



EXPLORING THE EXPERIENCES AND INNER
STRENGTHS OF CAREGIVERS OF CHILDREN
WITH LEUKEMIA IN MALAYSIA:
A QUALITATIVE STUDY

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UNIVERSITI SAINS MALAYSIA
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by

HAW YING HUEI

Thesis submitted in fulfillment of **Master of Psychology
(Clinical)** integrated program

UNIVERSITI SAINS MALAYSIA
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2025

DECLARATION

I hereby declare that the research work entitled “Exploring the Experiences and Inner Strengths of Caregivers of Children with Leukemia in Malaysia: A Qualitative Study” is a record of original work of my own. In making this declaration, I fully understand that any breaches of this declaration constitute academic misconduct and may lead to penalties.



.....
HAW YING HUEI
Candidate Signature

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This research project would not have been possible without the invaluable support, guidance, and encouragement I received from many individuals throughout this journey.

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ABSTRACT

Childhood leukemia presents not only a significant health challenge for young patients but also imposes a profound caregiving burden on their families. In Malaysia, where leukemia accounts for the highest childhood cancer mortality rate, there is a critical lack of qualitative research exploring the lived experiences and psychological resources of caregivers. This study aimed to explore the experiences and inner strengths of caregivers of children with leukemia in Malaysia. It sought to understand the multifaceted challenges they face and the coping mechanisms they utilize, filling a major gap in existing literature. A qualitative research design with a phenomenological approach was employed to gain in-depth insights into caregivers' lived experiences. Data were collected from 10 primary caregivers through semi-structured, in-depth interviews conducted online. Interpretative Phenomenological Analysis (IPA) was performed with the aid of Atlas.Ti software, and the identified themes were validated by one expert in the field to ensure credibility and trustworthiness. Findings revealed five experiential themes, which include emotional turmoil, social challenges, family and role conflict, work commitment challenges, and financial burden. Despite these challenges, caregivers exhibited four key inner strengths, which include positive appraisal, spirituality, resilience, and personal growth. Many caregivers reframed their experiences positively, found strength in religious beliefs, utilized support systems, and developed a deeper appreciation for life. This study offers a holistic understanding of the caregiving experience in the context of paediatric leukemia in Malaysia. The findings highlight the dual nature of caregiving, which is marked by emotional and practical struggles, yet also by the emergence of psychological resilience and growth. These insights can inform the development of culturally sensitive interventions, such as psychosocial support programs, caregiver education, and resilience training. Ultimately, this study contributes to a strengths-based framework for supporting caregivers and enhancing the well-being of families affected by childhood leukemia in Malaysia.

Keywords: Caregivers, Childhood Leukemia, Malaysia, Lived Experiences, Inner Strengths

ABSTRAK

Leukemia dalam kalangan kanak-kanak bukan sahaja merupakan cabaran besar dari segi kesihatan, malah turut memberi tekanan emosi dan tanggungjawab penjagaan yang besar kepada ahli keluarga, terutamanya penjaga utama. Di Malaysia, leukemia mencatatkan kadar kematian tertinggi bagi kanser kanak-kanak, namun kajian kualitatif yang menyelami pengalaman hidup serta kekuatan dalaman penjaga masih sangat terhad. Justeru, kajian ini dijalankan bagi meneroka pengalaman dan kekuatan dalaman penjaga kepada kanak-kanak yang menghidap leukemia di Malaysia. Kajian ini juga bertujuan memahami cabaran pelbagai dimensi yang dihadapi serta strategi daya tindak yang digunakan oleh penjaga dalam menjalani proses penjagaan, seterusnya mengisi jurang yang wujud dalam literatur sedia ada. Pendekatan kualitatif berasaskan fenomenologi telah digunakan bagi mendapatkan pemahaman yang mendalam terhadap pengalaman hidup penjaga. Seramai 10 penjaga utama telah ditemu bual secara dalam talian melalui temu bual separa berstruktur dan mendalam. Analisis data dijalankan menggunakan kaedah Interpretative Phenomenological Analysis (IPA) dengan bantuan perisian Atlas.Ti. Tema-tema yang dikenal pasti telah disahkan oleh seorang pakar dalam bidang berkaitan bagi memastikan kebolehpercayaan dan kesahihan dapatan. Hasil kajian mengenal pasti lima tema utama berkaitan pengalaman penjaga, iaitu pergolakan emosi, cabaran sosial, konflik kekeluargaan dan peranan, tekanan komitmen kerja, serta beban kewangan. Walaupun berhadapan pelbagai kesukaran, penjaga menunjukkan empat kekuatan dalaman yang ketara, iaitu penilaian positif terhadap situasi, sokongan kerohanian, daya ketahanan diri, serta pertumbuhan peribadi. Ramai penjaga berjaya menyesuaikan perspektif terhadap pengalaman mereka, memperoleh kekuatan melalui kepercayaan agama, memanfaatkan sistem sokongan sosial, serta membina penghargaan yang lebih mendalam terhadap kehidupan. Kajian ini memberikan gambaran menyeluruh tentang pengalaman penjagaan dalam konteks leukemia pediatrik di Malaysia dan menyumbang kepada pembinaan kerangka sokongan berasaskan kekuatan untuk meningkatkan kesejahteraan penjaga serta keluarga yang terlibat.

Kata kunci: Penjaga, Leukemia Kanak-kanak, Malaysia, Pengalaman Hidup, Kekuatan Dalaman

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LIST OF ABBREVIATION

IPA Interpretative Phenomenological Analysis

CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

This chapter begins by presenting the background of this study, which offers a comprehensive overview of childhood leukemia and its significant impact on caregivers, particularly in the Malaysian context. It outlines the research gaps, highlights the study's rationale, and states the research questions and objectives. Operational definition of key terms is also provided to ensure conceptual clarity.

1.2 BACKGROUND OF STUDY

Leukemia is a prevalent form of cancer that affects both children and adults. It begins when changes in the normal regulation of cell growth led to the uncontrolled proliferation of hematopoietic stem cells in the bone marrow (Davis et al., 2014). Childhood leukemia is a significant health concern worldwide, and it is the most prevalent type of cancer in children (Metayer et al., 2016). Three primary types of childhood leukemia include acute lymphoblastic leukemia (ALL), acute myelogenous leukemia (AML), and chronic myelogenous leukemia (CML), while CML remains the least common type (Kaplan, 2019). Genetic disorders, such as neurofibromatosis and Down syndrome, are linked to a higher likelihood of developing ALL and AML. In contrast, household pesticide exposure in infancy and during pregnancy is linked to ALL (Davis et al., 2014).

According to global research conducted by Namayandeh et al. (2020), which investigated the incidence and mortality rate of childhood leukemia, the cancer statistics in 2018 revealed that Malaysia has the second-highest incidence rate of leukemia worldwide, with approximately 8 cases per 100,000 children aged 0-14 years. This places Malaysia alongside Singapore (8.2 cases per 100,000 children) and the Republic of Moldova (2.7 cases per 100,000) as one of the countries with the highest incidence rates of childhood leukemia globally. Meanwhile, Malaysia was reported as having the highest mortality rate of childhood leukemia globally in both sexes, with approximately 4.2 cases per 100,000 children (Namayandeh et al., 2020).

The impact of childhood leukemia extends beyond the young patients themselves to deeply affect their caregivers, who play a central role throughout the treatment and recovering process (Mensah, 2023). The caregiving journey for families facing childhood leukemia is multifaceted, including emotional, social, financial, and environmental challenges (Atout et al., 2021; Chodidjah et al., 2022; Chong et al., 2022; Fisher et al., 2020; Lee & Lee, 2020; Melesse et al., 2023; Najjuka et al., 2023; Nightingale et al., 2022; Omari et al., 2022; Qiu & Wu, 2024). Caregivers' roles can be incredibly challenging when supporting their children, who might experience different symptoms of leukemia, such as infections, fever, pain, fatigue, etc. (Einungbrekke & Plank, 2016). Additionally, caregivers play a crucial role in supporting their children through complex treatment regimens and managing the day-to-day impact of the disease (PDQ, 2024). Caregivers also often face significant emotional burdens, including anxiety, depression, and stress, as they cope with their child's diagnosis and treatment and while caregiving their child (Ünal & Ordu, 2023). Moreover, they have to balance their caregiving responsibilities with other family obligations, work, social life, and their physical and mental health, which will often lead to feelings of overwhelm and burnout (Bialon & Cole, 2011; Duxbury et al., 2009; Lowder et al., 2005, Qiu & Wu, 2024).

However, in facing these overwhelming demands, many caregivers find themselves drawing upon internal sources, such as meaning-making, emotional endurance, and personal growth that help them sustain their caregiving role over time (Behzadi et al., 2018; Chen et al., 2022; Mehrotra and Sukumar, 2007). These inner resources not only help them cope with adversity but also foster strength and resilience. For instance, some caregivers might find positive meaning in their adverse caregiving

journey, which serves as one of their inner strengths (Chow et al., 2021). Understanding these caregiver experiences and adaptive strengths within the Malaysian context can provide valuable insights into how families navigate the challenges of childhood leukemia in diverse and meaningful ways.

1.3 PROBLEM STATEMENT

There is a significant lack of studies regarding caregivers' experiences within the Malaysian context, particularly concerning childhood leukemia. Few researchers have investigated the qualitative experiences of caregivers of cancer patients in Malaysia (Abdullah et al., 2023; Chong et al., 2022), and the experiences of caregivers for children with leukemia remain notably underexplored. Evidence of this gap is highlighted by the fact that only two qualitative journal articles are available in the Scopus and PubMed databases, specifically examining the caregiving experiences of patients with gastrointestinal cancer and acute lymphoblastic leukemia (Abdullah et al., 2023; Chong et al., 2022). This underscores a substantial gap in the literature, particularly in understanding the unique challenges of caregivers for children with leukemia in Malaysia.

Another notable gap in the literature is the limited exploration of caregivers' inner strengths and coping mechanisms, particularly within the Malaysian caregiving context. Caregiving for a child with a life-threatening illness like leukemia is widely acknowledged as a highly stressful and emotionally taxing experience (Atout et al., 2021; Borrescio-Higa & Valdés, 2022; Chodidjah et al., 2022; Chong et al., 2022; Fisher

et al., 2020; Lee & Lee, 2020; Mardakis et al., 2018; Melesse et al., 2023; Najjuka et al., 2023; Nightingale et al., 2022; Omari et al., 2022; Qiu & Wu, 2024). However, the psychological resources and strengths that caregivers draw upon to sustain their caregiving roles remain underexplored. These inner strengths play a critical role in helping caregivers manage stress, sustain emotional well-being, and persevere in their caregiving roles over time. Despite this, existing Malaysian literature has largely focused on the negative outcomes of caregiving, such as caregiver burden, stress, and reduced quality of life (Abdullah et al., 2019; Ahmad Zubaidi et al., 2020; Chong et al., 2022). Although Chong et al. (2023) made an important contribution by exploring spirituality as a coping mechanism among caregivers of children with leukemia in Malaysia, their study did not explicitly address broader dimensions of inner strength or other positive psychological resources, underscoring the need for further exploration in this area. By examining both the challenges and the inner strengths of caregivers, this study aims to provide a more balanced and holistic understanding of the caregiving experience.

Furthermore, there is a lack of qualitative research regarding caregivers' experiences and inner strengths in Malaysia. There are several quantitative studies that investigated the experiences of caregivers of cancer patients, particularly their quality of life, stress, and burden in Malaysia (Abdullah et al., 2019; Ahmad Zubaidi et al., 2020; Mahadevan et al., 2013). However, most of them are quantitative instead of qualitative research. Despite the fact that quantitative results could provide information about the experiences of caregivers, the qualitative study could provide a more in-depth and detailed understanding of their experiences. Therefore, this study aims to fill this

gap by employing a qualitative approach to investigate the experiences and inner strengths of caregivers for children with leukemia in Malaysia.

1.4 STUDY RATIONALE

This study aims to fill a significant gap in the academic literature on caregiving experiences for children with leukemia in Malaysia since there is only one past study related to this context (Chong et al., 2022). By exploring these aspects, it provided a foundation for future research and encouraged further exploration of this critical topic. Moreover, this study is significant in empowering caregivers by highlighting their inner strengths and fostering self-awareness in navigating the challenges associated with childhood leukemia caregiving. This self-awareness allows the caregiver to rely on their resources and strengths, thereby reducing dependence on external support. As a result, caregivers can develop greater confidence in their abilities to manage caregiving's emotional, social, and practical aspects.

Additionally, by delving into these caregiving experiences, the study aims to deepen the understanding of the caregiving journey for children with leukemia. This knowledge enables healthcare professionals, policymakers, NGOs, and support organizations to develop tailored interventions that can effectively improve the overall well-being of caregivers. Furthermore, the findings related to caregivers' inner strengths could help practitioners develop resources and training programs, allowing other caregivers to adopt similar strategies, which can further enhance their resilience and overall well-being.

1.5 RESEARCH QUESTIONS

- (1) What are the experiences of caregivers of children with leukemia in Malaysia?
- (2) What are the inner strengths of caregivers of children with leukemia in Malaysia?

1.6 RESEARCH OBJECTIVES

1.6.1 GENERAL OBJECTIVE

To evaluate the experiences and inner strengths of caregivers of children with leukemia in navigating the caretaking challenges in Malaysia.

1.6.2 SPECIFIC OBJECTIVES

- (1) To explore the experiences of caregivers of children with leukemia in Malaysia.
- (2) To determine the inner strengths of caregivers of children with leukemia in Malaysia.

1.7 CONCEPTUAL AND OPERATIONAL DEFINITION

1.7.1 CARETAKING EXPERIENCES

According to the dictionary of the American Psychological Association (n.d.), experiences are events or situations that individuals have lived through, involving their present awareness, and learning from stimuli encountered.

In this study, caretaking experiences were operationally defined as real-life events or situations related to providing care for a child with leukemia that participants recall and discuss during the interviews. These include the challenges, emotions, and interactions caregivers face in their caregiving journey (Hermanns & Mastel-Smith, 2012).

1.7.2 INNER STRENGTHS

Inner strength refers to an individual's innate mechanism for confronting challenging and stressful situations (Morgan et al., 2022). It is a quality and ability within an individual that contributes to their overall well-being and is closely linked to their physical and mental health (Lundman et al., 2019).

In this study, inner strength was operationally defined as the individual's demonstrated ability to persist in caregiving roles despite challenges, utilize positive

coping mechanisms, such as exhibiting resilience, and having positive appraisal in the case of adversity related to their child's leukemia diagnosis and treatment process.

1.7.3 CAREGIVERS

The caregivers were described as the family members of the patient with cancer who dedicate more hours each day to the patient's care, offer the most assistance and care, both financial and emotional support, and are aware of the health status of the patient (Barben et al., 2023; Kent et al., 2017; Thomson et al., 2021; Valeberg & Grov, 2013).

In this study, caregivers were operationally defined as family members actively involved in providing care to a child with leukemia for a minimum of one year and at least six hours per day. This operational definition is based on findings from Werdani (2020), which indicated that caregivers who provide care for more than six hours per day tend to experience severe stress levels compared to those who care for fewer hours.

1.8 SUMMARY

In this chapter, the researcher has provided the background and context of the study, emphasizing the impact of childhood leukemia on caregivers in Malaysia. It highlighted the research gaps, particularly the lack of qualitative studies on caregivers' lived experiences and inner strengths. The chapter outlined the study's rationale, research questions, objectives, as well as conceptual and operational definitions.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides a critical review of past literature related to caregiving in the context of childhood leukemia. It is divided into sections discussing caregivers' experiences and inner strengths. In addition, this chapter introduces and discusses two relevant theoretical frameworks, which serve to guide the interpretation and understanding of caregivers' experiences and inner strengths within this study.

2.2 CAREGIVERS' EXPERIENCES IN CANCER CARE

The experiences and challenges faced by caregivers can be very subjective and are always discrepant. It widely depends on various factors such as the stage of the patient's illness, the caregivers' relationship with the patients, the availability of resources, and the caregivers' inner strengths in coping with the caregiving challenges (DuBenske et al., 2008; Frank et al., 2023; Kastrinos, et al., 2021; Toledano-Toledano et al., 2020).

When looking at cancer in general, according to Mosher et al. (2015), when a patient with cancer reaches advanced stages, it can be especially stressful and challenging for the caregivers to deal with the patient's significant physical discomfort and unclear or unfavourable prognosis. Similar findings can be found in the study by Bahrami and Nasiri (2024), which investigated the caregiving experiences of patients with advanced cancer. Caregivers will feel especially helpless and incapable of offering their loved one useful care and treatment, particularly when the cancer is in its advanced stage. The same study also reported that when the patient has reached the final stage of cancer and is nearing death, the family system will deal with a severe crisis that is extremely draining and concerning on the life and future after losing their loved one (Bahrami & Nasiri, 2024). In addition, caregivers of patients in the late stages of cancer are often observed to be more vulnerable to adverse physical, psychological, and social consequences. This vulnerability arises from their frequent need to acquire new skills and techniques to support patients whose symptoms worsen over time, leading them to feel anxious and depressed (Morgan et al., 2022).

While some studies revealed that caregiving for patients with advanced-stage cancer can be particularly distressing, other studies found different outcomes, which highlighted that despite the stages of cancer, caregiving can be challenging and stressful (Nijboer et al., 2000; Sharma et al., 2024). A quantitative study conducted by Nijboer et al. (2000), which explored the experiences of caregivers in supporting their partners with cancer, demonstrated that even when their partners are in the early stages of cancer, caregivers still experience distress related to disrupted schedules, financial challenges, lack of family support, feelings of physical weakness and diminished self-esteem. Additionally, another study also found that depression and anxiety levels were higher when caring for patients with cancer at stage one and stage two, compared to caring for patients with cancer at stage three and stage four (Sharma et al., 2024). The fear that cancer will progress to advanced stages could be one of the reasons why caregivers experience higher distress when caring for patients with cancer in the early stage than in the advanced stage (Webb et al., 2023).

2.2.1 EMOTIONAL

When delving into the specific caregivers' experiences in terms of childhood leukemia, several key themes emerge that reveal the challenges and struggles in caring for children with this cancer. The first common theme is the emotional burden faced by the caregivers, such as stress, depression, anxiety, fear, worry, guilt, helplessness, etc. (Borrescio-Higa & Valdés, 2022; Chong et al., 2022; Lee & Lee, 2020; Qiu & Wu, 2024).

Due to the unique parent-child relationship between caregivers and patients with leukemia, caregivers often experience profound emotional distress. Based on a study by Chong et al. (2022), which explored the beliefs of caregivers about the caregiving of children with ALL, has found that the caregivers may experience an overwhelming emotional burden as they revealed that they are willing to trade their lives or absorb the stress in an attempt to replace or lessen their child's pain due to leukemia. As parents, witnessing their young child in pain and suffering is not an easy experience as it always evokes a sense of helplessness and hopelessness. This emotional burden is compounded by the unique parent-child relationship in caregiving, where parents always feel a profound responsibility to protect and care for their children. Similar findings can be found in the qualitative study by Qiu and Wu (2024), which evaluated the experiences of caregivers of patients with leukemia. The caregivers reported severe distress due to the concern about their child's health conditions, particularly worry about the increased risk of infection, intense pain, and recurrence of leukemia symptoms.

Not only qualitative studies but several quantitative studies have also demonstrated that caregivers reported higher levels of emotional burden in caregiving children with leukemia (Chivukula et al., 2018; Benedetto et al., 2022; Kumari et al., 2018). However, the level of emotional disturbance depends on the prognosis of the child's leukemia, as one study demonstrated that the majority of caregivers of long-term survivor children with leukemia have lower emotional distress because of the decrease in perceived caregivers' strain (Malpert et al., 2014).

2.2.2 ROLE CONFLICT

Besides being the primary caregiver of a child with leukemia, caregivers also face the pressure of fulfilling multiple roles within and between the family dynamic, including taking care of other family members such as other children and aging parents, managing their work commitments, and balancing various responsibilities (Qiu & Wu, 2024). The role conflicts in family dynamics are especially obvious when the caregiver needs to juggle caregiving duties between their child with leukemia and their other children. This is evidenced by the report of the respondents from several qualitative studies who revealed the overwhelming feelings of guilt and challenges associated with dividing their time and attention between caregiving for their children with leukemia and meeting the needs of the other children (Fisher et al., 2020; Lee & Lee, 2020).

Additionally, a study by Omari et al. (2020) further explained the alteration of caregivers' roles in their families. The caregivers described their parental roles as being interrupted and changed, particularly the mother who had to give up her responsibilities in handling household chores because of the need to accompany her child with leukemia, who has been hospitalized, while the father had to take on full responsibilities for the household tasks (Omari et al., 2020). This sudden shift in priorities led to a significant disruption in their daily routines and family dynamics.

Besides having role conflict in terms of family dynamics, role strain in terms of work commitment and caregiving can be found in a qualitative study by Najjuka et al. (2023), which investigated the caregivers' experiences for patients with advanced cancer in Uganda. One of the father caregivers of a child with ALL revealed the

difficulties in balancing his job and caregiver roles, in which he had to prioritize caregiving over his job, which eventually resulted in loss of income (Najjuka et al., 2023). Similar findings were observed in the studies conducted by Lee and Lee (2020) and Omari et al. (2020), where respondents disclosed the necessity of leaving their jobs because of the hospitalization or demanding treatment schedules for their children with leukemia.

2.2.3 SOCIAL

Social isolation is also another common theme that can be found when discussing the experiences of caregivers in caregiving their children with leukemia (Atout et al., 2021; Chodidjah et al., 2022; Fisher et al., 2020; Mensah et al., 2023). According to Atout et al. (2021), due to the need to take care of their children with leukemia and focus their full attention on them, the caregivers often isolate themselves from the outside world. The same finding was demonstrated in the study by Mensah et al. (2023), where the caregivers revealed that they chose to withdraw from social activities because they had to take care of their child with leukemia at home.

In addition to their sense of obligation to be present for their children, some caregivers disclosed that they tend to withdraw themselves from social interaction due to the fear of stigma and blame associated with their children's leukemia (Atout et al., 2021). This finding aligns with the results of a study by Chodidjah et al. (2022), which noted that caregivers of children with leukemia often experience cancer-related stigma from the people around them. This stigma arises due to the lack of knowledge about

leukemia among the general population, leading to resistance to interacting with the affected family. As a result, caregivers may choose to isolate themselves to avoid negative comments related to their child's disease (Chodidjah et al., 2022).

However, amidst these challenges, Fisher et al. (2022) shed light on a different perspective. Some caregivers expressed a desire for isolation to detach themselves from the complexities of the family system and reduce social pressures (Fisher et al., 2022). While most studies often highlight the negative consequences of social isolation, isolation provides a safe capacity for individuals to engage in self-reflection and create meaning to the events that happen to them (Brown et al., 2021). While social isolation among caregivers of children with leukemia presents both challenges and potential benefits, it ultimately depends on the individual's unique circumstances. Therefore, further exploration through qualitative research is necessary to gain a comprehensive understanding of how social isolation impacts caregivers and their ability to cope with the complexities of caregiving.

2.2.4 FINANCIAL

Apart from that, the financial burden is one of the most common topics that has been mentioned in studies regarding caregivers' experiences (Atout et al., 2021; Mardakis et al., 2018; Melesse et al., 2023; Nightingale et al., 2022). Based on a qualitative study by Nightingale et al. (2022), which investigates the financial burden among the caregivers of adolescents and young adults with cancer, the economic burden experienced by the caregivers encompasses both the direct and indirect expenses

associated with cancer. The direct costs include the tangible expenses directly linked to the sickness, such as those spent for treatment, transportation, food, accommodation, etc., while the indirect costs refer to the monetary value of reduced productivity due to the sickness, which may include reduced work hours, unpaid leave, or even leaving one's job (Ren & Li, 2019). According to the study by Ren and Li (2019), which examined the direct and indirect costs of a family who has a child with ALL shows that an urban family might need to spend an average cost of USD 36,125.00, while a rural family might need to spend an average cost of USD 25, 593.00, in managing their children with leukemia.

The tremendous financial burden faced by the caregivers of children with leukemia can be evidenced by a qualitative study by Mardakis et al. (2018). The findings of the study not only outlined the direct and indirect costs in relation to the disease but also mentioned the possible future expenses, for instance, the debts that the caregivers need to return to their family, relatives, or friends due to the financial strain caused by the ongoing management and treatment of cancer. Furthermore, a study by Melesse et al. (2023) adds another perspective to the financial burden. Caregivers in the study reported that the lack of health insurance has increased their burden and worry in managing the medical expenses associated with their child's illness (Melesse et al., 2023). This highlighted the critical role of accessible healthcare coverage in alleviating the financial strain experienced by caregivers.

2.3 INNER STRENGTHS OF CAREGIVERS

Inner strength is an individual's innate mechanism for confronting challenging and stressful situations (Morgan et al., 2022). It is a quality and ability within an individual that contributes to their overall well-being and is closely linked to their physical and mental health (Lundman et al., 2019). Inner strength has a vital function in maintaining good psychological wellness and emotional well-being and is, therefore, an essential element of overall healing. Individuals with strong inner strength possess the resources they need to sustain and support themselves, develop, and reach maturity, as well as the capacity to overcome challenges, endure pain, and achieve a fulfilling existence even in challenging circumstances (Hosseini et al., 2016). Moreover, developing inner strengths is especially crucial for caregivers who are caring for children with cancer. Developing inner strengths could increase the caregivers' self-awareness and self-acceptance of the hardships. In addition, it can also improve their problem-solving abilities and reduce emotional suffering, allowing them to have the capacity to handle the challenges and cope with the difficulties they may face in their caregiving journey (Ubolyam, 2017).

2.3.1 POSITIVE APPRAISAL

While previous studies have portrayed caregiving roles as obligations, duties, demands, or struggles for caregivers (Atout et al., 2021; Borrescio-Higa & Valdés, 2022; Chodidjah et al., 2022; Chong et al., 2022; Fisher et al., 2020; Lee & Lee, 2020; Mardakis et al., 2018; Melesse et al., 2023; Najjuka et al., 2023; Nightingale et al., 2022;

Omari et al., 2022; Qiu & Wu, 2024), it is essential to recognize the inherent value and significance of these roles.

Positive appraisal is the cognitive tendency to interpret adverse or threatening situations in a constructive and optimistic manner, serving as a key resilience mechanism that supports psychological well-being (Riepenhausen et al., 2022). A qualitative study by Mehrotra and Sukumar (2007), which examined the perceived sources of strength among women caregivers of relatives with cancer, revealed that caregivers often view their caregiving experiences as an opportunity to reciprocate kindness by caring for others. Additionally, some caregivers see the act of caregiving as an expression of giving, with the expectation of receiving care in return, particularly during times of need (Mehrotra & Sukumar, 2007). These findings emphasize the subtle viewpoints of caregivers and highlight the positive aspects of caregiving that extend beyond obligations and struggles.

While limited qualitative studies address how caregivers perceive the positive appraisal as their inner strength in navigating caregiving challenges, a study by Lyu et al. (2019) has provided similar insights. In this study, caregivers perceived their inner strength as being optimistic in terms of how they view their present circumstances (Lyu et al., 2019). This aligns with previous outcomes that have been discussed, indicating that caregivers search for favourable meanings and purposes to make sense of their current circumstances, which allows them to maintain balanced psychological and emotional states while navigating their caregiving experiences.

2.3.2 SPIRITUALITY

Spirituality is a multidimensional construct encompassing the search for meaning, purpose, and values that expressed through self-awareness, relationships with others, and transcendent relationship with God or a higher power (Lifshitz et al., 2019). Spirituality and faith are one of the inner strengths highlighted in the studies, which can serve as a protective factor for caregivers in facing challenging caregiving experiences (Boonchuaylua et al., 2023; Chong et al., 2023; Klassmann et al., 2008; LeSecure & Chongkham-ang, 2015; Mehrotra & Sukumar, 2007).

During the initial phase of the diagnosis, the caregivers often experienced a phase of questioning, anger, and injustice towards their faith or religious beliefs. However, they later transitioned to a more optimistic thought, perceiving the challenging circumstances they encountered as a test from God and a source of motivation to exert their greatest effort (Mehrotra & Sukumar, 2007). In addition, a systematic review by LeSeure and Chongkham-ang (2015) discovered that caregivers with strong religious and spiritual beliefs often turn to prayer and seek support from their religious communities. The caregivers perceived their faith as a means of obtaining psychological and spiritual resilience, which allowed them to find comfort in the thought that a greater power was looking after them and providing them with courage, which in turn reduced their anxiety during the challenging period (LeSecure & Chongkham-ang, 2015).

Similar findings can be found in a qualitative study by Chong et al. (2023), which explored the spiritual coping employed by the caregivers of children with cancer within a Malaysian Muslim context. Among the Muslim caregivers, they also perceived spirituality as a sense of hope that can relieve their child's pain and foster recovery; meanwhile, they are also more optimistic in accepting their challenging circumstances as a necessary component of the plan of God, which in turns providing them with solace and strength to navigate the difficulties of caregiving (Chong et al., 2023). Similarly, religious belief is seen as a vital aspect of spiritual support in the Thai Buddhist culture. The caregivers who hold a strong religious belief in Buddhism explained spirituality as a system of belief filled with optimism, which can offer them resilience through the integration of the body and mind and the strength to overcome their life's obstacles (Boonchuaylua et al., 2023). Therefore, despite the diversity of spiritual beliefs, which encompasses Allah, Buddhist, and Jesus teachings, the common thread is that a strong belief system serves as a foundational inner strength aiding caregivers to discover the positive side of their caregiving journey and promote their overall well-being.

2.3.3 RESILIENCE

Resilience explains how individuals who encounter challenges and stress can have a favourable outcome, and it focuses on how people adapt to events that they regard as stressful and challenging (Palacio et al., 2019). Resilience is a significant inner strength that is important for caregivers as individuals who demonstrate resilience are far more inclined to utilize positive coping strategies, such as openly discussing their worries and expressing their fears and emotions to others, which are crucial in maintaining their

psychological and emotional well-being during the challenging period (Ong et al., 2018).

According to a qualitative study by Chow et al. (2021), which interviewed the caregivers of stroke survivors, the caregivers emphasize the need to develop resilience by acquiring skills to handle self-care and the demands of life effectively. The caregivers realized that throughout their caregiving journey, those who have a high resiliency have a greater awareness of their own and others' well-being, which led to the improved ability to take care of themselves, manage their lives, provide care, interact with others, and fulfill their roles (Chow et al., 2021). In addition, individuals with resilience have the ability and capacity to be flexible in their thinking, behaviour, and emotion, which allows them to adapt more effectively to their significant stressful life changes (Tugade & Fredrickson, 2004). This is evidenced by a study that showed how resilient caregivers can accept the reality of illness, maintain a positive attitude, and take proactive steps toward adjusting to the situation when they face stressful caregiving experiences (Kuang et al., 2022).

Moreover, another study by Ciydem and Sinmaz (2023) highlighted the importance of resilience as an inner strength of caregivers in navigating their caregiving experiences. One of the respondents in this study discussed the challenges and hardships she had faced before starting her caregiving journey. Despite these difficult circumstances, the respondent expressed determination and strength in taking care of her current husband who is ill, which demonstrated her ability to cope with past challenges and continue providing support and care to her loved ones despite the difficulties she has faced. (Ciydem & Sinmaz, 2023). Therefore, the awareness of

resilience is always crucial as it empowers caregivers to recognize their capacity to overcome obstacles, maintain their well-being, and meanwhile effectively fulfill their caregiving roles.

2.4 THEORETICAL FRAMEWORK

2.4.1 CAREGIVING STRESS PROCESS MODEL

The caregiving stress process model by Pearlin et al. (1990) proposed a significant paradigm for comprehending the stress process and its connection to physical and mental well-being (Yu et al., 2020). It outlines that the stress of caregivers can originate from either the individual or the disability itself, or they can stem from the demands associated with the caregiving roles (Pearlin et al., 1990). Besides that, it focuses primarily on the contextual and macro-levels, and it posits that caregiver's stress is a complex and interconnected phenomenon consisting of four distinct components, which include the background and context of the stress process, primary and secondary stressors, mediators, and outcomes (Figueiredo, 2017).

Firstly, Pearlin emphasizes that personal factors, such as age, gender, employment, education, resources, and the relationship of caregivers with the patient, significantly influence the stress process (Schumacher et al., 1993). These factors are said to play a significant role in stress as they influence both the stressors individuals encounter and the resources and options they have for mitigating stress (Schumacher et al., 1993). For instance, in the context of caregivers for children with leukemia, the

nature of the caregiver's relationship with the child, such as the parent-child relationship, can influence the emotional and psychological impact of caregiving. Parents might feel an intense emotional burden due to their deep emotional connection with their children and the profound impact of the illness on their family dynamic (Chong et al., 2022; Qiu & Wu, 2024).

In addition, the second component described in the caregiving stress processing model is the primary and secondary stressors. The primary stressors refer to the specific factors resulting from the sickness or condition requiring caregiving, such as the patient's functional decline or problematic behaviour (Schumacher et al., 1993). The initial idea by Pearlin is proposed based on Alzheimer's patients, which he described as primary stressors as the challenges in caregiving Alzheimer's patients who suffered from cognitive impairment, such as memory loss (Pearlin et al., 1990). However, a similar idea can be applied to caregivers of children with leukemia, who face their own set of primary stressors, such as managing the child's symptoms and side effects from treatment, like pain, fatigue, and infections (Einungbrekke & Plank, 2016). On the other hand, the secondary stressor refers to the additional pressures and psychological stresses that arise as a result of the primary stressors (Pearlin et al., 1990; Schumacher et al., 1993). These stressors can include difficulties in managing family responsibilities, work-related stress, changes in daily routines, and impacts on the caregivers' physical and psychological health (Najjuka et al., 2023; Omari et al., 2020; Qiu et al., 2024).

Apart from that, the model highlights the role of mediators, such as social support and coping strategies, in mitigating the effects of stress (Murphy et al., 2006). Social support and coping strategies act as intermediary elements that reduce the impact