Revelation and Science: Special Issue
Postgraduate Colloquium 2024 (1446H/2025) 65-80

Distress Level and Its Contributing Factors Among Caregiver of Adolescent Cancer Patients: A Review

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ABSTRACT

Distress is defined as a negative state in which an individual's coping mechanisms fail to restore physiological or psychological homeostasis. This condition may arise from severe or prolonged stressors, or from the cumulative impact of multiple stressors, resulting in adverse effects on the overall well-being. In this study, the stressors are identified as challenges faced by the parents as the main caregivers for an adolescent with cancer. Despite their strong desire to support and protect children, parents must cope with their own fears and concerns (distress), creating a dual crisis for them. Understanding this situation would help to improve the provision of support and service towards the care of adolescent cancer patients by improving the support needed by the caregivers in managing their child's health. Hence**,** this study aimed to review the current literature of distress levels and its contributing factors among caregivers of adolescents diagnosed with cancer**.** Systematic searches from related databases have yielded 15 articles included in this review. Evidence reported that caregivers were affected with increased anxiety, depression, post-traumatic stress disorder, and decreased quality of life while caring for the patient. Five categories of contributing factors to the distress among caregivers were practical, social, emotional, cognitive, physical, and parenting problems. The findings could guide healthcare providers in addressing multiple dimensions of care when supporting parents of adolescents with cancer, thereby promoting holistic and comprehensive care.

Keywords: Distress level, caregiver, adolescent, cancer care, stress factors

ABSTRAK

Tekanan didefinisikan sebagai keadaan mekanisme daya tindak individu gagal untuk mengimbangi fisiologi atau psikologi. Ianya boleh berpunca daripada tekanan yang teruk atau berpanjangan, atau kesan kumulatif pelbagai tekanan, yang membawa kepada kesan buruk terhadap kesejahteraan individu. Dalam kajian ini, tekanan tersebut dikenal pasti sebagai cabaran yang dihadapi oleh ibu bapa sebagai penjaga utama remaja dengan kanser. Mereka mempunyai keinginan yang kuat untuk menyokong dan melindungi anak mereka. Pada masa yang sama, perlu mengatasi ketakutan, kebimbangan mereka sendiri (tekanan), yang mencipta krisis dua kali ganda. Memahami situasi ini akan membantu meningkatkan penyediaan sokongan dan perkhidmatan terhadap penjagaan pesakit kanser remaja dengan meningkatkan sokongan yang diperlukan oleh penjaga dalam menguruskan kesihatan anak mereka. Oleh itu, kajian ini bertujuan untuk mengkaji literatur semasa mengenai tahap tekanan dan faktor-faktor penyumbang di kalangan penjaga remaja yang didiagnosis dengan kanser. Carian sistematik dari pangkalan data telah menghasilkan 17 artikel yang dimasukkan dalam ulasan ini. Bukti melaporkan bahawa penjaga terkesan dengan peningkatan kebimbangan, kemurungan, gangguan tekanan pasca-trauma, dan penurunan kualiti hidup semasa menjaga pesakit. Lima kategori faktor penyumbang kepada tekanan di kalangan penjaga adalah masalah praktikal, sosial, emosi, kognitif, fizikal, dan keibubapaan. Penemuan ini dapat membimbing penyedia perkhidmatan kesihatan dalam menangani pelbagai dimensi penjagaan untuk ibu bapa remaja yang menghidap kanser, sekali gus mempromosikan penjagaan yang holistik dan menyeluruh.

Kata Kunci: Tahap tekanan, penjaga, remaja, penjagaan kanser, faktor tekanan

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INTRODUCTION

Cancer is fundamentally a genetic disease, as changes in genes regulate every cell's function, particularly cell growth and division. Under normal circumstances, the body eliminates cells with damaged DNA before they become cancerous. However, the efficiency of this process declines with age (National Cancer Institute, 2021). Despite its rarity in younger populations, cancer can also affect adolescents and can be fatal. The primary causes of cancer in this age group are mutations in genes that lead to uncontrolled cell growth. These genetic mutations can result from inherited genetic variants, known as germline variants, passed from parents to children. Additionally, spontaneous mutations can occur in cells during the development of the child (National Cancer Institute, 2023).

According to National cancer Institute (2023), although cancer is rare in children and adolescents, it remains the leading cause of death by disease after infancy among children in the United States. In 2024, it is estimated that 14,910 children and adolescents (ages 0 to 19) will be diagnosed with cancer, and 1,590 will die from it. Specifically, for children aged 0 to 14 years, an estimated 9,620 will receive a cancer diagnosis, with 1,040 fatalities. For adolescents aged 15 to 19 years, it is estimated that 5,290 will be diagnosed with cancer, with 550 deaths expected. Childhood cancer is relatively rare, but certain types are more prevalent across different age groups. The most common childhood cancers include leukemia, lymphoma, and brain tumors. As children transition into their teenage years, there is an increased incidence of osteosarcoma (bone cancer) (MyPortal Ministry of Health Malaysia, 2022). The cancer sites vary by type, leading to differences in treatment approaches and cure rates. Data from the Malaysian National Childhood Cancer Survey indicate that the most frequent childhood tumors are leukemia, brain and spinal cord tumors, lymphomas, neuroblastoma, gonadal and germ cell tumors, kidney tumors, soft tissue sarcomas, and retinoblastoma. The crude incidence rate of pediatric malignancies in Malaysia is 77.4 per million children under the age of 15 years (MyHealth Ministry of Health Malaysia, 2022).

Adolescents, when understanding by its definition by the World Health Organization as the phase of life between ages 10 and 19, bridges childhood and adulthood. At this age window of transitional age, it could be one of the most crucial phases when there is increasing recognition of the essential role that parents and caregivers play as key partners in fostering and supporting healthy adolescent development, particularly in contexts where families face challenges and adversity, as such in the context where they must live with cancer. Despite the growing independence and evolving capacities of adolescents, parents continue to exert significant influence over critical aspects of development, including identity formation, emotional well-being, and interpersonal relationships (Unicef, 2021). However, the responsibility carried by parents who caregiving adolescents with cancer could become more exhausting.

It emphasizes that caregivers frequently face considerable stress because of the various responsibilities of their role, such as emotional pressure, bodily fatigue, and the weight of making medical decisions. The research pinpoints the main elements that lead to caregiver stress, such as the way they adapt to new routines, the length of time spent caregiving, financial stress, and a dearth of social backing. Evidence has suggested that greater severity of the teenager's illness is associated with higher levels of stress for the caregiver which might be due to extended periods of providing care that were also linked to increased feelings of emotional and physical fatigue, underscoring the lasting effects of ongoing caregiving duties (Joen et al., 2022). Increased financial pressures, due to medical costs and lower income, were pinpointed as a major source of stress, with numerous caregivers facing challenges in fulfilling essential needs (Santerre-Theil et al., 2022). Furthermore, the absence of social backing, such as insufficient help from loved ones and community services, exacerbated caregivers' feelings of distress (Taylor et al., 2021).

Parents, as the primary caregivers, inherently possess a strong inclination to support and protect their children. However, while fulfilling this caregiving role, they concurrently manage with their own fears and concerns. This dual burden creates a crisis for parents, as they strive to support both their child and them (Ay Kaatsız & Öz, 2020; Fleary & Heffer, 2013). Recognizing this dynamic is crucial for enhancing the provision of support and services for adolescent cancer patients by addressing the specific needs of caregivers in managing their child's health. Besides, caring for adolescents has its unique developmental needs as informed earlier, such as independence and identity formation, which may complicate caregiving. It would be a huge gap to explore the specific challenges faced by caregivers of adolescents, particularly the interplay between supporting autonomy and managing medical responsibilities. Therefore, this study aims to review the existing literature on the challenges that led to distress and the contributing factors among caregivers of adolescents diagnosed with cancer.

REVIEW METHOD

Search strategy

Systematic search for literature review from SpringerLink, ProQuest, and Clinical Key databases have been used to obtain relatable and relevant research papers and articles. Besides, additional search has been conducted in Google Scholar (1st July 2024 to 31st July 2024) in view of limited studies were found among adolescent cancer patients. Boolean search, "AND" and "OR" have been applied and filtered to academic journals, peer-reviewed, open access to obtain related studies published between year 2013 to 2023. Keywords used were "distress level" AND/OR "contributing factors" AND/OR "caregiver", AND/OR "adolescent cancer patient". An overview of the selection process is according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram as presented in Figure 1. Articles included in this study are screened based on sets of inclusion and exclusion criteria. Articles would be included in the review if it is full text, published in English/Malay/Indonesia, study among adolescent cancer patients, and published in the year 2013 onwards. The articles would be excluded if the study had no full text available, or studies among other types of chronic illness. Review objective has been set prior to the search as follows.

1. To explore the distress level that affects the quality of life among caregivers of adolescent cancer patients or cancer patients in general (in view of limited studies among adolescent caregivers were found in the available databases for full text).
2. To explore the factors that contribute to distress among caregivers of adolescent cancer patients.

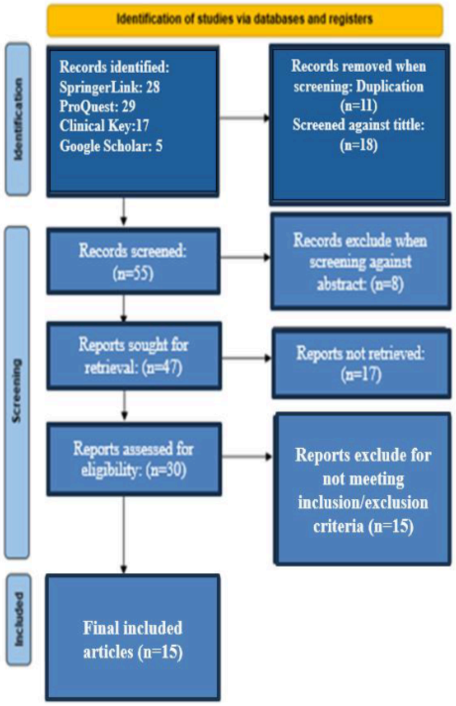

Figure 1: Flow diagram of the search and selection process

Data Extraction and Synthesis

The identified articles when using the keywords were 74. Nine articles were excluded due to duplication and 23 due to unrelated titles. Further screening of the abstract was conducted and 17 were excluded due to no full text being available and 15 due to unmet the inclusion criteria. The remaining 15 studies were finally selected as they met the inclusion and exclusion criteria in this review.

Generally, included studies were conducted in 8 different countries: Indonesia (3), Singapore (1), United States (5), Australia (2), Korea (1), Canada (1), Turkey (1), and Italy (1). The studies include quantitative and qualitative studies as well as review studies. Most of the studies imply the factors that affect the caregiver's distress level while taking care of the cancer patients. Overall, in view of limited studies that were found among adolescent caregivers, searches of articles was expanded towards cancer caregivers in general as well to help in understanding this phenomenon of interest. This also reflected that little is known about the hardship or challenges of the caregiver's adolescent cancer patients that are worth further research.

The critical appraisal is carried out to appraise and describe the methodological quality of the studies included in this review as in Appendix. Nonetheless, this appraisal does not aim to highlight or exclude any weak methodological studies because of the few related studies found and to capture as much possible understanding of the phenomenon of this current study. The synthesis of the data from the included articles was summarized in Table 1 (refer appendix)

Several themes were synthesised narratively from the literature to aid the understanding of the factors of stress among the caregivers of adolescents with cancer. However, as informed earlier, due to limited studies found among adolescent cancer patients, literature search was expanded on studies on stress burden among caregivers of cancer patients in general as well. Synthesising these themes is done while analysing the literature to find similar major concerns highlighted in the reviewed studies. Thus, pooling together the similar subjects of concern in each study will provide a better understanding of this issue. The themes emerged from the review are as follows, presented in the finding sections.

REVIEW FINDINGS

Findings of the studies

The findings of the studies were presented based on following themes as follows:

1. *Distress level of caregivers of adolescents with cancer*

The word 'distress' can be expressed in a lot of meanings. It's an unpleasant feeling, emotion, thought, condition, or behavior. Distress can result in patients with cancer as they find it hard to cope with the conditions they have been diagnosed with. Research shows that stress can influence how to take a decision and someone's actions regarding health such as having trouble focusing on treatment decisions, making follow-up appointments, or even taking the necessary medication regularly (American Cancer Society, 2020).

For adolescent cancer patients, they tend to depend on their parents as their caregiver and the ones who did everything in terms of decision making, note down the next follow-up, and remind them when to take the medication. A study among American pediatric cancer caregivers recorded over 84% of them were highly distressed and it's found to affect the adherence of the child to seek treatment (Isabel Tan et al., 2021). The increase of anxiety, depression, post-traumatic stress disorder, and decreased quality of life were reported by the caregivers as the after effect of taking care of the adolescent cancer patient (Jeon et al., 2021). Besides, a study among pancreatic cancer patients has reported that patient distress was a significant predictor of concurrent caregiver distress, anxiety, depression, and perceived burden (Xia et al., 2022).

2. *The Contributing Factors*

Unmet need

Caregivers for cancer patients are usually friends or family members who provide unpaid care such as emotional support, help with daily tasks, and nursing responsibilities like medication administration and monitoring the patient's condition. The unmet needs of caregivers were found to increase distress levels among caregivers of cancer patients. Previous research has pointed out many needs that have not been addressed, such as information (Taylor et al., 2021), education, emotional support, healthcare services, and communication with health care staff (Jeon et al., 2021). Research also suggested that when considering the caregiver burden, it is important to look at subjective and objective factors from a wide perspective. The concept of subjective burden refers to the personal perception of the financial, social, emotional, and physical stress associated with caring for someone with a debilitating illness. Conversely, objective load refers to the amount of time devoted to caregiving and the number of tasks accomplished (Soto-Guerrero et al., 2023).

The heightened problems

i. Practical Problems

Caregivers of adolescents with cancer face a myriad of practical problems that significantly contribute to heightened distress levels. The emotional toll of witnessing a loved one battle a life-threatening illness, especially during the vulnerable adolescent years, can be overwhelming. Managing the financial burden associated with cancer treatment, including medical bills, travel expenses, and related costs, places an additional strain on caregivers, often leading to anxiety and distress. This is in reaction to the report's findings that found family income is significantly predicting the functioning or not affecting the function of a family (Deatrick et al., 2014; Indra Ayu Astarini et al., 2023). The disruption of daily life is inevitable, as caregivers must navigate the delicate balance between providing constant support to the adolescent undergoing treatment and managing their own work, household responsibilities, and other obligations. This study findings echoed another study among Latino community where they reported that the caregivers were frequently experience high-intensity burden of care that mostly related to amount of time spent to care for the patient which was about 14.5 hours per day (SD = 8.8), while at the same time they had to work and without any help and caregiving training exposure (Soto-Guerrero et al., 2023). Apart from that, it was also reported that the number of caregiving activities (Indra Ayu Astarini et al., 2023) and caregiver overall health status were predictors of concurrent caregiver depression and perceived stress (Xia et al., 2022). These practical problems collectively shape a complex web of challenges that significantly impact the mental well-being of caregivers of adolescents with cancer, highlighting the need for comprehensive support systems and interventions to address these multifaceted issues.

ii. Social Problems

Caregivers of adolescents with cancer not only struggle with the medical challenges but also face profound social and family problems that escalate distress levels. Several studies have highlighted the burden placed on caregivers of dependent adults, which includes those caring for adolescent cancer patients. The emotional toll extends beyond the caregiver's immediate relationship with the patient to impact the entire family dynamic. Siblings may experience feelings of neglect or jealousy as attention understandably centers around sick adolescents (Fleary & Heffer, 2013). Besides, conflict between working and social responsibilities would introduce distress for caregivers who work. For instance, findings from a study of caregivers who are also healthcare providers reveal that while their professional knowledge aids in patient advocacy, their dual role often results in over-solicitation from others, a heightened sense of responsibility, increased burden, and significant distress. Further research on the critical ramifications of simultaneously undertaking informal and professional caregiving across various health contexts is necessary to inform supportive care strategies for this understudied yet increasingly prevalent segment of the caregiver population (Santerre-Theil et al., 2022).

iii. Emotional Problems

Caregivers of adolescents battling cancer cope with profound emotional challenges that deeply impact their distress levels. Witnessing a young loved one confronts a life-threatening illness that triggers a torrent of emotions, ranging from profound sadness and fear to helplessness and grief. The caregiver often experiences a rollercoaster of emotions, mirroring the emotional turbulence of the adolescent undergoing treatment. This could be reflected from a report finding of a study among caregivers of leukemia adolescent patients in Indonesia where more than 50% of the participants suffered from a distress level of moderate to severe (Lesmana Wati & Fashalna Qoyyimah, 2018). The often-longitudinal nature of cancer brings with it the potential risk for caregivers to experience high levels of distress and physical decline. Elevated distress among caregivers can be commensurate or exceeding that of the patients they care for, and up to 40% have reported ongoing distress (Taylor et al., 2021). Based on a study in Korea, when compared to father-caregiver, mother-caregivers had greater unmet needs related to health and psychological problems, family/social support, and religious/spiritual support, with odds ratios (95% confidence interval) of 3.79 (2.52–5.69), 3.17 (2.09–4.81), and 1.69 (1.14–2.50), respectively (Jeon et. al, 2022). This mirrored another finding that suggested gender has a stable causal relationship to health readiness and readiness to care for patients with cancer (Surtiyan Surya et al., 2021). Furthermore, coping with the persistent fear of loss and the uncertainty of the future can lead to anticipatory grief, adding an extra layer of emotional distress. It was reported that almost 20% of caregivers appear to suffer from prolonged grief disorder that persists at least three years post bereavement. These findings evidenced the emotionally affected emotional well-being and mental health of the caregivers (Zordan et al., 2019). Balancing hope with the reality of the situation becomes an intricate emotional dance, and caregivers may find it challenging to express these complex emotions to friends or family who may not fully comprehend the depth of their emotional struggle. Furthermore, it is in the impact of the diagnosis and definition of treatment that these feelings emerge, creating a difficult period for the assimilation of information verbally transmitted by health professionals to caregivers. When information is transmitted in an accumulated way and with the use of technical language, caregivers /parents experience greater tension and lack of understanding about the disease and treatment (de Oliveira Silva et al., 2023). Addressing these emotional challenges is crucial in providing holistic support for caregivers of adolescents with cancer, acknowledging the profound impact that emotional distress can have on their overall well-being.

iv. Cognitive Problems

The constant influx of complex medical information, treatment options, and changing care plans requires caregivers to navigate a steep learning curve, often leading to cognitive overload and feelings of overwhelm. Processing and understanding the intricacies of the disease, potential side effects of treatments, and medical jargon demand considerable cognitive resources, which can be particularly taxing for caregivers already under emotional stress. Decision-making becomes a demanding task as caregivers are confronted with choices that have profound implications for the adolescent's health and well-being (Testoni et al., 2023). The need to coordinate appointments, manage medications, and track the patient's progress adds a layer of cognitive burden. This was intensified by evidence reported in a study that out of the six problems (practical, social, emotional, physical, cognitive, parenting) only the category of cognitive problems (concentration and memory) was found to predict distress. It could be explained by the stress and burden of caregiving, which has been shown to negatively impact one's cognitive functioning as compared to parents of healthy children (Isabel Tan et al., 2021). Recognizing and addressing these cognitive challenges is essential in providing comprehensive support to caregivers, acknowledging the cognitive toll that accompanies the complex caregiving role. On the other hand, objective load describes the quantity of time spent providing care as well as the volume of tasks completed (Soto-Guerrero et al., 2023).

v. Parenting Problems

The challenge of maintaining a sense of normalcy for adolescents amidst the chaos of medical treatments and emotional upheaval is a daunting task. Parenting becomes a delicate balancing act as caregivers must simultaneously provide emotional support and enforce necessary medical routines, often leading to feelings of guilt or inadequacy. The inherent role reversal, where the caregiver must navigate the delicate line between maintaining authority and being a source of comfort, adds a layer of complexity to parenting. The unpredictability of illness can disrupt established routines, impacting the caregiver's ability to provide consistent structure and stability for the adolescent. Siblings may witness their parents' emotional strain and, in turn, experience their own distress, further complicating family dynamics. Balancing the needs of sick adolescents with those of siblings requires exceptional parenting skills and emotional resilience (Mooney-Doyle et al., 2018). This mirrored another study in Turkey and Texas that reported siblings with cancer patients also struggles in adapting and coping with the patient's new condition (Ay Kaatsız & Öz, 2020; Fleary & Heffer, 2013), which in turn reflects the hardship of the parents to balance care between their sick adolescent children and the healthy one who also need support and attention. They have difficulty adapting to new family roles and routines, mostly using several coping strategies and expect health care professionals to support and understand them. The inherent uncertainty surrounding adolescents' health may also prompt caregivers to handle difficult conversations about the future, leading to additional emotional and communication challenges within the family. Addressing caregiver related factors is important because the health of the surrounding support system directly and reciprocally influences cancer specific outcomes for patients (Xia et al., 2022). These parenting problems are intricately intertwined with emotional, social, and cognitive challenges, collectively contributing to the heightened distress experienced by caregivers of adolescents with cancer. Comprehensive support systems that address the unique parenting dynamics in the context of pediatric cancer are crucial for ensuring the well-being of both the adolescent patient and the entire family unit.

LIMITATION OF THE STUDY

The literature search was conducted across three accessible databases, supplemented by Google Scholar, due to the limited number of studies available on the topic. Despite these efforts, only a few relevant studies were identified that specifically focused on caregivers of adolescent cancer patients. This scarcity of research highlights a significant gap in the literature, underscoring the need for further scholarly investigation to enhance patient care.

CONCLUSION

In summary, the reviewed literature highlights the significant distress experienced by caregivers of adolescents with cancer, underscoring the multifaceted nature of their challenges. The primary sources of distress are rooted in unmet needs, practical and social problems, emotional turmoil, cognitive overload, and parenting difficulties. These caregivers face overwhelming emotional and cognitive demands, exacerbated by the complexity of medical information and the responsibilities of maintaining daily routines and providing consistent support. The strain is further intensified by financial burdens, lack of social support, and the need to balance caregiving duties with personal and professional/working responsibilities. The emotional and physical toll on caregivers, often mirroring or exceeding the distress levels of adolescent patients, reveals the profound impact of their caregiving roles.

The findings suggest an urgent need for comprehensive support systems and interventions tailored to address the unique challenges faced by caregivers of adolescent cancer patients. Such support systems should encompass practical assistance, emotional support, and educational resources to alleviate cognitive burdens and enhance caregivers' coping mechanisms. Moreover, recognizing the pivotal role of caregivers in the well-being of adolescent patients, healthcare professionals should integrate family-centered approaches that consider the holistic needs of both patients and their caregivers. By addressing these critical factors, it is possible to improve the quality of life for caregivers and, consequently, for the adolescents they care for, fostering a more supportive and effective caregiving environment.

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Article History
Received: 14 October 2024
Accepted**:** 3 February 2025

APPENDIX

Table 1: Summary of included studies

Author	Country/year	Study participant	Type of study	Key findings
Xin Wei Isabel Tan, Siti Zubaidah Mordiffi, Violeta Lopez, Katherine Leong	Singapore (2021)	Caregivers of children with cancer (in treatment)-outpatient/inpatient	Descriptive correlational	The mean DT-P Score=5.07 (standard deviation = 2.78), out of a maximum of 10. Distress was reported among 67.9% (n = 55) of caregivers. The cognitive domain of caregiving problems on the DT-P was found to correlate with distress. Parents most frequently reported cognitive problems (n = 21, 25.9%) and, least often, social problems (n = 6, 7.4%). Practical (P = 0.040), emotional (P = 0.001), physical (P = 0.026), and cognitive problems (P = 0.001) of caregiving were statistically significantly associated with distress
Keun Hye Jeon, In Young Choi, In Young Cho, Dong Wook Shin, Ji Won Lee, Hee Jo Baek, Nack-Gyun Chung, Ki Woong Sung & Yun-Mi Song	Korea (2021)	Caregivers of childhood cancer survivors	self-administered questionnaires and a review of medical records.	to evaluate the unmet needs of caregivers of CCS. The greatest unmet needs =healthcare staff, followed by information. unmet needs mother–caregivers > father–caregivers in health and psychological problems, family/social support, and religious/spiritual support, with odds ratios (95% confidence interval) of 3.79 (2.52–5.69), 3.17 (2.09–4.81), and 1.69 (1.14–2.50), respectively. Compared with caregivers of the youngest CCS (< 6 years), caregivers of CCS aged 12–18 years and caregivers of the oldest CCS (≥ 19 years) respectively showed 2.62 (1.24–

				5.52) and 3.18 (1.34–7.55) times greater unmet needs for information. Caregivers of CCS who received haematopoietic stem-cell transplantation had a 2.01-fold (1.14–3.57) greater need for practical support.
Kim Mooney-Doyle, Janet A. Deatrick, Connie M. Ulrich, Salimah H. Meghani, and Chris Feudtner	United States (2018)	Parent of children with life-threatening illness	concurrent, cross-sectional mixed-methods study to describe challenges parents face prioritizing tasks and goals for each child with qualitative data, compare parents' tasks and goals for children with LTI and healthy siblings with quantitative data, and describe parenting in terms of the process of prioritizing tasks and goals for all children in the family.	Qualitative interviews revealed how parents managed children's needs and their perceptions of the toll it takes. Quantitative data revealed that parents prioritized “making sure my child feels loved” highest for ill and healthy children. Other goals for healthy siblings focused on maintaining emotional connection and regularity within the family and for ill children focused on illness management. Mixed-methods analysis revealed that parents engaged in a process decision making and traded-off competing demands by considering needs which ultimately transformed the meaning of parenting.
Sasha A Fleary, Robert W Heffer	United states (2013)	Family siblings	semi structured interview,	this study provides evidence for some lingering negative effects of growing up with an ill sibling on well siblings' late adolescent functioning. Additionally, evidence for siblings' development of positive characteristics that may act as protective variables as they face the stressors of late adolescence was also highlighted.
Soto-Guerrero et al.	United States (2023)	Caregivers and advanced cancer patients	cross-sectional study Caregivers; questions to describe the caregiving phenomenon and	high-intensity caregiver burden was associated with caregiver depression (59%vs. 27%; $p < 0.001$), anxiety (86% vs. 67%; $p = 0.003$), caring for the patient alone (45% vs. 24%; $p = 0.002$), perception of patient symptom distress, patient religion, and worse patient QOL (mean [standard deviation] 58

			burden of care, psychological distress, and perception of patients' symptoms; Patients: surveys to assess physical distress and quality of life (QOL)	[33] vs. 68 [27]; p = 0.03). In multivariate analysis, FC depression (OR [95% confidence interval] 3.07 [1.43–6.60]; p = 0.004), anxiety (3.02 [1.19–7.71]; p = 0.021), caring for the patient alone (2.69 [1.26–5.77]; p = 0.011), caregiver perception of patient's fatigue (1.26 [1.01–1.58]; p = 0.04), and patient's religion (3.90 [1.21–12.61]; p = 0.02) were independently associated with caregiver burden
Janet A Deatrick , Wendy Hobbie , Sue Ogle , Michael J Fisher , Lamia Barakat , Thomas Hardie , Maureen Reilly , Yimei Li , Jill P Ginsberg	United States (2014)	Caregivers(mother) of Adolescent and Young Adult Childhood Brain Tumor Survivors	structured self-report questionnaires were conducted in this cross-sectional study	The final SEM model suggests that survivor health and family functioning directly predict caregiver competence. Caregiver health indirectly predicts caregiver competence through caregiver demands and then family functioning. Family income directly predicts family functioning. The model showed adequate fit (CFI = 0.905, TFI = 0.880, and RMSEA = 0.081). Overall, the model accounted for 45% of variance in caregiver competence.
Xia et al	United States (2022)	patient and patient-caregiver(adult patient)	Primary caregivers; validated instruments investigating anxiety, depression, perceived stress and caregiver burden. Both caregivers and patients; the National Comprehensive Cancer Network Distress Thermometer	Patient and caregiver distress scores were not affected by patient clinical disease burden. Patient distress was a significant predictor of caregiver distress, anxiety, depression, and perceived caregiver burden Younger caregiver age was associated with higher caregiver anxiety and perceived burden. Additional predictors of caregiver depression and perceived stress included number of "other" caregiving activities (e.g., provision of emotional support, decision-making support) and overall health status.
Jo Taylor, Elizabeth Fradgley, Tara Clinton-McHarg,	Australia (2021)	Caregivers for a persons with cancer	grounded theory approach, semi-structured interviews	Six major themes (in relation to sources of distress): (1)a lack of sufficient and timely information;(2)uncertainty;(3) the role and duties of

Emma Byrnes & Christine Paul				caregiving;(4) lack of family-centred services;(5) practical challenges; and (6)impact of distress. Caregivers face a number of specific challenges beyond those experienced by patients. It is essential to ensure that Caregivers are actively well-informed and well-supported alongside the person who is diagnosed with cancer.
Zordan et al	Australia (2019)	Family caregiver of patient with cancer	A cohort of primary family caregivers of patients admitted to one of three palliative care services in Melbourne, Australia, participated in the study (n = 301). Sociodemographic, mental health, and bereavement-related data were collected from the caregiver upon the patient's admission to palliative care (T1). Further data addressing circumstances around the death and psychological health were collected at six (T2, n = 167), 13 (T3, n = 143), and 37 months (T4, n = 85) after bereavement	At T4, 5% and 14% of bereaved caregivers met criteria for PGD and subthreshold PGD, respectively. Applying the total PGD score at T4, linear regression analysis found preloss anticipatory grief measured at T1 and self-reported coping measured at T2 were highly statistically significant predictors (both $p < 0.0001$) of PGD in the longer term.

Made Indra Ayu Astarini, Ni Putu Wulan Purnama Sari, Lidya Costansa Wihelmina Oraplawal	Indonesia (2023)	Caregivers for a persons with cancer	Descriptive, cross sectional	Majority 53% of family caregivers were having stress in caring for patients with cancer
Nenden Lesmana Wati , Dinan Fashalna Qoyyimah	Indonesia (2018)	Mother of children with leukaemia		53 (39%) severe level of stress (overall 1356 mothers0 Physiological stress (moderate) 34% Psychological stress (severe) 39% Behavioural (moderate) (35%)
Rizki Surtiyan Surya , Christantie Effendy , Ridho Rahmadi	Indonesia (2021)	Family caregiver of cancer patient	Questionnaire survey	To understand factors to family caregiver burden -Caregiver Reaction Assesment (CRA) This study uses a causal modeling algorithm called Stable Specification Search for Cross-sectional Data with Latent Variable (S3CLatent) to obtain a causal model between the relevant caregiver family load factors. The results of modeling analysis showed that there are 3 factors which have a causal relationship and 2 factors have an association relationship. Gender has a stable causal relationship to health readiness and readiness to care, Moreover, the caring readiness factor affects the family caregiver activity factor, and the financial factor has a strong association with the activity factor and family relationships. This causal modeling can be used as a reference for health workers so as to give health services which are precise, efficient, and effective in dealing with caregiver burden
Ariane Santerre-Theil · Tyler L. Brown Annett Körner, Carmen G. Loiselle	Canada (2022)	Caregivers (who work as a health care providers) of cancer patients	Individual face-to-face semi-structured interviews	(1) salient dual role advantages, (2) significant challenges related to this role, (3) changes in professional practice as a consequence of informal caregiving, and (4) important palliative and end-of-life care access issues. Whereas professional knowledge helped advocate on behalf of patients, the dual role often came with over-solicitation from others,

				enhanced sense of responsibility, increased burden, and significant distress.
Ines Testoni , Anna Elena Nicoletti , Matilde Moscato and Ciro De Vincenzo	Italy (2023)	pediatric and adolescent oncology patients	Qualitative, semi structured interview	oncological diagnosis triggers different emotions taking the scene in the attempt to cope with the threats of meaning that the diagnosis poses. However, such intense experience promotes transformative feelings in parents and young patients, leading to important personal growth.
Melike Ayça Ay Kaatsız , Fatma Öz	Turkey (2020)	Family (siblings) of paediatric cancer patients	qualitative study hermeneutic phenomenological approach	Family siblings seek ways to make sense of the disease as they experience dramatic changes in all aspects of their lives (high level themes - first encounter with the disease and changes in life). They expect their parents and relatives to support them (expectations) when they turn to various methods to cope with the changes (coping styles).