



University of Hormozgan

Mothers' Lived Experiences of Losing a Child to Cancer: A Phenomenological Study

Farideh Sadat Sajjadipour¹ | Marieh Dehghan Manshadi² | Najmeh Sedrpoushan³ |
Mohammad Hosein Fallah⁴

1. PhD. Student, Department of Counseling, Yazd Branch, Islamic Azad University, Yazd, Iran. E-mail: faridesajady@pnu.ac.ir
2. Corresponding author, Assistant professor, Department of Counseling, Yazd Branch, Islamic Azad University, Yazd, Iran. E-mail: Dehghan@yahoo.com
3. Assistant professor, Department of Counseling, Yazd Branch, Islamic Azad University, Yazd, Iran. E-mail: sedrpoushan@iaukhsh.ac.ir
4. Associate Professor, Department of Counseling, Yazd Branch, Islamic Azad University, Yazd, Iran, Iran. E-mail: fallahyazd@iauyazd.ac.ir

Article Info

Article type:

Research Article

Article history:

Received 10 May 2023

Received in revised form Aug. 2023

Accepted 25 Sep. 2023

Published online 01 December 2023

Keywords:

Lived experience,
Mothers
Grief,
Cancer,
Death of a child

ABSTRACT

Objective: The death of a child is undoubtedly the most arduous encounter for a mother in her lifetime, and it elicits numerous psychological detriments. Specifically, the death of a child resulting from cancer carries its own set of challenges. Analyzing the lived experience of these mothers can serve as a means to identify and comprehend their grief, thus becoming the foundation for efficacious interventions. Consequently, the objective of the present investigation was to scrutinize the lived experiences of grieving mothers whose children had succumbed to cancer.

Methods: The current research was conducted utilizing a qualitative and phenomenological approach. The sampling technique employed was purposive, encompassing a maximum variation sampling. The study included a total of 13 bereaved mothers residing in Yazd city, who had lost their children to cancer. The methodology employed for data collection involved semi-structured interviews.

Results: Subsequent to conducting the interviews and documenting them, each recorded session was transcribed and examined utilizing Colaizzi's method. This process yielded six primary themes and twenty-four secondary themes through the analysis of the data. The primary themes comprised emotional experience, physical experience, cognitive experience, challenging experience, the meaning of life, and avoidance.

Conclusions: These findings demonstrate the nature of the grief experienced by mothers, and these themes have the potential to facilitate effective interventions aimed at mitigating the symptoms of grief.

Cite this article: Sajadipour, F., Dehghan Manshadi, M., Sedrpoushan, N. & Fallah, M. (2023). Mothers' lived experiences of losing a child to cancer: a phenomenological study. *Iranian Evolutionary Educational Psychology Journal*, 5 (4), 281-299.

DOI: <https://doi.org/10.22034/5.4.281>

© The Author(s).

Publisher: University of Hormozgan.



DOI: <https://doi.org/10.22034/5.4.281>

Introduction

Cancer is a chronic ailment that afflicts a significant number of children. The occurrence of childhood cancer-related deaths is a grave concern on a global scale, with an estimated 413,000 child deaths attributed to cancer in the year 2020 alone (American Children's Cancer Society, 2021). This figure has displayed an upward trajectory, and projections indicate that approximately 14 million children will be diagnosed with cancer between the years 2020 and 2050 (Aton, Bacta, Denberg, Frazier, Frederick et al., 2020). In Iran, nearly two thousand children under the age of 15 receive a cancer diagnosis on an annual basis (Pakpour et al., 2019). Consequently, cancer ranks as the second leading cause of death among children below the age of 14 in Iran. Furthermore, cancer accounts for approximately 4% of deaths among children under the age of 5 and 13% of deaths in the 5 to 10-year-old age group (Paksaresht et al., 2018).

Cancer generates a range of physical, psychological, social, economic, and emotional responses for both the child and their family, thereby imposing a substantial care burden on the latter. The loss of a child to cancer constitutes a profoundly distressing event that engenders protracted grief (Snaman et al., 2020). The bereavement experienced by parents following the death of a child entails complex traumatic reactions, detachment from the deceased child, and feelings of guilt.

The grieving process for parents following the loss of a child to cancer spans a duration of 5 to 7 years. Furthermore, this bereavement is intensified during specific periods, such as holidays, resulting in a form of re-bereavement for parents (Nappa et al., 2016). Numerous studies have explored the psychological challenges faced by parents with a child afflicted by cancer. A majority of these parents undergo depression and anxiety, bereavement, existential anxiety, identity and spiritual crises, post-traumatic stress disorder, deleterious effects on coping mechanisms, blame and guilt, adverse impacts on health, impaired social interactions, and heightened levels of psychological distress. Such cases necessitate the intervention of specialists. Moreover, despite the involvement of all family members, the experience of losing a child to cancer is more arduous and distinct for the mother, given her role as the primary caregiver (Lichtenthal et al., 2015).

Bereavement signifies an internal reaction to the loss of something that is cherished or highly regarded. The process of mourning encompasses typical stages that individuals traverse. Nonetheless, individuals exhibit diverse responses to bereavement, with certain individuals displaying adaptability and progressing through these stages, while others necessitate intervention

and specialized aid. In specific cases, such as the loss of a child, grief can manifest as intricate or abnormal (Duta et al., 2018). In the majority of instances, grieving parents undergo a complex form of grief following the loss of their child. These parents encounter difficulties in deviating from the natural trajectory of familial expectations. This is despite the strong connection and attachment to the child, and the majority of parents attempt to derive meaning from this loss and confront a crisis of meaning (Nimer, 2019). Various models have been proposed to explain the intensity of this experience. Factors such as early loss, the quality and nature of the relationship with the deceased, the role of the deceased, characteristics of the death, and the quality of the supportive social network are variables that collectively contribute to the profundity of the bereavement experience in parents (Zhu et al., 2020). This form of bereavement often becomes heightened in parents who have experienced continuous loss, and parents bereaved by cancer are susceptible to long-term bereavement and psychological symptoms even after a span of six years (Pollkamp, 2020). Despite the challenges associated with articulating this experience in numerous research studies, there have been limited investigations conducted on the quality of this experience specifically in mothers, particularly in relation to the bereavement of a child with cancer. Hence, the primary inquiry in this study revolves around how mothers undergo the grieving process resulting from the death of a child with cancer.

Materials and Methods

The current research design was qualitative and phenomenological. The number of sample people in this research was 13 mothers bereaved of a child with cancer in Yazd city in 2022. The sampling method was purposive, encompassing a maximum variation sampling. Sampling adequacy was determined by data saturation. In this way, no new categories were added after conducting 10 interviews, but for more certainty, 3 more people were also interviewed. A semi-structured interview method was also used to collect data.

After interviewing the participants and recording the interview, each of the recorded interviews was written down on paper and analyzed using the Colaizzi's method. It should be noted that after analyzing each interview and shaping the organized concepts, the next interview was conducted. This method continued until the completion of all interviews. The data analysis was done in such

a way that first the interviews were re-read several times to understand the interview atmosphere and the participants. The written information related to the interviews was read several times to understand the general content, this was done along with listening to parts of the recorded information. In the next step, the main codes and important phrases of each interview were extracted. In this way, the sentences and phrases related to the questions in the interviews were separated and kept in another file. This was done so that information that was less important would not be lost because their importance might be determined in the next steps. In the third step, the meaning of each phrase was explained and summarized with the meaning of its part. In this way, a short description of its hidden meanings is written for each important sentence and this work was done by two people. Then the meanings extracted from the sentences are combined to obtain a common meaning. In the fourth step, the meanings were organized into categories of codes. That is, the meanings obtained in the previous stage were placed in separate clusters and discussed. In the fifth step, the codes were placed in the form of categories related to each other in a more general category and then clusters from which the core concepts were obtained. In the sixth stage, the findings were discussed and described, and finally we answered the structure of the phenomenon. Validity checking methods in this research also included the criteria of validity, transmission, trust and verifiability, and authenticity. To increase the credibility in this research, long-term and continuous engagement, avoiding premature conclusions without sufficient observations, constructive discussion about the findings with impartial and honest colleagues, progressive mentality means monitoring the formulated structures and documenting the change process from the beginning to the end. The end of the study, the review of the participants and the confirmation of the findings of the analysis by the participants and the researcher's self-review have been effective in the process of data collection and analysis. The transfer in this research was done through the development and rich description of the data set during the collection and the use of special coding methods. In the present study, all the interviews were conducted for 60 to 90 minutes and in order to gain trust, all the interviews were recorded and then implemented verbatim. Coding was done and compared by the researcher and another expert in the qualitative field. Also, it was used to review and adapt the opinion of some qualitative researchers as well as participants in the research. In the current research, in order to obtain confirmation, the researcher has carefully

recorded and noted all the steps and reported them in different ways so that other people can use and follow up the necessary items if needed. The coding process was also fully explained.

6 main themes and 24 secondary themes were obtained from the analysis of mothers' lived experience.

Results

Six primary themes and twenty-four sub themes were derived from the examination of the maternal lived experiences. The outcomes have been displayed in Table 1.

Table 1. Main and secondary themes of mothers' lived experiences of bereavement of a child with cancer

Main themes	Sub themes
Emotional experience	1- Feeling guilty
	2- Anger
	3- Sadness and depression
	4- Anxiety
	5- Longing
	6- 6- The feeling of going crazy
Physical experience	1- Feeling of heaviness in the chest and difficulty in breathing
	2- Feeling hot
Cognitive experience	1- Denial
	2- Why did this happen?
	3- Preoccupation
	4- Idealization of the dead person
	5- Belief in dreaming
Difficult experience	1- Sadness is always accompanied
	2- Deep sadness
	3- Burning sadness
	4- Endless sadness
	5- Suffering of the child due to illness
The meaning of life	1- Sense of emptiness
	2- Change in importance
	3- Getting stronger
	4- Divine test
Avoidance	1- Behavioral
	2- cognitive

Main theme one: emotional experience

The participants have experienced many emotions and their most conflict was dealing with emotions after the death of their child. In the following, sub-themes related to this theme are explained.

Guilt: The experience of guilt has been one of the painful and unpleasant emotions for bereaved mothers. Feeling guilty about whether they had spent all their efforts to treat the child's illness and whether there was a deficiency on their part was the main reason for the guilt experienced by mothers. Anger when tired and inappropriate behavior in some cases with a sick child was another reason for feeling guilty in these people. Also, the survivor felt guilty for feeling happy and happy after the death of the child.

Participant number 5: *"I feel guilty and short, I did everything for him. I wish I had stayed with him more in the hospital. Or, for example, when I was looking for work at home, I was more with him"*.

Anger: Anger was experienced especially in participants who blamed others or felt anger because of the incident. Anger towards God and why this happened and why the child did not recover despite prayers and vows were among other experiences. The experience of anger was in mothers who had not yet accepted the issue of bereavement to a great extent and had not come to terms with it.

Participant number 13: *"I have no hope anymore. I am angry with everything and everyone, I cried out to God so much, but I didn't hear an answer"*.

Sadness and depression: The most common emotion experienced by the participants was sadness and depression and emotions from this family such as despair, helplessness, feeling helpless and tired. These people experienced grief intensely and expressed it in various ways.

Participant number 1: *"Life has no meaning anymore. I am all sad. I don't get out of his mind for a moment. I can't do anything. I got depressed. I don't want to do anything. There is only sadness. My child is nothing. I did not mother him at all. I put him aside and now after eight months he is not with me at all. It is not closed much at home. I'm not bored at all"*.

Anxiety: having anxiety was mentioned by the participants without giving a specific reason for it. Participant number 3: *"I don't know what's wrong with me? I don't want to My heart is confused. I have anxiety, I'm not going. My soul is tired. To the extent that nothing makes me happy. Nothing just Helia. I mean, God knows how many tears I have shed for Helia in these ten months, in my solitude..."*.

Missing: Feeling of missing the lost child due to not seeing him and not seeing his sleep and the absence of the child were other feelings experienced.

Participant number 9: *"I am the same now, I am never ungrateful, I say whatever I miss, God, whatever is best for you." You gave and you took... When I am alone, I sit and cry. I put his picture on the wall when I miss him, I sit in front of him, cry and talk to him.*

Feelings of going crazy: Participants stated that they were unable to think deeply about the loss and that they would go crazy if they tried to think deeply about the loss. They have experienced the feeling of madness in connection with the loss and sadness of not having a child.

Participant number 13: *"I can't think that it is not, that is, if I say that it is not, I will go crazy. I don't think so at all. I never think about it. I am sitting alone at home, I call him, I talk to him. What should we make for lunch? Get up, how long do you sleep?"*

Main theme two: physical experience

The physical experiences of the participants were many. Psychological symptoms caused by bereavement and loss are physically experienced, and especially the feeling of sadness caused by loss is expressed in physical terms.

A feeling of heaviness in the chest and difficulty in breathing: this feeling was expressed in the participants without having a related physical problem or disease. This feeling is experienced when experiencing grief and thinking about a lost loved one.

Participant number 8: *"It was very difficult for me. I feel that something has been standing on my chest for a while and I can't breathe, but I have no choice, I have four other young children and I have no choice, I have to take care of myself".*

Feeling hot: Another physical experience described as being intensely experienced is hotness. According to the participant, this feeling of being hot was exactly experienced and they experienced this feeling not in their mind, but in their body, especially their heart and chest.

Participant Number 7: *"At that time, when I sleep at night, my heart beats a lot, I feel so hot that I think hot wind is coming out of my eyes and ears, my mouth is dry, I get up, I warm my heart a bit, drink some water and sleep".*

Main theme three: cognitive experience

The cognitive experiences of the participants were also numerous. They always had thoughts in their mind that were lost in connection with the child.

Denial: Denial had occurred or was still being experienced at some level for each participant. It can be said that there was a range or degree of denial for each participant. Some, even after resuming normal life, were still engaged in denial of this loss in some way. But the denial in people who had stronger emotional experiences in connection with the deceased was still much more intense and had many behavioral manifestations in addition to a mental form.

Participant number 6: *"I can't even think about not being there, if I think about not being there, I can't bear it anymore, we'll lose control." That's why I don't think it is. I say it is still there, or at least I don't think it is anymore"*.

Why did this happen: Participants are involved in various dimensions of why this happened. Why is their child not healthy like the others, especially the people around them, and is sick?

Participant number 3: *"I say, God, why me, why my child, why does it have to be like this. I wish he was my child now, he was playing like everyone else, he was studying, why should this happen to my child..."*.

Preoccupation: The most common mental experience and perhaps the most painful part of this experience has been mental preoccupation with the deceased in various ways. In a way, the rest of the cognitive experiences can also be included in the subcategory of mental preoccupation, because all these cases were centered around the thought and preoccupation with the thought of the deceased. Reminiscing has happened a lot. Memories with children and especially memories during illness are one of the most important mental occupations. In many cases, the participants are very willing to talk about the missing child. In their daily life, they constantly talk to their child and are involved with the thought of seeing and wishing to see him. Among other behaviors that happened due to mental preoccupation, frequent visits and visits to the beloved land were lost.

Participant number 5: *"However, I say that he is by my side. I don't think about it for one hundredth of a second that it is not there and the thought goes out of my mind."*

Idealization of the dead person: idealization does not mean that the lost child does not have good qualities and the mother performs this idealization, but the mother described the child as an example of a very good person and only expressed his positive characteristics. And in his opinion, he was a very good child.

Participant number 3: *"She was a very nice girl at all. Very. You will not believe anything I say. You will not believe anything I say. A kind, gentle, calm, beautiful girl, you won't believe what I say. noble She was a girl who could not be compared with other children."*

Belief in dreaming: Beliefs and thoughts about dreaming were also strong cognitive experiences. People considered seeing the deceased in a dream as a special sign and expressed a way to relieve the longing and satisfaction of the deceased, and some wished to see their child's dream.

Participant number 10: *"I want to see his dream. I say that if I don't dream of him, it is because he is not happy with me. I wish I could dream of it. Pray for me to sleep"*.

Main theme four: difficult experience

One of the interpretations that all participants expressed was that the experience was difficult. They expressed these expressions that it is very hard and difficult and that it is impossible to bear this sadness or it happens with difficulty and they considered it as a pain in their hearts forever. Meanwhile, the difficulty of this experience was due to the sadness they felt about not having their child.

Always accompanying sadness: The participants described this experience as a sadness that never leaves them alone and is always with them even after a long time has passed.

Participant number 7: *"Since you wake up in the morning, it is in your heart that you are no longer a child, this is with you every day. The sadness that is always with you. You have to live. Apparently, you are like them in the company of loved ones and do not show that they are bothered"*.

Deep sadness: The intensity of this sadness is described in such a way that no other sadness can match it and it is so deep that it burns your entire being. In the opinion of the participants, it is not a superficial and ordinary sadness and it is different from all the sadness in the world.

Participant number 6: *"It's not a sadness that you can say it will get better now or it will get better tomorrow. This grief is so intense that you feel like it's burning you, you can't bear it at all." It is very hard to bear, may God not bless any mother"*.

Burning sadness: The burning experience of this grief is another interpretation expressed by the participants and stated as if they were literally burned by this grief. It has even been described as "hot" in the literal sense of its burning intensity.

Participant number 5: *"Yes, it was beautiful. I used to burn. You thought to set fire to my heart. This is not the case now, but it used to be. It was so burning that I pressed hard. His sadness sets a person on fire"*.

Endless grief: another description of this grief by the participants was that the loss of a child has no end and no end can be imagined for this grief.

Participant number 11: *"This sadness is endless. You can't say when it will end, it never disappears like something that always stays there."*

Suffering of the child due to illness: One of the difficult aspects of this experience is stated that due to the illness and treatment conditions of the deceased, he suffered a lot and finally died. Remembering the memories related to this disease and bearing hardships by the child are among the difficulties and hardships of this loss.

Participant number 12: *"He suffered a lot. The pain, the chemotherapy, was very difficult. I remember wishing I hadn't been so bothered. It was so hard and it ended. The more I think about how hard it is, the sadder it gets"*.

Main theme five: The meaning of life

After the death of a child, there have been changes in people's attitudes and beliefs, or some beliefs have become stronger than before. These changes have been both positive and negative and inconsistent.

Sense of emptiness: The feeling of absurdity and meaninglessness was one of the attitudes expressed by the participants, and this was the case of the participants who have not yet come to terms with the issue of bereavement in any way and were experiencing a high degree of denial.

Participant No. 3: *"Life has no value for me anymore. It is meaningless to me. I feel empty. Nothing and no one matter to me anymore. Even parents, who are the most important people in everyone's life."*

Change in importance and prioritization: The participants stated that the priorities and importance of many things have changed for them and many things and issues have lost color for them.

Participant number 11: *"Before, you might have thought more about material things, why didn't I do this now. why not buy this Now I have a child, and people have empty thoughts. At the same*

time, some things are important to me. But I say again, it's done, it's done. It didn't work, it didn't work...".

Getting stronger: After this absence, several changes have been made, and one of these significant positive changes was the feeling of becoming stronger psychologically for the participants. Previously, many events were unbearable and unimaginable for them, and now many events are not difficult for them and they have described their ability to cope much more than before.

Participant number 6: *"I hated being sick or anything that made me uncomfortable. I thought a lot about what would happen if I got this disease now... I became much stronger, stronger in terms of suffering. I say now I have become braver. I became bolder. This is how I became like someone who is said to make life"*.

Divine test: According to the participants, this event was a test from God and they had no role in its occurrence. The participants have stated that because they consider this event to be a divine test, it has become bearable for them.

Participant number 13: *"It was God's test, I don't think you can say it is the biggest divine test because we may have bigger events ahead, but so far it has been a very big test. It was and still is very difficult for us"*.

Main Theme Six: Avoidance

Avoidance has been experienced in many different forms. After the experience of loss, the survivor in many cases was not able to resume normal life and his lifestyle changed. In many cases, these changes have been in the form of avoiding and staying away from doing certain tasks and behaviors.

Behavioral: Many activities have not been done after the death of the child. Social relationships, contact with family and relatives, and favorite personal activities are often left out or reduced. This case was manifested in people who had a lower level of positive category. Avoidant behaviors related to body and health are also experienced in survivors. The participants did not want to eat certain foods or do physical activities or pay special attention to their health.

Participant number 4: *"I don't feel like eating anymore. I don't eat some of the foods he liked at all. My health is not important to me"*.

Cognitive: In many cases, the participants tried not to think about some issues and events, especially in relation to the deceased. Despite reviewing memories, they had a tendency to forget and not think about many issues, and they tended to increase their tolerance threshold to deal with this suffering by not thinking.

Participant number 13: *"I try not to think about it. If I think that it is not, it is very difficult for me. I don't want to think about how it happened, I never think deeply about it".*

Discussion

Among the predominant maternal experiences, there have been numerous emotional encounters, resulting in a considerable conflict with their own emotions. Mothers have encountered various forms of exhilaration, including sentiments of guilt, rage, sorrow, depression, anxiety, homesickness, and a sense of irrationality.

Numerous studies have also concurred with the current findings, indicating that both bereaved individuals and mothers undergo a multitude of emotions. Seifi and Farah Bejari (2017), Ismailpour and Moradi (2013), Lee and Elsen (2003), Hendrickson (2009), Boyi et al. (2015), Davis (2017), Hollander (2016), October, Dryden-Palmer, Kopnel, and Mirt (2018) have also delineated various emotional experiences in survivors and bereaved mothers within their respective research. Oktober et al. (2018) explicated child bereavement as being accompanied by the most profound and devastating emotional encounters, illustrating the diverse array of emotions experienced by mothers. Lichtenthal et al. (2015) further examined the emotional predicaments and psychological disturbances encountered by parents with a child suffering from cancer, highlighting feelings of anxiety, depression, blame, guilt, anger towards oneself, and others as the most notable experiences.

These encounters can be comprehended through Elisabeth Kubler-Ross's theory of mourning. Kubler-Ross identified five dominant and widespread stages within the various forms of grief. The initial stage entails denial and disbelief, exhibited by the survivor when confronted with the demise of a loved one. In the subsequent stage, the survivor experiences anger and fury towards death and the ensuing loss. The third stage involves the commencement of bargaining, while the following stage encompasses feelings of disappointment and desolation. Finally, the last stage necessitates acceptance, which becomes the sole option.

From the moment the conflict arises in diagnosing a child's illness, parents, particularly mothers, are subjected to unpleasant sentiments and emotional encounters. Anxiety emerges as the dominant facet of this experience, with the mother being perpetually apprehensive about her child developing cancer. The mother incessantly oscillates between despair and hope, anxiety and tranquility, until the final outcome of the disease is disclosed. Disappointment, depression, and anxiety are profoundly experienced once a child receives a cancer diagnosis. The entirety of a mother's existence becomes encapsulated within her child, and when the child falls victim to cancer, the essence of life itself is irrevocably lost. Consequently, the mother becomes embroiled in a multitude of emotions. Due to the nature of the illness and the arduousness of the treatment for both the patient and the family, increased levels of anxiety are encountered. Simultaneously, the challenges of caring for the parents, particularly the mother, can lead to moments of exhaustion. This fatigue also impacts their interactions with the patient, resulting in feelings of anger, subsequently followed by guilt.

Due to the multitude of treatment options and the influence of other patients and opinions within the hospital, the mother is faced with numerous decisions regarding the course of treatment. Consequently, following the death of her child, she becomes burdened by feelings of blame and guilt for the choices she made.

Moreover, the mother experiences guilt as a result of the stringent care and restrictions imposed on the child. Particularly when the child passes away, she wishes that she had not been so strict during this brief period of time.

The mother not only loses her closest companion, but also endures a profound sense of longing due to the significant psychological and emotional investment made from the formation of the fetus until the child's demise. The intensity of emotions experienced, coupled with the subsequent feelings of loss and sadness, becomes so overwhelming that the mother fears losing control and losing her sanity.

The participants in these circumstances undergo a multitude of physical experiences. Numerous studies have indicated that mothers encounter various physical symptoms and discomforts following the death of their child. Bergstrasser et al. (2015) identified bereaved parents as being exposed to physical risks, such as heart attacks and other ailments, and even suggested a shortened

lifespan. Price and Jones (2015) have also noted the adverse impact on the physical health of these parents, including reduced health-related quality of life, increased risk of heart disease, and even heightened mortality rates (Dias, Bacherty, and Brandon, 2017).

The intensity of emotion resulting from this loss can manifest in physical symptoms experienced by mothers. From a psychoanalytical standpoint, it can be argued that the physical experience serves as a defense mechanism to cope with the overwhelming stress and intensity of the emotional experience that exceeds one's psychological capacity. By engaging with the physical sensations, individuals attempt to increase their tolerance and coping abilities, thereby reducing the intensity of the psychological experience.

The mothers' cognitive experience was accompanied by an emotional experience. Consistent with the recent findings of Azim Oghli Eskoui, et al. (2021), the experience of bereavement in survivors involves the cognitive mechanism as a common mechanism. Myth-making was identified as one of the dominant cognitions among the survivors in this study. Additionally, the research explored the topics of denial, non-acceptance of loss, and mental preoccupation with the deceased. Snaman et al. (2020) and Napa et al. (2016) have also discussed symptoms, cognitive distortions, and mental preoccupation with the deceased as changes and events following bereavement, particularly in cases of bereavement caused by cancer.

The findings concerning the challenging experience align with the significant research conducted by Oghli Eskoui et al. (2021) and Seifi and Farah Bijari (2017). In most cases, parents, especially mothers, undergo a complex grief process after losing a child. The difficulty and complexity of the bereavement experience stem from parents grappling with the disruption of their natural expectations for family life. Despite the strong attachment parents have to their child, they strive to find meaning in this loss and often face a crisis of meaning (Nimer, 2019). Hollander (2016) also asserts that the death of a child, regardless of the cause, is the most traumatic event parents can encounter and the most challenging experience they can endure. According to Oktober et al. (2018), parental bereavement is one of the most intense, painful, devastating, and enduring forms of grief, evoking a stronger and more profound reaction compared to other losses.

One of the difficulties associated with this experience is related to the illness and treatment conditions of the deceased, who endured significant suffering before passing away. Recalling memories associated with the disease and enduring the hardships alongside the child constitute

additional challenges and burdens of this loss. Therefore, the experiences of bereaved parents with children suffering from chronic terminal illnesses involve more suffering and follow a distinct trajectory (Kamihara et al., 2015). Another explanation for the difficulty of this experience can be attributed to attachment theory. The bond between parents, especially the mother as the primary caregiver, and their child is an incredibly strong bond. However, with the child's death, this bond is physically severed. This physical separation triggers a profound emotional conflict and a struggle for complete separation, which is particularly challenging due to the powerful bond between the mother and the child. This struggle can persist for months or even years, resembling a psychological surgery that the mother must undergo in order to accept the separation of this bond. The investigation conducted by Seifi and Farah Bijari (2017) also asserts that one of the significant changes in the lives of mothers after experiencing the loss of a loved one is the attainment of meaning and the alteration of life prioritization. Polita et al. (2020) further support this notion in their own study, discovering that the loss of a child undeniably brings about profound changes in the lives of parents, leading to an identity crisis and a loss of life purpose. Throughout the course of their existence, parents construct new meanings that aid in their coping with grief. They employ strategies that enable them to regain a sense of purpose in life. They encounter feelings of emptiness, witness transformations in the meaning of life, and, in some instances, undergo a shift in their perspective and attitude towards death, with some even expressing a desire to die. Furthermore, the values and important aspects of life acquire new significance as a result of the child's demise. This experience is highly intense, leaving no room for solace or justifications for the bereaved mother. However, the association of this experience with divine will and testing imbues it with a transcendent quality. The belief that God is a benevolent, capable, and wise entity in relation to this event makes it easier to endure this suffering, and one may even assert that God will bestow rewards in the face of this trial.

Regarding the topic of avoidance, Seifi and Farah Bijari (2017) also shed light on behavioral and cognitive avoidance in their analysis. The research also indicates that the survivors' social and familial relationships have been impacted, leading to changes in their lifestyles. Gilmer et al. (2012) and Weber Falk et al. (2020) corroborate these findings in their own studies, revealing that survivors also exhibit avoidant behaviors in their relationships and activities. Individuals who

engage in avoidance find it more challenging to cope, whereas those with lower levels of avoidance experience better coping mechanisms. The intensity of emotional experiences resulting from the death of a child is so immense that individuals attempt to avoid such situations in order to manage their emotions. In fact, avoidance is considered a coping mechanism for individuals. Many situations serve as reminders of the deceased, prompting survivors to avoid them in order to prevent the recurrence of painful memories and negative emotions.

Among the limitations of the present study, one difficulty and arduous task was interviewing bereaved mothers due to their emotional turmoil. This circumstance slowed down the interview process, necessitating the need for effective management and a high level of empathy towards the participants.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by ethics committee of Islamic Azad University. The patients/participants provided their written informed consent to participate in this study.

Author contributions

F.S, M.D, N.S and M.F contributed to the study conception and design, material preparation, data collection and analysis. All authors contributed to the article and approved the submitted version.

Funding

The authors did (not) receive support from any organization for the submitted work.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

References

- Atun, R., Bhakta, N., Denburg, A., Frazier, A. L., Friedrich, P., Gupta, S., ... & Rodriguez-Galindo, C. (2020). Sustainable care for children with cancer: a Lancet Oncology Commission. *The Lancet Oncology*, 21(4), e185-e224.

- Azim Oghli Eskoi, Parveen Bano. Farahbakhsh, Kyomarth. Moradi, Omid. (2021). Staying in mourning: A phenomenological study of the abnormal grief experience after the death of a family member. *Knowledge and Research in Applied Psychology*, 22(4), 28-42.
- Bergstraesser, E., Inglin, S., Hornung, R., & Landolt, M. A. (2015). Dyadic coping of parents after the death of a child. *Death studies*, 39(3), 128-138.
- Bui, E., Mauro, C., Robinaugh, D. J., Skritskaya, N. A., Wang, Y., Gribbin, C., ... & Shear, M. K. (2015). The structured clinical interview for complicated grief: reliability, validity, and exploratory factor analysis. *Depression and anxiety*, 32(7), 485-492.
- Davis, K. G. (2017). Pediatric cancer and end-of-life. *Dying and death in oncology*, 147-169.
- Dias, N., Docherty, S., & Brandon, D. (2017). Parental bereavement: Looking beyond grief. *Death Studies*, 41(5), 318-327.
- Dutta, O., Tan-Ho, G., Choo, P. Y., & Ho, A. H. Y. (2018). Lived experience of a child's chronic illness and death: A qualitative systematic review of the parental bereavement trajectory. *Death Studies*.
- Gilmer, M. J., Foster, T. L., Vannatta, K., Barrera, M., Davies, B., Dietrich, M. S., ... & Gerhardt, C. A. (2012). Changes in parents after the death of a child from cancer. *Journal of pain and symptom management*, 44(4), 572-582.
- Hendrickson, K. C. (2009). Morbidity, mortality, and parental grief: a review of the literature on the relationship between the death of a child and the subsequent health of parents. *Palliative & supportive care*, 7(1), 109-119.
- Hollander, T. (2016). Ambiguous loss and complicated grief: understanding the grief of parents of the disappeared in Northern Uganda. *Journal of Family Theory & Review*, 8(3), 294-307.
- Ismailpour, Khalil, Bakhshalizadeh Moradi, Shahnaz. (2014). The severity of grief reactions caused by the death of first-degree relatives. *Iranian Journal of Psychiatry and Clinical Psychology (thought and behavior)*, 20 (4), 363-371.
- Kamihara, J., Nyborn, J. A., Olcese, M. E., Nickerson, T., Mack, J. W. (2015). Parental hope for children with advanced cancer. *Pediatrics*, 135(5), 868-874.
- Li, J., & Olsen, J. (2003). Mortality in parents after death of a child. *The Lancet*, 361(9370), 1748.

- Lichtenthal, W. G., Sweeney, C. R., Roberts, K. E., Corner, G. W., Donovan, L. A., Prigerson, H. G., & Wiener, L. (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric blood & cancer*, 62(S5), S834-S869.
- Näppä, U., Lundgren, A. B., & Axelsson, B. (2016). The effect of bereavement groups on grief, anxiety, and depression-a controlled, prospective intervention study. *BMC palliative care*, 15(1), 1-8.
- Neimeyer, R. A. (2019). Meaning reconstruction in bereavement: Development of a research program. *Death Studies*, 43(2), 79-91.
- October, T., Dryden-Palmer, K., Copnell, B., & Meert, K. L. (2018). Caring for Parents after the death of a child. *Pediatric Critical Care Medicine*, 19(8S), S61-S68.
- Pakseresht, M., Baraz, S., Rasouli, M., Reje, N., & Rostami, S. (2018). A comparative study of the situation of bereavement care for children with cancer in Iran with selected countries. *International Journal of Pediatrics*, 6(2), 7253-7263.
- Pohlkamp, L. (2020). Factors during a Child's illness are associated with levels of prolonged grief symptoms in bereaved mothers and fathers. *Journal of Clinical Oncology*, 38(2), 137-144.
- Polita, N. B., de Montigny, F., Neris, R. R., Alvarenga, W. D. A., Silva-Rodrigues, F. M., Leite, A. C. A.B., & Nascimento, L. C. (2020). The experiences of bereaved parents after the loss of a child to cancer: A qualitative metasynthesis. *Journal of Pediatric Oncology Nursing*, 37(6), 444-457.
- Price, J. E., & Jones, A. M. (2015). Living through the lifealtering loss of a child: A narrative review. *Comprehensive Child and Adolescent Nursing*, 38(3), 222-240.
- Seifi, Fatemeh, Farah Bijari, Azam. (2017). Changes and needs of bereaved parents after the death of their child due to cancer: a qualitative study. *Qualitative Research in Health Sciences*, 7 (1), 48-59.
- Snaman, J., Morris, S. E., Rosenberg, A. R., Holder, R., Baker, J., & Wolfe, J. (2020). Reconsidering early parental grief following the death of a child from cancer: A new framework for future research and bereavement support. *Supportive Care in Cancer*, 28(9), 4131-4139.
- Vahid Pakpour, Leila Sheikhejad, Sediqa Salimi, Azad Rahmani, (2018). Optimism and its relationship with depression in parents of children with cancer referred to Tabriz Children's Hospital, *Urmia Journal of Nursing and Midwifery*, 17(7), 563-573.

- Weber Falk, M., Alvariza, A., Kreicbergs, U., & Sveen, J. (2020). The grief and communication family support intervention: intervention fidelity, participant experiences, and potential outcomes. *Death Studies*, 1-12.
- Zhou, N., Wen, J., Stelzer, E. M., Killikelly, C., Yu, W., Xu, X., ... & Maercker, A. (2020). Prevalence and associated factors of prolonged grief disorder in Chinese parents bereaved by losing their only child. *Psychiatry Research*, 284, 112766.