RESEARCH Open Access

# Check for updates

# Mothers' efforts to overcome difficult twists and turns in living with children with cancer: a phenomenological study

Mahnaz Ghaljeh<sup>1</sup>, Sally Pezaro<sup>2</sup> and Marjan Mardani-Hamooleh<sup>3\*</sup>

# **Abstract**

**Background** Child cancer impacts the entire family. However, those who identify as mothers may be most negatively affected due to the societal expectations placed upon them in primary caregiving. This study was conducted with the aim of exploring the lived experiences of mothers of children with cancer and their adaptation to their child's illness.

**Methods** This study employed a qualitative and hermeneutic approach using Heideggerian phenomenology as a philosophical framework. Our sampling strategy was purposive. Mothers (n = 14) of children diagnosed with cancer participated in face-to-face semi-structured interviews. The seven-steps of critical hermeneutic analysis were used to summarize and interpret findings.

**Results** Analysis revealed that participants' adaptation to their child's illness occurs through comprehensive support and the utilization of empowering beliefs. The theme of comprehensive support included sub-themes of seeking informational support, seeking psychological support, and seeking social support. The theme of utilizing empowering beliefs encompassed sub-themes of resilience against cultural misconceptions and reliance on spiritual beliefs. Furthermore, one constitutive pattern 'mothers' efforts to overcome difficult twists and turns in living with children with cancer' was identified. This related to participants' striving to navigate the twists and turns of life's hardships.

**Conclusions** Relationships and social context are vital and important features of this phenomena. Employing a team approach to provide comprehensive support to mothers of children with cancer involving physicians, nurses, and psychologists can be supportive in their adaptation to their child's cancer. Additionally, reductions in cultural taboos surrounding cancer could facilitate improved adaptation to childhood cancer for these mothers.

Keywords Cancer, Children, Mother, Qualitative research

\*Correspondence:

Marjan Mardani-Hamooleh

mardanimarjan@gmail.com

<sup>&</sup>lt;sup>3</sup>Department of Nursing, Nursing and Midwifery Care Research Center, University of Medical Sciences, Vanak Sq., Zafar St, 1996713883 Tehran, Iran



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material described from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

<sup>&</sup>lt;sup>1</sup>Department of Nursing Management, School of Nursing and Midwifery, Community Nursing Research Center, Zahedan University of Medical Sciences, Zahedan, Iran

<sup>&</sup>lt;sup>2</sup>School of Nursing, Midwifery and Health, Research Centre for Healthcare and Communities, Coventry University, Coventry, UK

Ghaljeh et al. BMC Women's Health

#### Introduction

Childhood cancer is one of the leading causes of morbidity and mortality in the pediatrics age group, affecting both developed and developing countries [1]. The most common childhood cancer worldwide is acute lymphoblastic leukemia [2]. In some areas, approximately 4% of deaths among children under five years old and 13% of deaths among children aged 5 to 15 occur due to cancer [3]. However, in recent years, survival rates from childhood cancers have increased [4]. A child's diagnosis with cancer not only affects their own life but also poses challenges for their entire family [5]. Often, child cancer requires long-term engagement with healthcare services [6], imposing significant pressure upon caregivers, and adaptation to chemotherapy, sometimes on a daily basis [7]. These factors increase the negative impact on the mental health of wider family members [8], and families can feel disabled when trying to cope [9]. The news of a child's cancer diagnosis is notably stressful and shocking, and parents can experience significant distress from this [10], alongside social anxiety, depression, and stress concerning a child's illness [11]. Older parents with increased income tend to experience less stress and adopt better coping strategies [12]. Nevertheless, all families of children with cancer can lack adequate coping strategies for adapting to their child's illness and thus are considered to be vulnerable overall [9]. Parents are particularly challenged in this context as they spend a disproportionate amount of time with their child affected by cancer as opposed to their other children [13].

A study conducted in Belgium revealed how family members experienced significant disruption in overall family unity following the child's cancer diagnosis [5]. Research involving parents of Hispanic/Latino origin highlighted the profound exhaustion and detrimental health effects experienced while caring for a child with cancer [14]. In Turkey, parents caring for children with cancer experienced what is termed as 'compassion fatigue' [15], whilst parents of children with cancer in Korea reported experiencing anxiety related to mortality, feelings of guilt, and an exhaustive lifestyle due to caregiving responsibilities [16]. Families of children with cancer in Hong Kong were afraid of disease recurrence and the consequences of cancer [17]. In Ireland, families of children with cancer experienced fear and guilt related to cancer, which affected their family interactions [18]. The results of a study in Denmark showed that childhood cancer had disturbed the daily life of the family and its dynamics [19]. A study conducted in Iran similarly highlighted how having a child with cancer significantly affects family members, diminishing their overall quality of life [20]. Collectively, these findings suggest that parental challenges in this context are shared and must be met with effective support. Yet prior to this it will be important to uncover how these challenges are experienced in more depth.

Whilst findings in a variety of geographical areas appear relatively consistent, scoping reviews of the literature suggest that there remains a lack of evidence with regards to the lived experiences of those who identify as mothers with children diagnosed with cancer adapting to their children's illness in Iran. An understanding of these lived experiences would inform the provision of more effective care and services in this context, particularly for mothers, who may be most affected due to the societal expectations placed upon them in primary caregiving. Considering the above, this study aimed to uncover the shared and common meanings in the lived experiences of those who identify as mothers with children diagnosed with cancer, and their adaptation to their children's illness.

# **Methods**

# Design, sample, and recruitment

Using Heideggerian phenomenology as a philosophical background, the study employed a qualitative and phenomenological hermeneutic approach in order to reveal new phenomena in this particular area of exploration. Phenomenological hermeneutics serves as an appropriate framework to comprehend the underlying meanings inherent in human experiences within their lived world. This approach also facilitates the unearthing of individuals' lived experiences by uncovering the associated variables through deep exploration of phenomena and providing a pathway to gain insights by revealing meaning. Essentially, this approach enables a comprehensive and in-depth exploration, and a proper understanding and interpretation of their beliefs, convictions, interests, values, and lived experiences [21].

Gadamer followed the works of Heidegger and was a student of Heidegger's in the mid-1920s. Heidegger and Gadamer describe hermeneutics as "the theory and practice of interpretation and understanding in different types of human contexts". Individual lived experiences and interpretation are essential elements to understand the phenomenon that is explored [22]. Gadamer, said that understanding can only come about through language. He saw language, understanding and interpretation as inextricably linked. For Gadamer, language is not independent of the world: the world is represented by language and language is only real because the world is represented within it [23]. Phenomenological research using Heideggerian philosophy have explored in women's health, mental health, and cancer studies [24-30]. Considering the above, this approach was considered appropriate to use in meeting our aim as it allowed for more meaning to be unearthed in this context for those we intended to include as participants.

Our sampling strategy was purposive. Those who identified as mothers were invited to participate if their children were undergoing treatment for cancer at the Pediatric Oncology Department in the Ali Ibn Abi Talib Educational Hospital located in Zahedan. These mothers had firsthand experience, spanning a minimum of three months, in living with their child's cancer diagnosis during their hospital stay. We aimed to capture diverse perspectives by considering variables such as age, educational background, and the duration of time participants had been caregiving. Recruitment began in the Pediatric Oncology Department once ethical approval had been granted. Potential participants were first invited to read information about the study and participation whilst in the department. They were then invited to offer their written informed consent to participate by signing a consent form. Subsequently, face to face interviews were arranged at a time most convenient to participants. This sampling continued until data saturation was reached in our analyses.

# **Data collection**

Data collection occurred in the first three months of 2023, utilizing semi-structured and face-to-face interviews. The interview guide was developed by the research team drawing from previously published research conducted in similar contexts, and comprised of questions such as: "What experiences do you have with having a child diagnosed with cancer?"; "What strategies have you used to adapt to your child's cancer?" and "Based on your experiences, what does this adaptation mean?" Additionally, probing questions and phrases such as "Is your intention with ... to convey this?"; "Please elaborate further," or "Could you provide an example to clarify your point?" were also used to prompt further information during interviews. These interviews lasted between 45 and 65 min and were conducted in private either within the hospital premises or in the hospital's playroom away from other patients and/or family members. Interviews were recorded with participants' permission. The principle of confidentiality was also observed throughout the process.

# Data analysis

Data collection and analysis occurred simultaneously. After each interview, audio recorded data were transcribed onto paper. We then utilized a 7-step method proposed by Diekelmann and colleagues (1989) for critical hermeneutic data analysis [31]. This method of analysis is common in hermeneutic phenomenological research [3, 32–34], as it uses a team approach and enables the highest level of interpretation when compared with other approaches. We undertook the following steps using this method:

- 1. All interviews were assessed for familiarization with the overall dataset.
- 2. Probable common meaning units were recognised, using extracts to support interpretations and interpretive summaries, which were typed up for each interview.
- 3. Selected versions of interview texts were subsequently analysed until themes were identified.
- 4. Interview texts and participant feedback were used to clarify discrepancies and contradictions in interpretations, aiding us to craft an overall combined analysis for each interview.
- 5. All texts were revised to verify emergent themes and subthemes, which were then classified by the research team.
- One constitutive pattern was identified that linked themes and subthemes together and presented the relationships between themes and subthemes across all texts.
- 7. The final findings in the form of primary themes were presented in a final report which included quotes to highlight salient meanings throughout.

Interview texts were analysed hermeneutically using Heideggerian phenomenology [21] as a philosophical framework and lens with which to view the data. As outlined above, transcripts were reviewed multiple times to gain an overall understanding of the data. Subsequently, an interpretive summary was written for each text, focusing on understanding and extracting implicit meanings. The research team then engaged in discussions regarding the identification of sub-themes and themes. As subsequent interviews unfolded, previous topics became clearer or evolved, and sporadically as new subjects were introduced. To clarify and resolve any discrepancies or contradictions in interpretations, frequent referencing of texts occurred back-and-forth, alongside analytic discussions with both the research team and participants. Common meanings began to emerge, and themes that described these meanings as relational across texts were illuminated. At each stage, interpretive summaries were integrated to form a broader analysis and establish cohesive connections among the derived themes. Finally, primary themes and subthemes were written up and are presented using participant quotes to highlight the overall sentiment of themes and phenomena.

To ensure the rigor of the results, criteria such as credibility, dependability, confirmability, and transferability were employed [35]. For credibility, continuous engagement with the subject matter and data was maintained. Findings were also shared with some participants and two nursing PhD candidates for validation. To ascertain dependability, the input of an external observer outside of the research team who was familiar with both the

studied phenomenon and qualitative research was also sought to sense check interpretations. For confirmability, all authors read the transcript and agreed on the meaning units, subthemes and themes. Also, all activities were recorded in detail and a report of the research process was finalized. For transferability, findings were shared with two mothers of children with cancer who were not part of the study who further validated and confirmed congruence with our interpretations. We combined this with an exhaustive description of the study's setting, participants, context and method.

# **Results**

# **Participants**

Participants taking part (n=14) were aged between 25 and 48 years old, with the majority holding a high school diploma (n=10). The average duration of participants caring for a child with cancer was approximately three years. The children of participants were aged between 3 and 12 years old, and had been living with cancer diagnoses from 1 to 5 years. Among the children, twelve were diagnosed with leukemia, while two were diagnosed with brain tumors.

# **Overall experiences**

Analyses revealed mothers' adaptation to their child's illness through comprehensive support and leveraging effective beliefs. The theme of comprehensive support encompassed sub-themes such as seeking informational, psychological, and social support. Leveraging effective beliefs involved sub-themes like resilience against cultural misconceptions and reliance on spiritual beliefs. These themes and sub-themes represented the meaning of adaptation for mothers of children with cancer based on their lived experiences. Furthermore, one constitutive pattern; 'mothers' efforts to overcome difficult twists and turns in living with children with cancer' was identified.

#### Comprehensive and supportive care

Participants engaged in comprehensive supportive care to adapt to their child's illness. Accordingly, they sought and received various types of informational, psychological, and social support.

# Seeking informational support

Following their child's cancer diagnosis, participants had specific informational needs and pursued informational support. They received a range of informational support from healthcare providers, which facilitated the path to adaptation to cancer.

"When my daughter was diagnosed with cancer, I was unaware. I had many questions and expected nurses and doctors to respond. I regularly asked

them about the type of illness, treatments, and what the outcome would be. I truly didn't know anything." (Participant (P) 2).

"When chemotherapy started, its side effects were truly distressing. My child's hair fell out, she lost her appetite, and she was always fatigued. However, teachings and guidance from healthcare workers were helpful to me." (P8).

Additionally, participants strived to update their knowledge about childhood cancer, obtained through means such as online searches and reading relevant articles and books.

"To enhance my knowledge about leukemia, I use the internet and visit scientific websites about cancer, which have been very helpful... I've joined a Telegram channel that regularly posts new articles about childhood cancers... If a book is recommended, I buy and read it." (P11).

# Seeking psychological support

Participants aimed to alleviate the distress of living with a child with cancer and overcoming the challenging conditions resulting from this situation by seeking assistance from psychological services.

"Mothers of children with cancer, including myself, strive to accept and adapt to these challenging circumstances by seeking help from psychologists. I firmly believe that the psychologist can help us pass the life deadlock in this situation... I feel that living with a child with cancer is akin to standing on the edge of a precipice. Hence, the assistance of a psychologist is crucial." (P5).

Obtaining family counseling, where counselors empathized with mothers, aimed to uplift their hope and assured them of their child's recovery and return home, was another strategy aiding adaptation to having a child with cancer.

"I remember when I went to the family counselor, I was in tears, but they spoke to me attentively and listened to my concerns. While offering me comfort, they mentioned, 'Your child is undergoing treatment and will get better, returning home soon. Be attentive; if you surrender, you'll lose. You must remain hopeful for the future." (P12).

# Seeking social support

One of the most influential positive factors in the lived experiences of mothers was receiving adequate support from family and relatives. Receiving familial support and companionship with other mothers of children with cancer had a significant impact on navigating life crises and adapting to having a child with cancer.

"If I have made it to this point and endured, the primary reason has been the support I received from my family. Initially, my parents supported me. If it weren't for their empathy and understanding, especially at the beginning of my child's illness when I felt my world had collapsed, perhaps I wouldn't have coped with this pain... Apart from my family, my relatives and my husband also provided significant support. They never let us be alone." (P10).

Being in the company of other parents of children with cancer and befriending them facilitated changes in life circumstances, aiding mothers in better adaptation. A significant impact of interacting with other parents of children with cancer in the lived experiences of mothers was comparing themselves to these parents, which significantly influenced their perspectives.

"When I found and befriended other parents of children with cancer, I noticed differences between their situations and mine, either worse or better. Observing the situation of some of their children compared to mine... well, I compared myself with those who, despite having a child with cancer, managed to adapt appropriately and succeed, aiming to improve my own life." (P4).

# **Utilizing adaptive beliefs**

In order to truly accept the reality of their child's cancer and adapt to it, mothers used strategies of resilience against the misconceptions rooted in their culture and heavily relied on their spiritual beliefs.

# Resilience against cultural misconceptions

Throughout the journey of adapting to their child's cancer, participants faced misconceptions stemming from their societal culture. In their lived experiences, they encountered the taboo of associating cancer with death. Nonetheless, they utilized strategies such as refraining from dwelling on this issue and continuing with life despite these limitations.

"Unfortunately, there's a cultural poverty in our country. It's very challenging for a child diagnosed with cancer because their mother can't talk to any-

one about it for a long time. People believe cancer means the end of life, that if a child gets cancer, they'll definitely die! But I try not to dwell on this issue; these beliefs exist in our society, and we have to live with these cultural constraints." (P13).

Participants expressed in their lived experiences the suffering caused by the stigma around cancer, as well as the pitying and sympathetic views of others in society. To adapt to these circumstances, they employed strategies such as disregarding these mistaken cultural beliefs.

"In our country, culturally, it seems like cancer is a stain, and people look at it in a terrible way. I understand the severity of others' perspectives and their sympathetic behaviors. I heard one of our neighbors, with a pitying tone, talking about us, saying, 'Oh, their child has cancer'... Although it hurt to hear, it didn't make me value these wrong beliefs, and it didn't drive me into isolation." (P9).

#### Relying on spiritual beliefs

Relying on spiritual beliefs emerged as a positive and influential factor in the genuine acceptance of a child's cancer reality. Through seeking solace in the divine, having faith in a higher power, and believing in divine providence, mothers strived to adapt to their child's cancer.

"The belief I held helped me; belief in divine providence and faith in divine trials and wisdom... Honestly, at the beginning of the illness, I felt guilty, thinking it was a punishment for something I had done wrong, that my child's cancer was a consequence of my wrongdoing. I was on the verge of losing faith in God. What I asked from God was not to be shaken in my beliefs, not to become distrustful of Him due to my son's cancer... I pray to God to remove any obstacles in my path because I believe my son's affliction with cancer is part of his life journey." (P7).

Amidst having a child with cancer, focusing on the meaning of life brought forth a sense among mothers that the efforts and endurance following cancer were not futile or purposeless, but rather held profound wisdom and meaning.

"I concluded that my child's cancer signifies God's special attention and kindness to him and me. I have a mission here to seek patience for my child's recovery and endure these hardships, especially when my child undergoes chemotherapy and I witness its side effects, which is when I suffer the most

and need to endure these hardships... I believe God selects certain individuals for certain circumstances; I know we became like this because we truly needed to cope with these conditions, and it holds wisdom for itself." (P3).

The constitutive pattern Mothers' efforts to overcome difficult twists and turns in living with children with cancer.

The meaning of adaptation to a child's cancer for mothers is embedded within the cultural and social context of Iran. In their endeavor to navigate life's difficult twists and turns throughout the challenging journey of adapting to a child's cancer, mothers seek various forms of informational, psychological, and social support from family, relatives, healthcare professionals, psychologists, family counselors, and other mothers of children with cancer. The inevitability of adaptation to a child's cancer is made possible by leveraging elevated beliefs such as spiritual beliefs and resilience against cultural misconceptions. Yet these beliefs, rooted in erroneous societal thoughts, were perceived by these participants as stigmatizing.

#### Discussion

This study aimed to uncover the shared and common meanings in the lived experiences of mothers with children diagnosed with cancer, and their adaptation to their children's illness. Findings revealed that these mothers' endeavor to navigate the complexities of life to adapt to their child's illness. In this regard, they experienced multifaceted support strategies and utilized empowering beliefs. The idea that we adjust to deal with our affairs as we respond to what we are confronted with is central to Heidegger's notion of coping. Indeed, this relates to "our everyday being-in-the-world", as the entities we encounter which are "closest to us" become the objects of our everyday dealings or coping [21]. As illuminated here, and based on the quotations from participants mothers' changed both in behaviour and attitude as they battled to adjust to new ways of being in the world, and therefore became what Heidegger calls resolute in grappling with their new reality [21].

In pursuit of comprehensive support, mothers sought this from informational, psychological, and social sources. They accessed diverse informational resources, including medical staff-provided education, online platforms, and social networks to address their varying informational needs concerning their child's illness and treatment. Nevertheless, human support has been considered the most important source of support for successful coping of families with children with cancer elsewhere [36]. In Australia, the parental requirement for further insights into their child's condition was

similarly highlighted as an ongoing need that dynamically evolves throughout the stages of the child's illness [37]. Likewise, parents of children diagnosed with cancer in China expressed a dynamic spectrum of informational needs from the disease's inception to its conclusion [38]. As such support is so sought after, future research could usefully explore effective modes of information delivery from staff and services in this context.

Studies involving Hispanic and Latino parents underscore the significance of having support from the medical team [14]. Guatemalan families with cancer-diagnosed children addressed their informational needs through various sources such as medical centers, media, and the community, seeking guidance from oncologists and other caregiving entities within these centers [39]. One study demonstrated how such informational support from medical teams in caring for children with cancer had reduced the burden of care [14]. Metaphors like 'life deadlock' and 'precipice edge' illustrated participants' encounters with life alongside caring for a cancer-diagnosed child, emphasizing their reliance on psychological support to navigate the impasse and edge, and fostering hope for the future. Similarly, Irish families with cancer-diagnosed children had unmet psychological needs affecting family dynamics. This exacerbated the psychological impacts resulting from the child's diagnosis and treatment, further emphasizing the necessity for family psychological services [18]. Moreover, hope for the future served as a driving force for Australian parents of cancer-diagnosed children in their caregiving [37]. Consequently, support which cultivates hope will be important in designing future support services.

Our participants sought diverse forms of social support from relatives, other cancer-diagnosed children's mothers, and extended family members, fostering connections as a means of support. The findings of a study in the United States highlight how families who received social support had also reduced the suffering caused by their child's cancer [8]. In Sweden, findings similarly echo the necessity for social support among families with cancer-diagnosed children [7]. Hispanic and Latino parents also experienced enhanced self-efficacy, empowerment, and comfort through social support during their care for cancer-diagnosed children [11]. From a Heideggerian perspective and based on quotations from participants 2, 4, 5, 8, 10, 11 and 12, such connectedness to others is considered both important and of consequence to our very being in the world [21]. Indeed, interactions with parents of other children diagnosed with cancer played a pivotal role in adapting to and being with their child's cancer. This bond facilitated an environment for sharing experiences and utilizing others' experiences to better cope with difficulties and recognize their potential for change and empowerment. Similarly, Guatemalan Ghaljeh et al. BMC Women's Health

families found solace in interacting with families facing similar challenges [39]. Overall, the findings from this study and various others from across the globe underscore the importance of many forms of support provided to families of cancer-diagnosed children, significantly contributing to their adaptation to their child's illness. Such findings emphasize the need for supporting and connecting with this vulnerable group as a globally recognized strategy.

Our study further found that participants, in their pursuit of adapting to their child's cancer, utilized positive and effective beliefs as part of resilience strategies against cultural misconceptions, relying predominantly on their spiritual and religious beliefs. Similarly, parents of cancer-diagnosed children in Israel also sought assistance in achieving adaptability through positive thinking [40]. Participants also expressed grappling with a range of cultural misconceptions in their journey towards adaptation to their child's illness. Their strategy involved resilience against these beliefs by refraining from dwelling on them and ultimately transcending these limitations. These cultural misconceptions encompassed notions such as the stigma surrounding cancer, societal sympathies towards the imminent death of a child, disparaging attitudes, and mothers facing the taboo of equating cancer to death. Whilst Harmen (2011) suggests from a Heideggerian perspective that death is not usually a shocking event, the death of a child may be considered shocking and unexpected in a context where children more generally have years of life ahead of them [41]. Participants perceived these misconceptions as stemming from prevalent cultural deficiencies within society. Heidegger suggests that such judgment or imagined truth without evidence whilst on the way to understanding is everywhere and is an inescapable part of human life [21]. This concept was unearthed via the quotations given by participants number 9 and 13. Conversely, those leaning on spiritual beliefs managed to overcome feelings of guilt and the sense of culpability they assumed about their child's cancer diagnosis, dispelling potential doubts they might have harbored in this regard. Thus, future research could usefully explore how faith and societal beliefs may interact in this context to unearth how resilience may be fostered more readily.

Spiritual beliefs clearly aided participants in enduring difficult circumstances. In this regard, Hispanic parents of cancer-diagnosed children in the United States also resorted to strategies such as embracing spirituality to cope with cancer-induced stress [42]. The results of other studies conducted in Iran and Malaysia also indicated that mothers of children with cancer used spirituality to cope with cancer [20, 43]. Similarly, families of cancerdiagnosed children in Taiwan experienced feelings of guilt concerning their child's cancer [44]. In line with this,

Chinese participants also felt guilt due to the potential loss of their child and witnessing their child's suffering. They held themselves accountable for their child's cancer. Nonetheless, they expressed their ability to overcome hardships [38]. Heidegger (1962) contends that in proximity to death and dying, the waiting tends to immortality as happiness - toward union with God (theology) and, coming from a Christian perspective, contends that the totality of entities is subdivided into God, Nature and man [21]. This statement appeared in the quotations of participants number 3 and 7 and illuminates the ways in which spirituality is connected to the inevitability of death and dying.

Our study uniquely uncovers the shared and common meanings in the lived experiences of those identifying as mothers with children diagnosed with cancer, and their adaptation to their children's illness. Since few studies of this nature have been conducted specifically in the cultural context of Iran, our findings provides important and novel contributions to the evidence base and early understandings in this area. Nevertheless, our study is limited as the findings of qualitative research are always context-dependent and therefore cannot be generalized to other contexts and/or cultural backgrounds.

# **Conclusions**

This study reveals how relationships are vital in the lived-experience of being a mother of a child with cancer and adapting to this reality as a new way of being. Seeking comprehensive support relates to interpersonal and social relationships in this context, further emphasizing the influence of the social environment upon the phenomena of these experiences and adaptations. Future exploration of relationships between internal and social dynamics may enable deeper understandings in relation to adaptation to a child's cancer diagnosis. Employing a team approach to provide comprehensive support involving physicians, nurses, and psychologists is one way to assist in families' adaptation. Adaptation and efforts to navigate life's difficulties in this context are also deeply influenced by cultural factors. Consequently, cultural taboos regarding cancer must be addressed to facilitate better adaptation and will require extensive cultural interventions within the healthcare system. The most significant cultural taboo in relation to cancer reflected within our findings in the context of Iran is that cancer equated to death. To ease human suffering, television may be used as an effective intervention for the promotion of public awareness and change in this regard.

# Acknowledgements

The researchers are thankful to all of the participants who participated in this research.

#### **Author contributions**

Study design: MG, MMH. Data collection: MG, MMH. Data analysis: MG, MMH. Study supervision: MG, MMH, SP. Manuscript writing: MG, MMH, SP. All authors have read and approved the final manuscript.

#### **Funding**

The author(s) reported there is no funding associated with the work featured in this article.

#### Data availability

The datasets generated and analysed during the current study are not publicly available due to the confidentiality and the traceability of the qualitative data but are available from the corresponding author on reasonable request.

# **Declarations**

#### Ethics approval and consent to participate

All methods were performed in accordance with the relevant guidelines and regulations. This study was registered with the Ethics Committee of Zahedan University of Medical Sciences under the code IR.ZAUMS.REC.1401.439. Written informed consent was obtained from all participants, and the right to withdraw at any stage of the research was respected.

#### Consent for publication

Not applicable.

#### **Competing interests**

The authors declare no competing interests.

Received: 6 January 2024 / Accepted: 6 August 2024 Published online: 17 August 2024

# References

- Endalamaw A, Assimamaw NT, Ayele TA, Muche AA, Zeleke EG, Wondim A, et al. Prevalence of childhood Cancer among children attending referral hospitals of outpatient Department in Ethiopia. BMC Cancer. 2021;21(1):271. https://doi.org/10.1186/s12885-021-08014-0.
- Camiré-Bernier É, Nidelet E, Baghdadli A, Demers G, Boulanger MC, Brisson MC, Michon B, Lauzier S, Laverdière I. Parents' experiences with Home-based oral chemotherapy prescribed to a child diagnosed with Acute Lymphoblastic Leukemia: a qualitative study. Curr Oncol. 2021;28(6):4377–91. https://doi. org/10.3390/curroncol28060372.
- Ghaljeh M, Rezaee N, Mardani-Hamooleh M. Nurses' effort for providing endof-life care in paediatric oncology: a phenomenological study. Int J Palliat Nurs. 2023;29(4):188–95. https://doi.org/10.12968/ijpn.2023.29.4.188.
- Lan X, Wu J, Liao Z, Wu Y, Hu R. Prevalence of symptoms in children with acute lymphoblastic leukaemia: a systematic review and meta-analysis. BMC Cancer. 2023;23(1):1113. https://doi.org/10.1186/s12885-023-11581-z.
- Schoors MV, Mol JD, Laeremans N, Verhofstadt LL, Goubert L, Parys HV. Siblings' experiences of Everyday Life in a family where one child is diagnosed with blood Cancer: a qualitative study. J Pediatr Oncol Nurs. 2019;36(2):131–42. https://doi.org/10.1177/1043454218818067.
- Chaudhuri T, Nandakumar D, Datta SS, Husain Z, Sukumaran RK, Yadav IS, Krishnan S, Panda S. Information-sharing experiences of professionals looking after children with cancer: a qualitative exploration from a specialist paediatric oncology unit in India. Ecancermedicalscience. 2022:16:1399doi: https:// doi.org/10.3332/ecancer.2022.1399
- Andersson CB, Karlsson AK, Bergsten U. Togetherness in loneliness experiences of a group activity for families with a child suffering from cancer as described from the parents' perspective. Scand J Caring Sci. 2022;36(2):439–45. https://doi.org/10.1111/scs.13057.
- Smith SM, Teer A, Ariceaga ET, Billman E, Benedict C, Goyal A, et al. A
  qualitative study of childhood cancer families' post-treatment needs and
  the impact of a community-based organization in a rural, socioeconomically disadvantaged, majority Hispanic/Latino region. Pediatr Blood Cancer.
  2024;71(2):e30798. https://doi.org/10.1002/pbc.30798.
- Christensen SR, Carlsen LT. From well-known to changed everyday family life in families with childhood cancer: a grounded theory of disrupted

- family dynamic. Psychooncology. 2022;31(2):282–9. https://doi.org/10.1002/pon.5809.
- Yamaji N, Nagamatsu Y, Kobayashi K, Hasegawa D, Yuza Y, Ota E. Information needs of children with leukemia and their parents' perspectives of their information needs: a qualitative study. BMC Pediatr. 2022;22(1):414. https:// doi.org/10.1186/s12887-022-03478-w.
- Ochoa-Dominguez CY, Chan RY, Cervantes L, Banegas MP, Miller KA. Social support experiences of hispanic/latino parents of childhood cancer survivors in a safety-net hospital: a qualitative study. J Psychosoc Oncol. 2023;1–14. https://doi.org/10.1080/07347332.2023.2259365.
- Atout M, Almomani EM, Alhusban RY, Al-Tarawneh FS, Mohammad S. Stress levels and coping strategies among Jordanian parents caring for newly diagnosed children with leukemia: a cross sectional descriptive correlational study. J Psychosoc Oncol. 2022;40(5):632–51. https://doi.org/10.1080/073473 32.2021.1995802.
- McEvoy B, Creaner M. The experiences of mothers who have a child diagnosed with cancer. Psychol Health. 2022;37(5):597–614. https://doi.org/10.10 80/08870446.2021.1872791.
- Ochoa CY, Chan RY, Cervantes L, Baezconde-Garbanati L, Farias AJ, Milam JE, Cho J, Miller KA. Barriers and facilitators of Hispanic/Latino parents caregiving for a childhood cancer survivor: a qualitative study. Cancer Causes Control. 2023;34(2):151–60. https://doi.org/10.1007/s10552-022-01651-1.
- Orbay İ, Baydur H, Uçan G. Compassion fatigue in Informal caregivers of children with Cancer; a section from Turkey. Soc Work Public Health. 2022;37(8):729–43. https://doi.org/10.1080/19371918.2022.2085837.
- Lee D, Lee S. Clinging to my child: mothers' experiences taking care of a child hospitalized with leukemia. Clin Nurs Res. 2021;30(4):415–22. https://doi. org/10.1177/1054773820957479.
- Yeung NCY, Cheung KC, Chau HC, Leung AWK, Li CK, Lam TTN, et al. Transition from Acute Treatment to Survivorship: exploring the psychosocial adjustments of Chinese parents of children with Cancer or Hematological disorders. Int J Environ Res Public Health. 2021;18(15):7815. https://doi.org/10.3390/ijerph18157815.
- Barrett PM, Mullen L, McCarthy T. Enduring psychological impact of childhood cancer on survivors and their families in Ireland: a national qualitative study. Eur J Cancer Care (Engl). 2020;29(5):e13257. https://doi.org/10.1111/ ecc.13257
- Petersen NN, Hansson H, Lie HC, Brinkkjaer M, Graungaard B, Larsen MH, et al. A qualitative study of young childhood cancer survivors and their parents' experiences with treatment-related late effects in everyday life post-treatment. J Adv Nurs. 2022;78(3):858–68. https://doi.org/10.1111/jan.15073.
- Ghasemi SS, Bagheri-Saveh MI, Shali M, Zakariaee S, Zakaryaee NS. Explaining the process of spiritual Adjustment in parents of a child with Cancer: a qualitative study. J Caring Sci. 2022;11(4):232–8. https://doi.org/10.34172/ics.2022.27.
- 21. Heidegger M. Being and Time. Translated by Macquarie & Robinson, 1st ed. Basil Blackwell, Oxford. 1962.
- Suddick KM, Cross V, Vuoskoski P, Galvin KT, Stew G. The work of Hermeneutic Phenomenology. Int J Qualitative Methods. 2020;19:1–14. https://doi.org/10.1177/1609406920947600.
- Sloan A, Bowe B. Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. Qual Quant. 2014;48(3):1291–303. https://doi.org/10.1007/s11135-013-9835-3.
- Ebrahimi E, Mohammadi Shirmahaleh F, Mardani-Hamooleh M, Habibi Asgarabad M. Iranian obese women's lived experiences of Social and linguistic factors shaping emotional eating behavior: a phenomenological study. J Qual Res Health Sci. 2023;12(4):195–200. https://doi.org/10.34172/jgr.2023.28.
- Kissiwaa AVM, Fouché N. Ghanaian women's experiences of unsuccessful in-vitro fertilisation treatment, unravelling their meanings: a heideggerian hermeneutic phenomenological study. BMC Pregnancy Childbirth. 2024;24(1):212. https://doi.org/10.1186/s12884-024-06365-7.
- Leekuan P, Kane R, Sukwong P. Narratives on sex and Contraception from pregnant adolescent women in a Northern Province in Thailand: a phenomenological study. Inquiry. 2021;58:469580211056219. https://doi. org/10.1177/00469580211056219.
- Riahi S, Thomson G, Duxbury J. A hermeneutic phenomenological exploration of 'last resort' in the use of restraint. Int J Ment Health Nurs. 2020;29(6):1218–29. https://doi.org/10.1111/inm.12761.
- Gamm S, Ummel D, Vasil N, Grenier S. Getting insight to the lived emotional experience of people with Alzheimer's disease shortly after diagnosis: a

- Phenomenological Approach. J Alzheimers Dis. 2024;99(3):1129–45. https://doi.org/10.3233/JAD-231403.
- Shahmari M, Nikbakht Nasrabadi A, Rezaie E, Dashti S, Nasiri E, Zare L. Lived experiences of young adults facing a recent diagnosis of cancer: a phenomenological study. Health Expect. 2023;26(5):1874–82. https://doi.org/10.1111/ hex.13793.
- Borimnejad L, Mardani-Hamooleh M, Seyedfatemi N, Tahmasebi M. Palliative nursing for Cancer patients as an Abstract Concept: a hermeneutic study. J Nurs Res. 2018;26(4):260–5. https://doi.org/10.1097/jnr.000000000000232.
- Diekelmann N, Alien D, Tanner C. The NLN Criteria for Appraisal for Baccalaureate Programs: a critical hermeneutic analysis. New York: National League for Nursing; 1989.
- Ratta CD. The art of balance: Preceptors' experiences of caring for deteriorating patients. J Clin Nurs. 2018;27(19–20):3497–509. https://doi.org/10.1111/jocn.14579
- Minyaev S, Harrington A, King L. Could standing orders have a place? A
  phenomenological exploration of experienced ward-based registered
  nurses' views on the escalation protocol for patient deterioration. J Clin Nurs.
  2022;31(11–12):1669–85. https://doi.org/10.1111/jocn.16022.
- Omoya OT, De Bellis A, Breaden K. Death, dying, and end-of-life care provision by doctors and nurses in the Emergency Department: a phenomenological study. J Hosp Palliat Nurs. 2022;24(2):E48–57. https://doi.org/10.1097/ NJH.000000000000837.
- 35. Lincoln YS, Guba EG. Naturalistic Inquiry. London: Sage Publications Inc; 1985.
- Nielsen CL, Clemensen J, Callesen MT, Jensen CS, Smith AC, Holm KG. Who is supporting the parents during their child's cancer treatment? A qualitative study through the lens of compassion. Eur J Oncol Nurs. 2024;70:102534. https://doi.org/10.1016/j.ejon.2024.102534.
- Vetsch J, Wakefield CE, Duve E, McGill BC, Warby M, Tucker KM, Malkin D, Lau L, Ziegler DS. Parents', Health Care professionals', and scientists' experiences of a Precision Medicine Pilot Trial for patients with high-risk Childhood Cancer: a qualitative study. JCO Precis Oncol. 2019;3:1–11. https://doi.org/10.1200/ PO.19.00235.

- Lyu QY, Wong FKY, You LM, Zhou XZ. Unmet Family Needs Concerning Healthcare Services in the setting of Childhood hospitalization for Cancer Treatment in Mainland China: a qualitative study. J Pediatr Nurs. 2019;44:e66–71. https://doi.org/10.1016/j.pedn.2018.11.003.
- Graetz D, Rivas S, Fuentes L, Cáceres-Serrano A, Ferrara G, Antillon-Klussmann F, Metzger M, Rodriguez-Galindo C, Mack JW. The evolution of parents' beliefs about childhood cancer during diagnostic communication: a qualitative study in Guatemala. BMJ Glob Health. 2021;6(5):e004653. https://doi. org/10.1136/bmjgh-2020-004653.
- Schwartz-Attias I, Krulik T, Aharon AA, Ronen T. Perceptions of children with cancer and their parents regarding illness: a qualitative study. J Pediatr Nurs. 2023;71:32–41. https://doi.org/10.1016/j.pedn.2023.03.006
- 41. Harman G. Heidegger explained. From Phenomenon to Thing. Open Court. 2011
- 42. Ochoa-Dominguez CY, Miller KA, Banegas MP, Sabater-Minarim D, Chan RY. Psychological impact and coping strategies of hispanic parents of children with Cancer: a qualitative study. Int J Environ Res Public Health. 2023;20(11):5928. https://doi.org/10.3390/jjerph20115928.
- Chong ASS, Ahmad MB, Alias H, Hussain RBI, Lateh AB, Chan CMH. Spiritual coping among families of children with Cancer: a qualitative study. Asia Pac J Public Health. 2023;35(6–7):408–12. https://doi.org/10.1177/10105395231190830.
- Chen CF, Huang FL, Chen YC, Wang IF, Huang YP. Maternal caregiving for children newly diagnosed with Acute Lymphoblastic Leukemia: traditional Chinese mothering as the double-edged Sword. J Pediatr Nurs. 2020;53:e64–71. https://doi.org/10.1016/j.pedn.2020.02.008.

# **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.