

Original Article

Spiritual Issues and Challenges of Children with Cancer: Mothers' Experience

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ABSTRACT

Background and Aim: Cancer is a chronic disease and the second leading cause of death in children. In addition to clinical issues, challenges regarding spiritual issues exist. This study seeks to identify spiritual issues and challenges faced and experienced by mothers of children suffering from cancer.

Methods: The current research was conducted using a phenomenological approach and content analysis. To gather information, 21 mothers were selected none randomly and were interviewed for a period of three months. Data were analyzed by comparing the responses of the interviewees constantly during the three months.

Ethical Considerations: The study followed standard ethics guidelines concerning informed consent and confidentiality.

Results: Seven themes were extracted via content analysis: philosophical questioning, faith and hope, relationship with nature, play and leisure, love and social support, expressing fear and anxiety and aggression, and expressing hope for the future. It was found that mothers were concerned about various philosophical questions raised by their children as well as issues regarding faith and belief and the quality of love, attention, and social support received.

Conclusion: It is argued that empowering parents to play a more effective role in the spiritual care of children suffering from cancer may be a vital step in improving palliative care for these children as well as improving the psychological well-being of both cancer patients and their parents.

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Introduction

Illness may be considered a major obstacle in the development of any child and cancer is a chronic disease and a leading cause of death and disability in children (1). Due to the chronic nature of cancer, the patient is forced to accept long-term treatment with toxic drugs which cause inevitable side effects such as nausea, hair loss, fatigue, muscle pains, weight change, and mental health problems (2).

During a time when people's lives are threatened, various issues and challenges arise. One of these challenges is spiritual issues and finding meaning for suffering. This challenge becomes more apparent during chronic illness (3-5). Thus

spiritual issues and challenges may constitute the core of the patient's life (6-7). The question is whether or not children may be considered an exemption to this rule. Spiritual development is a lifelong process (8-9). It has been shown that spiritual development begins in childhood and that children develop cognitive abilities through which can explore various aspects of "self" hence curiosity about spiritual issues arise at an early age (10). It has been shown by both research and clinical data that children do engage in spiritual issues such as talking about God, death, heaven, and hell as well as being involved with and enjoying nature and showing and receiving love and compassion. Most children are concerned with concepts such as hope for the future, and fear

of the unknown and express a desire for understanding (11).

Mc Sherry and Smith (12) believe that life events and coping with various crises in adults and children are based on their past experiences and spiritual and religious beliefs. Spirituality may pave the way for the development of values and beliefs which make children's lives meaningful and thus more purposeful (9). Experimental studies show that a significant relationship exists between religion, spirituality, and health, and there is a significant positive relationship between mental health, physical health, life satisfaction, vitality, and spiritual beliefs (13).

When children are diagnosed with cancer, it seems that several important questions become important for them. Children ask questions about why they are suffering from pain and the cause of their suffering. When a person is suffering, the first question they ask is "why" and start to search for possible meanings and reasons for their suffering (14). This can inevitably raise issues about their relationship with God and how and why they have become ill and why they should suffer. Death may become another concern for children. They may ask about the nature of death and the time of death (15). Thus, when a child becomes ill, spiritual concerns may become salient. The need for meaning and purpose helps patients to deal with crises arising from illness. Inability to find meaning and purpose in life confuses and may hamper recovery and well-being. Spiritual crisis may lead to lack of energy, anxiety, depression, increased pain, grief, loss of control over thoughts and emotions as well as an increase in feelings of guilt, anger, denial, frustration and helplessness (16-17). The positive consequences are repairing beliefs and desires, intellectual, spiritual resiliency, and hope (16, 18). Muscari (19) has set pros and cons for spiritual concerns of patients and has argued that spiritual concerns if they develop positively, may result in divine pity and compassion, love, friendship, forgiveness, pleasure, and joy. On the other hand, the same spiritual concerns, if continue to cause confusion and discourse, may result in fear, anxiety, anger, and pessimism (20).

As early as the late 1970's researchers were concerned with the negative consequences of spiritual crisis. Miller (21) argued that spiritual crisis in children manifests itself in fear. The fear in children under six years is in form of fear of sudden moves, loud noises, loss of support, and

fear of loneliness, darkness, physical damage, and amputation. In school-aged children, fear of being punished, going to hell, violating ethics, and natural hazards form the core fears arising from spiritual crisis.

As a result, children may show aggressive, regressive, and self-destructive behaviors, they may stop interacting with others, cry, and suffer from nightmares or sleep disturbances, and experience feelings of disability, frustration, irritability, confusion (16).

Also, early studies have shown that children with chronic illnesses such as cancer become anxious about looking after themselves following the loss of an organ. They fear being away from home and lack of relationships with peers will lead to feelings of inadequacy, low self-worth, and frustration (21, 22). So the experience of pain in children with cancer is not only physical but also emotional, social, and spiritual factors play a vital role (23).

These issues are significant for the mental health of sick children and their parents. For parents, the fact that their child has become ill and hospitalized always provokes intense emotions (24, 25). Parental participation in the care of hospitalized children is an important aspect of the so-called parent-centered care (26). This approach emphasizes the active involvement of parents in the physical and mental - spiritual health of hospitalized children (27). Family-centered care is another form of palliative care that involves the participation of all family members alongside the health care team to ensure a comprehensive approach to the palliative care of children with chronic illnesses (28).

It is argued that parental involvement in treatment may cause a stress reduction and promote parental awareness about their children (29-31). This kind of approach is beneficial to children as well (32).

Most previous studies have focused on Spiritual Issues and need in adolescent and adult with cancer (2, 13, 33-37) and Few studies related to Spirituality with Chronic Disease in Pediatrics have been performed (38). Pendleton (39) in their study about Religious/Spiritual Coping in Childhood Cystic Fibrosis showed that Children with CF (cystic fibrosis) reported a variety of religious/spiritual coping strategies they nearly always associated with adaptive health outcomes. Cottonn (40) showed a stronger relationship between existential (spiritual) well-being and emotional well-being for those with IBD

(Inflammatory Bowel Disease) to healthy adolescents. Benore (41) et al. showed adolescents with asthma experienced negative religious coping more frequently (such as thinking God is “punishing me”). Cotton (42) reported high rates of religious attendance weekly, belief in God, and weekly prayer in children with SCD (Sickle cell disease). Studies suggest that children have a rich and complex spiritual life and spiritual beliefs have the potential to support as well as hinder children’s ability to cope with chronic illness (43).

Nascimento⁴⁴ shows that the nurses understood spirituality as an important part of caring for children, families, and health professionals in critical care settings. Reisi-Dehkordi (45) in this study aimed to identify the psychological challenges of the children with cancer and their mothers’ experience showing that one of the challenges of this mother is a spiritual issue. Thus, Identification of the spiritual challenges, issues, and crises from the perspective of parents of children with cancer are essential. It is also important to identify parents' needs so that effective strategies and methods may be designed to help parents deal with possible crises arising from spiritual issues and concerns. This qualitative study aimed to identify the challenges and spiritual crisis of children with cancer from the viewpoint of their parents.

Ethical Considerations

The study followed standard ethics guidelines concerning informed consent and confidentiality.

Methods

This study was performed using content analysis and a phenomenological approach. Phenomenology aims to understand the basic structures of the human experience through an analysis of the phenomenon. This is done via analyzing verbal descriptions of participants’ experiences. Interpretive phenomenology refers to the process whereby other persons’ verbal descriptions of their experiences are recorded by the listener and then these personal accounts are interpreted without allowing interference through the experimenter's biases and personal opinions (46). Hence the researcher objectifies abstract material presented by the participant. A content analysis approach was used for data analysis. Content analysis as a research method is a

systematic and objective means of describing and quantifying phenomena (47).

Participants

In Iran when a child is hospitalized for any period it is usually his or her mother who stays with her child in the hospital and hence, compared to fathers, mothers are relatively more available for research purposes. Thus, 21 mothers aged 21 to 36 years ($M = 29.23$, $SD = 4.42$) were invited to participate in the study. They're Muslim and believe in Islam. Islam is a monotheistic faith centered on the belief in one God (Allah). Children (11 Boys and 10 Girls) were aged 6 – 14 years old ($M = 10/05$, $SD = 0/373$). The children of these mothers were hospitalized in Mahak Hospital which is a specialized cancer center for children located in northeast Tehran. Interviews were deep semi-structured interviews and the interviews were conducted over a period of three months during the winter and spring of 2015-2016.

Procedure

Each mother was seen individually by the first author who explained that the purpose of the study was to find out concerns and issues raised by their children as a result of her illness. After agreeing verbally, mothers were asked to sign a written consent form. They were assured of the confidentiality of their responses and were told that they were free to stop the interview at any point or that they could ask any questions they wished, although they were told that questions concerning the welfare of their children or the process of the treatment could not be answered in the interview session but would be dealt with either by a specialist or one of the authors at a later date. Mothers were then asked questions about the experiences and cancers of their sick children. Essentially four questions were asked: 1. what did your child feel and react when she became ill? 2. What type of questions and issues did your child ask after becoming ill? 3. What problems did your child have that you think may be related to her illness? 4. What issues and activities became important for your child who was not so important before? At the beginning of the interview, a short explanation of the purpose of the study was provided. Interviews took between 40 to 110 minutes to complete. All interviews were recorded on audio tape. The content of the interviews was subsequently transcribed by two research assistants. The

contents of the interviews were then read, coded, and analyzed separately by the three authors, and data were prepared for analysis. To analyze the data, the first recorded statements of participants were listened to several times and transcribed verbatim expression, and the outcome was reviewed carefully several times. In this study, for data analysis, open coding and axial method were used. Open coding is the process whereby the data is broken into words and expressions and codes are allocated to words to form separate concepts⁴⁷. After the interview, all notes from the interview sessions were arranged and organized. Interview transcripts were examined line by line, and the words and phrases that had similar meanings were coded, compared, and sorted into different categories. Then phrases that had similar meanings were extracted and sorted so that major themes could be identified. For reliability of the study was examined using the criteria suggested by Krippendorff⁴⁸. We used to duplicate the process of coding, categorizing, or measuring a sample of data by two Researchers in the spiritual field.

In this research, the validity of the study was examined using the criteria suggested by Guba⁴⁹. For assessing the trustworthiness, we used for conformability of data. The context of the interviews, codes and the extracted categories were reviewed by the research team and three authors were collated in several sessions of data analysis.

Findings

To identify the problems and needs of the spiritual care of children with cancer, after discussion with their mothers, first similar words and expressions from the answers were extracted, then the concepts were classified. Concepts were extracted and grouped into seven main themes: 1. Philosophical questions (life and death); 2. Religious beliefs and faith; 3. Relationship, love, and social support; 4. Need to play, the experience and connection with nature; 5. Hope for the future; 6. Expressing aggression and 7. Expressing fear and anxiety.

1. Philosophical questions about life, illness, and death

Most mothers participating in the study indicated that their children asked questions about why they had become sick. These also included questions regarding death and dying (the child's death but

also others'), life after death, and heaven and hell. Questions asked by the child in this category included: "why am I sick?"; "Why isn't anyone else in the family sick?"; "How come it is only me who is sick and all my other relatives are OK?"; "How come all bad things happen to me?"; "How do I die?"; "What will happen after somebody dies?"; "Will I be able to see you from the other world?"; "How far are heaven and hell?"

2. Religious beliefs and faith

In most cases, the mothers that were interviewed said that their child expressed religious beliefs more after being diagnosed with cancer. It was reported by certain mothers that their child began to pray more and constantly asked God to make him healthy again. Also following Shi'a belief, it was reported that children prayed also to seek help from the Imams in particular the third and eighth Imams who are particularly popular in the Iranian culture. One mother reported of her nine-year-old son: "Immediately after the call to prayer (Azhan), he performs ablutions (washes his hands, face, and feet) and prays. After the ritual of prayer is over, he prays loudly resorting to Imam Hussein (the third Imam) asking him to heal him and reduce his suffering."

3. Relationship, love, and social support

Many mothers reported that their children had become more dependent on them and found themselves constantly looking after their children. It was also reported that many children had developed various degrees of separation anxiety. The mother of a ten-year-old said: "As soon as the diagnosis was made, he became extremely dependent. He even goes to sleep in my arms"; "if I am not in the room, he becomes very wary and wants to follow me everywhere" (mother of an 11-year-old boy).

Mothers participating in the study also expressed differences in their children's relationships with their siblings who were different from the past: "When his sister is next to him, he is doing well and seems happy but when she is not around, he becomes upset and cries. I think he needs her more than ever" (mother of an eight-year-old boy).

4. Need to play, the experience and connection with nature

Another issue that became salient in mothers' accounts was games played by children during

their leisure time. Most mothers believed that their children feel good during the hours that they play and some could be engaged in playing for hours at a time and during this time would report less pain: "My child enjoys making things in particular puppets". Many mothers reported that their children had begun asking to be taken outdoors such as in parks or the countryside: "Being physically in nature and being involved with issues concerning nature such as gardening always makes my daughter feel better"; "he feels happy when playing games in the playroom"; "my daughter injects medicine into her dolls when she plays" (mother of six-year-old girl); "when we are in the hospital, he asks me to take him to the mountains near the hospital. When we go to the house and he is involved in the garden around the house, he is less stubborn and less angry" (mother of the seven-year-old child).

5. Hope for the future

Another issue discussed during the interviews with the mothers of children with cancer, was hope. They often reported that their child often talked about plans for the future or asked about events that might take place in the distant future such as during the child's youth or middle age: "After I become well I'll stay awake the whole night and we'll watch TV together"; "when will I become a bride?"; "When will I become a mom?" (An 8-year-old child).

6. Expressing aggression

One of the common problems among these children reported by their mothers was aggression. Most mothers stated that their children were extremely agitated and aggressive after the illness. "When we're in the hospital for treatment, he is very angry and beats me. He throws things away when he is angry" (mother of an 11-year-old boy).

7. Expressing fear and anxiety

Another common problem among children raised by their mothers who were raised by their mothers was fear and anxiety. Fear and anxiety were most expressed towards illness, the hospital, and surgical and medical activities: "He becomes afraid when we come near the hospital and he has become sleepless after becoming aware that he is ill. He is so anxious about hair loss (mother of a 10-year-old child).

Conclusions

Like most other chronic illnesses, cancer provides an opportunity for reflection and self-assessment in children and adolescents and this reflection is very important in the process of spiritual and emotional growth (8,9). The present study aimed to examine some aspects of spiritual crisis from the viewpoint of mothers of children with cancer. The results obtained from this study showed that patients may experience a severe crisis during treatment and they experience challenges and concerns to combat illness during the treatment process. The most important issue raised by parents of children with cancer was that certain challenging philosophical issues and questions, particularly questions concerning life and death are raised by children. This result is congruous with Drutchas (50) studies showing that the diagnosis of cancer increases the child's curiosity and often perplexity about spiritual issues such as the meaning of suffering and death and the relationship between man and God. In the present study, mothers stated that their children ask them repeatedly why they were suffering, and why they were sick. Most mothers stated that their child makes comparisons with other friends and family members and asks questions about why others were not sick. In some cases, mothers stated that their children asked why God had made them sick. Studies show Spiritual beliefs as a coping strategy, can provide answers to existential questions elicited by the illness (Why me? What comes after death?). They can also provide additional social support from a god-figure when other sources are not available (51).

Mothers also expressed that their children asked questions about death and life after death. These findings are consistent results of Ito et al (52) and Kreicbergs (53)⁵³ studies who reported that death is an important aspect of the Spiritual Life of Children with cancer. Although religious education is a very important aspect of both formal and informal education in Iran, philosophical questions regarding life and death and in particular the philosophical meaning of suffering is very difficult to communicate to young children when they are raised. This issue may be considered an important challenge in the spiritual care of children.

Another important issue raised by mothers was the question of religious faith. One of the highlighted aspects of children with cancer was God and seeking his help for improvement⁵⁴. This

finding is supported by previous study^{55,56} in which the authors pointed out that at this time they felt hope, searching for meaning and purpose in life is the foundation of religion which is an important source to strengthen their faith and prayer. They used spiritual beliefs to cope with their condition (e.g., praying to get better, asking God to give them strength) (57).

In this regard, mothers stated that in many cases, a marked increase in abiding by religious behaviors such as performing ablutions and prayer became apparent in children. This was particularly heightened just before medical examination and/or painful medical procedures such as chemotherapy. In most cases, children would pray aloud and ask their mother to accompany them in prayer. In some cases, the intensity of religious beliefs was after partial remission therapy. Mothers indicated that their children often resorted to prayer and getting more involved in religious ceremonies. Similar results were also observed in the study of Meireles et al (58) and Petersen et al (59) studies have shown that children with cancer sought more spiritual support. One of the sources of support for them was to seek a closer relationship with God, asking him to heal them and bless them. This tendency has also been reported by Kamper et al (60). It has been shown that a relationship with God is very similar to patterns of attachment formed during childhood towards parents so that secure and insecure patterns of attachment can be identified during adulthood (61). It is interesting that during the stress of illness, these attachment patterns can form from an early age. Bull et al (54) have pointed out that the child's relationship with God during hospitalization, helps the child to deal effectively with fear and anxiety, presumably by paying attention to religious teachings, hope is generated in the individual (59). This in turn can act as an effective defense mechanism. The positive relationship between religiosity and physical and mental health has been well documented in the literature and can act as an effective defense mechanism. Researchers have shown the influence of religious beliefs on physical health well (62). The reiteration of Islam on the healing powers of God and that trusting God is important is apparent throughout the Quran (e.g. verse 82, Sura 'Asra'; verse 123, Sura 'to be' and verses 59 and 114 in Suras 'Hud' and 'Ankaboot'). Furthermore, various prayers in the Shi'a religion such as 'Komeil' encourage the

faithful to seek healing and well-being from God and the twelve Imams in particular Imam Hussein and Imam Reza. Results of the present study clearly show the important role cultural and religious beliefs play in Iranian sick children and their families' lives. These findings are consistent with experimental research conducted by Taleghani et al (63) and Renani et al (51). In some cases, however, particularly in older children, the opposite effect was observed. Some mothers reported that their child had denied God already and questioned his authority, kindness, or powers. This was shown either by direct reprisal or more commonly through philosophical questioning.

The third issue the interviewed mothers were concerned with was love and social support. They expressed that their children had become strongly dependent on family members. Various researchers have discussed spirituality as a characteristic that often has close ties with the meaning of love (64). Shelly (65) argues that the need for love, belonging and continuity is one of the children's fundamental spiritual needs which is positively correlated to the development of self-confidence. But in more severe cases, a sense of belonging and continuity may also be considered a sign of spiritual stress in children with cancer⁶⁶. The interviewed Mothers in the present study stated that their children continuously expressed a desire to be close to them and were more dependent and attached than before. They depended more on their parents to perform their daily chores and often went to sleep while being embraced by their parents. They also quickly and strongly reacted to their mother's absence.

During this time, it was reported that the child's relationship with his / her father dramatically increased. This was most salient in the form of joking and laughing rather than physical/emotional contact (e.g. embrace). Sense of humor is also considered an important facet in the development of spirituality (67). Attention to play, experience, and connectedness with nature are also topics that mothers emphasized in their interviews. Mountain (68) considers playing as part of the children's spirituality. Rossiter⁶⁹ believe that through play, children make sense of the world around them.

Another issue emphasized by the majority of mothers was aggression as well as fear and anxiety expressed by their children. Their children become aggressive with the smallest issue and this anger was directed particularly toward the

mother and other children. Reisi-Dehkordi (45) reported higher stress, anxiety, and depression levels in a child with cancer. Often the child attacked the other person or threw things at them. Hospitalization not only caused such blatant behaviors in children but certain personality traits were also observed. In many cases, mothers reported that their child had become more stubborn and introverted than before. Interviewed Mothers stated that their children also suffered from fear and anxiety about their illness and some had developed sleep problems. In isolated cases, behavioral problems such as nail-biting, phobia, and compulsive behavior were reported. Nevertheless, all mothers reported various degrees of fear and anxiety in their children. It seems that as Steel and Anderson (70) have suggested anxiety and fear may be considered an inseparable part of any psychological crisis and the spiritual crisis seems to be no exception.

Finally, mothers reported that their children were concerned about the future both in terms of expressing hope and worry. Researchers have agreed that a hopeful and forward-looking approach to life is an important sign of spiritual development in children (19, 64, 71). Children in our sample asked repeatedly questions about marriage, parenthood, plans, and possible decisions in the future.

Children suffering from cancer seem to face several clear challenges. These challenges are clinical, psychological, and spiritual. The issues most important to children diagnosed with cancer seem to be issues regarding various philosophical questions raised concerning faith and belief and the quality of love, attention, and social support received. It was found that these children may experience spiritual crisis as a result of their illness and that this crisis is expressed through aggression, fear and anxiety, and an array of possible behavioral and psychological problems. Since it is now established that the palliative care of sick children, especially children with cancer is a team activity, it is also of paramount importance that firstly health professionals as well as parents take the spiritual development of the child seriously and become aware that after the diagnosis of cancer spiritual crisis may occur and understand what kind of spiritual issues are raised and what challenges are faced by children diagnosed with cancer. Secondly, the result of the present study raises the importance of finding ways to enable health professionals and

parents/care to look after the needs of children with cancer. This can be done by implementing the spiritual needs of children into programs designed to provide and improve a home or palliative care. For example, the care can learn how to help children manage negative emotions such as fear and anxiety. In the Iranian culture, religion plays a significant role in people's lives. Religious education and teaching should be modified to cater to the needs of sick children and parents could be taught by experts how to face inevitable questions by their children regarding death and dying.

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All persons listed as authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

Conflict of Interest Statement

The author declares that they have no conflicts of interest.

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Table 1 shows the description of themes and subthemes.

Themes	Description of subtheme
Philosophical questions (life and death)	What is pain? What is illness? Why is there disease and suffering? Who or What Is God? when I will die? what is life after death?
Religious beliefs and faith	do pray participation in religious places and religious ceremonies pray for other sick friends read the Quran and dua
Relationship, love, and social support	the need to be the proximity of the mother the joy of being with siblings happy time at home fear of separation from her mother the nostalgia of distant siblings
Need to play, the experience and connection with nature	feeling happy when playing and painting Doll Making playing with Medical toys like injection request for going to the mountains and forests Requires to being in nature
Hope for the future	hope for healing planning for a successful future Fatherhood and Motherhood talks about the future
Expressing aggression	beating mother throwing items Aggressive after learning about the disease aggressive treatment time nervousness and irritability during hospitalization
Expressing fear and anxiety	fear of hospitals fear of sitting in the wheelchair Fear of the dark nail biting no reason to cry withdrawal taciturn latest