higher distress too through increased sympathetic activity (Medic et al., 2017), being a cyclic relationship (Rensen et al., 2022).

Another original consequence of parental distress found in this review was the decreased likelihood of believing that treatment risks had been explained clearly at diagnosis, which can be due to the poor capacity of parents to absorb much information after the communication of such a threatening diagnosis (Ruccione et al., 1991). Thus, addressing distress management is an essential component of cancer care, from diagnosis and throughout the treatment process. Additionally, caregiver burden, at the initial stage of treatment, was one of the consequences of distress found in this review. Considering the possibility of losing a child, parental distress may increase, impacting parents' caregiving burden (Wang et al., 2017). This is consistent with results found in a recent study, with a strong positive correlation emerging between depressive feelings and burden (Benedetto et al., 2022).

Regarding family consequences, distress symptoms of survivors' parents contributed to family strain and parental protective behavior (Huang et al., 2018). Indeed, such a life-threatening illness has a negative impact on the parent's psychological well-being (Long & Marsland, 2011), leading them to use preventive-focused parenting strategies and restrict the child's activities (Eiser et al., 2002). Importantly, as for consequences of parental distress for both parents and children, this review found a longitudinal study to support the effect of parental distress symptoms, at diagnosis, on short-term parents' and children's adjustment to the illness (Magni et al., 1988). The study emphasizes that the capacity of the whole family, and not only the parents, to respond to their emotional needs is negatively influenced by their initial psychological suffering. This pattern is consistent with previous literature reviews in childhood cancer domain (Jantien Vrijmoet-Wiersma et al., 2008; Klassen et al., 2007; Sultan et al., 2016) and is coherent with the integrative model of pediatric medical traumatic stress (Kazak et al., 2006) that suggests that parents' responses immediately following the trauma may predict the course of traumatic responses over time. Thus, these results underscore the importance of supporting parents in the earlier phases of the child's disease.

When considering the psychological consequences of parental distress for children, an original finding emerged, with parental distress contributing to survivor's burden (i.e., perceived abnormal physical, emotional, and cognitive symptoms; Huang et al., 2018). Although there is evidence that supports that distress in parents placed children at risk for symptom burden, especially somatization and emotional distress (e.g., Holley et al., 2016), recent studies found the opposite interaction (e.g., Lam et al., 2022) which may lead to the assumption that parental distress and child's symptom burden influence each other. Furthermore, this review found a positive association between parental distress and child's anxiety disorders (Liu et al., 2018), although it was found only in parent report, but not in the child's self-report (Liu et al., 2018). Previous reviews similarly reported this association (Ljungman et al., 2014; Sultan et al., 2016). In addition, one more study found an association

between parental distress and child's psychiatric condition (Sharan et al., 1995). However, this article was rated as poor and, in this specific case, does not provide sufficient information on how the child's psychiatric condition was measured and the performed statistical analysis, requiring careful interpretations.

Concerning child health consequences of parental distress, original findings were found. Coherent with the social–ecological model (Kazak, 1989) that postulates that parent adjustment contributes to a child's adaptation to chronic illness and medical conditions, studies in this review found associations between parental distress and impaired child sleep (Steur et al., 2020) and QoL reported by parents and children themselves (Huang et al., 2018; Irwanto et al., 2020). Also, recent studies corroborate these results (e.g., Bakula et al., 2020). However, a poor agreement between parent and child reports was found regarding QoL and psychological consequences described above (Liu et al., 2018; Vance et al., 2001), which may reflect interpretation differences (Vance et al., 2001) or the parent's biased evaluation of their children's problems due to their emotional status (Liu et al., 2018).

Finally, in accordance with a previous systematic review, mothers' distress symptoms influenced the child's participation in education and social life (Khazaeli et al., 2021), probably because the symptoms hinder the mother's effort to participate in their children's education (Noreau et al., 2002) and in the promotion of social skills (Priel et al., 2019).

Limitations and Future Directions

In addition, there are several limitations in the current systematic review that must be recognized and highlight the need for further research. First, almost 90% of the studies had cross-sectional designs that do not allow for causal inferences, limiting the classification of the results as factors or consequences of parental distress. However, the classifications were made considering the interpretations given by the study authors. Second, this review only found variables associated with and that contributed to parental distress since none of the three longitudinal studies explored predictors. Therefore, more longitudinal studies that explore predictors are needed to better understand the phenomenon and its consequences, since the clear deficit in the literature limits the conclusions we can make about distress over time. Third, only variables such as female gender, unemployment, sleep problems, and child QoL were analyzed in more than one study, indicating that the remaining of the findings should be interpreted carefully since it becomes difficult to find homogeneity. Fourth, parental distress was accessed by 24 different measures which may explain the variability of the results. Thus, the operationalization of parental distress should be clearly defined, valid, reliable, and implemented consistently. Also, none of the included studies explored uncertainty, one of the indicators of distress operationalized in this review, which accordingly to the literature may affect the ability of parents to adapt to their child's diagnosis (e.g., Eche et al., 2019). Fifth, there were many different sample characteristics which may difficult the generalization of the findings. On the contrary, studies that explore children's characteristics such as gender and age are needed, since they are important variables related to parental distress. In this line, compared to previous reviews, although we found fewer studies only with mothers, there are a considerable number of studies with more mothers than fathers included in this review which may hamper the generalizability of the findings. Indeed, future studies should consider fathers since they are at risk of distress after the child's treatment. Sixth, two studies assessed were of overall poor quality. These studies were conducted by the same author and were among the oldest of the reviewed studies and their main limitations were related to the research question not being explicit, the population not being properly defined, the participation rate of eligibility not being reported, and key potential confounders not being controlled. Finally, this review was performed only with quantitative studies leaving qualitative studies out that could add detailed information about the parents' and children's suffering that quantitative research cannot grasp.

Implications and Conclusion

This systematic review synthesizes the existing literature over the last 38 years on factors and consequences of parental distress. The main findings highlight several clinical, policy, educational, and psychological implications to inform future evidence-based interventions and best clinical practice guidelines in the context of childhood ALL. First, the results underline the need to monitor parents of children diagnosed with ALL throughout the several phases of treatment to identify early symptoms of parental distress and promote better parental participation in the maintenance of the child care and health outcomes. Since the relationship between parents' and children's symptoms is well established, this screening is essential from a perspective of maintaining and recovering health and preventing maladaptive adjustment. Furthermore, each phase of treatment poses different challenges that contribute to parental distress and must be recognized by health care teams that follow these parents and their children in order to improve the care provided and mitigate the effects on parental distress and its consequences.

According to the designed model based on the results (Figure 2), in the diagnostic phase, it is important to promote resources for these parents to activate and enhance social support. At the initial/intermediate phases, further interventions should consider parents' sociodemographic and psychological factors, particularly in mothers who seem to be most vulnerable, and in those who reported more threatening illness representations and fewer internal resources (e.g., coping). In the subsequent phases, the review findings indicated that lower levels of parental distress are observed compared to the previous disease phases; however, the importance of adopting self-care and stress management strategies and the promotion of internal resources, such as active coping and resilience, are central to decrease parental distress. Therefore, psycho-oncology family centered care interventions are recommended to address and relieve the parent's distress symptoms, showing high efficacy (e.g., Willingham Piersol et al., 2008). Moreover, supporting parents in this transition period may also improve child outcomes over time. These suggestions are consistent with the current literature on psychological interventions targeting parents of children with cancer and have shown promising results in reducing parental distress and improving child outcomes and overall well-being (e.g., Bougea et al., 2011).

Thus, future interventions in ALL should continue to consider the several treatment phases, emphasizing the original factors found in this review (i.e., illness cognitions, sense of competence, attachment to the child, perception of the child's emotional functioning, and restrictions imposed by the illness) that should be targeted for

intervention. Therefore, there is an emerging need to focus on a preventative paradigm, focusing on the factors, in order to eradicate the consequences of parental distress.

Finally, this review summarizes a list of parental distress measures that are commonly used, valid, and reliable, to facilitate assessment and inform the direction of intervention, as well as a comprehensive and inclusive definition of parental distress that must be followed.

Overall, the results of this systematic review underscore the necessity to address the mental health needs of parents in an early and ongoing assessment in order to promote healthier outcomes for both parents and children. Also, future protocols based on the results of this review should be consistently implemented to ensure that all parents benefit and are not systematically neglected.

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