

## RESEARCH ARTICLE

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# Psychological Limbo as a Barrier to Spiritual Care for Parents of Children with Cancer: A Qualitative Study

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### Abstract

**Background:** Pediatric cancer causes reduced life quality and psychological problems for parents. It is necessary to pay attention to spirituality, which plays a significant role in increasing the life quality of these parents and their patient children and managing the conditions associated with the disease. This study was performed to determine factors predisposing to spiritual care in parents of children suffering from cancer. **Methods:** This qualitative study was conducted by conventional content analysis. Fifteen parents of children with cancer hospitalized in the oncology and hematology wards of governmental hospitals in Iran were selected using a purposive sampling method and underwent semi-structured deep interviews from 2015.1.10 until 2017.3.10. **Results:** On data analysis, 12 subcategories emerged leading to extraction of three : “projection”, “mental concern”, and “psychological pains”. The final result was a focus on the theme “psychological limbo”. **Conclusion:** Our findings showed that cancer induces psychological problems in parents, which may serve as factors that drive them towards spiritual affairs. Hence, attention should be paid to predisposing factors of spiritual care to facilitate tranquility and an ability to adapt to their circumstances in affected parents.

**Keywords:** Spiritual care- cancer- nursing- qualitative study

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### Introduction

One of the important issues, which may occur in any family, is the individuals' affliction with the so-called refractory disease. These disorders include a wide range of conditions the most well-known and tangible of which are various types of cancers. Affliction with cancer is one of the most serious and stubborn problems faced by an individual because despite considerable advancements made in the diagnosis and treatment of the disease, many people believe that affliction with these diseases means the end of life (Sankhe et al., 2017). The diagnosis of chronic and refractory diseases is associated with great mental shock for many individuals. For example, cancer may induce considerable psychological stress for the patients and their family (Jabaaij et al., 2012). The cancer patient's families are put under great cancer-induced pressures more than any other person. In other words, since the family is the major caregiver to the child, the psychological, economic, and social pressures induced by the child's disease affect the familial life deeply exerting a deep influence on all aspects of the health and life of family members (Masa'Deh et al., 2013). Families with a cancer

child encounter an annoying experience in the family, face a great shock with unbelief upon diagnosis, have to live with a double burden, and experience a reduced life quality (Khoury et al., 2013). Compared to other diseases with a poor prognosis, cancer creates more fear and anxiety in the patients and their families (Mehranfar et al., 2012). The diagnosis of cancer and its invasive long-lasting treatment remove the pleasure of patients' life in many cases. It causes many of them to lose the goal, value, and meaning of life; hence, in addition to rehabilitative measures, attention should also be paid to the spiritual needs of these patients to create spiritual welfare for them affecting positively the life quality of these individuals and their families (Kandasamy et al., 2011). Most often, individuals are inclined to spirituality in the face of difficult life situations to find a way to cope with these incompatible conditions (Karekla and Constantinou, 2010). Spirituality can increase resistance against the psychosomatic crises induced by the diagnosis and treatment of cancer (Fallah et al., 2011). It also decreases the anxiety, depression, and loneliness of the patients and promotes their life quality following increased positive feelings and pleasure. Moreover, noticing this aspect of care may foster adaptive

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ability in these patients affecting their overall health and well-being (Sankhe et al., 2017). Spiritual beliefs help one understand the meaning of life events, specially the painful and worrying experiences of life, and creates optimism and satisfaction in their mental state leaving them in a contented frame of mind. Various studies round the globe have introduced spirituality as a supporting force in reducing the mental pressures, decreasing inclination for corruption, and increasing satisfaction in life (Salakari et al., 2015). In fact, spiritual intervention can increase life quality in cancer patients and their care-givers through attenuating the cancer effect (Bar-Sela et al., 2016). Other studies have demonstrated that spirituality plays a key role in adaptation with stressful life conditions induced by chronic disorders. Based on some studies conducted by the American Cancer Association, the course of treatment in cancer patients who enjoy stronger beliefs in spirituality and praying is significantly more successful compared to others. Furthermore, these patients display stronger coping strategies and abilities in encountering and accepting the disease conditions (Garssen and Visser, 2016). Patients and their families experience more or less some degrees of stress at the time of hospitalization in the hospital. Mental stress affects the patient not only physically but also psychologically. These factors may induce not only physiologic changes, but also cause some mental states such as anxiety, denial, and depression in patients and their families. Here, spiritual interventions will be most effective (Memyan et al., 2016). Spiritual care is a mental phenomenon perceived and experienced by individuals. Thus, to investigate it, we should seek it in the individuals' mind and experiences. Consequently, the researcher attempted to identify the predisposing factors of spiritual care by surveying the participants' experiences.

## Materials and Methods

This study was an endeavor to determine the experiences of parents of cancer children about predisposing factors in producing spiritual care using conventional content analysis. In so doing, fifteen parents of cancer children were selected for participation by purposive sampling method applying the greatest diversity in sampling during 2015-2016. The participants were selected to be interviewed from the oncology, radiotherapy, and hematology wards of oncology clinics of governmental hospitals round the country. Sampling continued until data saturation was achieved. To analyze the data, the interviews were transcribed verbatim, investigated completely and coded. Then, the codes were attributed to different categories based on similarities and differences. Subsequently, the categories were integrated after continual comparative investigations and placed in the main category of the study (Graneheim and Lundman, 2004). The data were collected using deep semi-structured interviews and recorded by a voice recorder. Field notes and memos were also used to complete the data. The interviews began with general questions such as: "Please explain your experience with the affliction of your child with cancer". The interview was then co-constructed by asking more probing questions on parents' experiences that

varied from individual to individual. Each interview lasted between 30-90 min. MAXQDA was used to facilitate the course of data analysis.

Lincoln and Guba recommendation were used for ensuring the trustworthiness and rigor of the study. For Trustworthiness, credibility, dependability, transferability and conformability was considered. Credibility was established by Choosing participants with various age, and gender; experiences, a prolonged engagement with participants; and peer checking. For dependability, in addition to the members of the research team, two external researchers were asked to evaluate the data separately. To facilitate transferability, a clear description of the details of the study including culture and context, selection and characteristics of participants, data collection, process of the analysis, and providing enough quotes were used. For supporting conformability, all research steps were documented on a regular basis.

Ethical considerations were observed in this study with ethics code of IR. SBMU.REC.1395.11 bestowed by Committee of Ethics in Medical Research at Shahid Beheshti University of Medical Sciences. The qualified persons were identified for participation, informed written consent was obtained from each participant, the research goals and procedures were explained, principles of information confidentiality and anonymity were observed, and finally, the participants could leave the study at any stage.

## Results

The participants of this study were fifteen parents (eleven mothers and four fathers) of cancer children hospitalized in pediatric oncology clinics. To ensure of sample diversity, participants with maximal variation in age, occupation, and education were selected. The results of data analysis yielded "psychological dead end" as the main category including the subcategories of "projection", "mental concern", "psychological pains" (Table 1).

The first category of the study was "projection" which means attributing one's unconscious actions, faults, and unfavorable intentions to others. It is a process which individuals impose ideals, pictures, and wishes on the external environment. The participants manifested their sorrow, agony, and anger in the form of having quarrel with others, insulting the medical staff, and getting angry with other members of the family. They also sought the person guilty for their child's disease so that they continually bargained with the medical staff and rendered others as guilty in their child's disease. As an example, participant #5 said in this regard: "Sometimes, I had a dispute with the personnel and uttered insulting words at them. Then, I got regretful why I had done it. This was due to the nervous strain that I tolerated. Now, I try my best not to scold anybody and just say some praying to calm myself down". Moreover, participant #9 stated: "I always ask myself: "Why is it me? Why do we behave like this?"

The second main category was "mental concern" indicating the participants' mental engagement at the time of hearing the bad news of their children's refractory disease and during treatment. It manifested itself in various

Table 1. Classified Concepts

Main category	Subcategories	Peripheral subcategories
	Projection	Anger
		Seeking for the guilty
		Fear and apprehension
	Mental concern	Confounding thoughts
		Negative imaginations
Psychological limbo	Psychological pains	Intolerance
		Sadness
		Disturbance
		Willingness for seclusion
		Wonder and unbelief
		Disappointment and pessimism
		Dependence

forms. For example, the participants declared that they are involved in fear and apprehension and that they are afraid that their children's disease may recur or lead to their death. Moreover, they suffered from confounding thoughts of suicide or intolerance of stubborn conditions since they thought that their children's condition is due to their negligence or fault. All these led them to have a negative attitude towards their children and equal it to the end of the life road and death. In this regard, participant #3 asserted: "I am always afraid that may be the disease may recur. Do you know what it means? In cancer, you always expect that the disease may betray itself again despite treatment. So, I am always worried about the recurrence of my daughter's disease. Then, I tried to remove these thoughts from my mind by confiding God Almighty and ask Him for help". Participant # 11 reported: "I felt very bad. I continually searched for a high place to throw myself down it". Additionally, participant #14 explained like this: "Some people equate cancer to death as soon as they hear the bad news about it. There is the fear of losing the child causing in many cases psychological problems for parents: yet, I try to throw away this fear through saying prayers and performing religious rituals". Ultimately, the created problems imposed some psychological problems on parents, which manifested themselves as sorrow, passion, and sadness so that the parents could not tolerate the difficult conditions. They felt that they have got tired of everything and cannot withstand the children's suffering and distress. Moreover, these conditions are difficult for the medical staff to tolerate imposing an emotional crisis on them, either. Participant #1 said: "It was a very difficult experience because it demands much endurance to be able to withstand such a great pressure. It was one of the worst periods of my life. Only God Omnipotent helped and saved me by fostering my patience and tolerance". The participants stated that this issue had affected their mental status profoundly so that they cried frequently and got depressed. Participant #4 asserted in this regard: "Whoever called me up, I burst to cry. It was a very bad condition and I could not avoid shedding tears. Additionally, the parents were very upset and felt lost with indecision so that participant #15 expressed their feelings in this way: "At that moment, the

world collapsed on me and I could not hear the doctors anymore". Some participants claimed that they don't want to talk to others and are not interested in explaining about their children's disease to others. Participant #1 said in this respect: "I tried not to talk much to anybody about this problem. I did not want to bother or sadden others". Almost all participants stated that at first they could not believe it, as they were bewildered and were not able to accept their child's disease. They hoped that the doctors have misdiagnosed the disease and denied the child's cancer. For instance, participant #1 said: "I cannot express my feelings. I felt I am not in the worldly time. I was suspended in a time that I can call 'the period of stoppage". Some participants finally achieved a feeling of disappointment and pessimism and expressed that they felt nihilistic and found a vacuum in their life so that life had no meaning to them. Participant #13 put it like this: *Believe me that I know nothing about life. My mind is obsessed with the thought of my son. Life is not meaningful for me anymore. I don't know how to express it, but when I say nothing is meaningful for me, it means the end of life for me. Yet, this state is not permanent since I try to control myself and manage the situation by asking help from God and doing good things to others or helping those who need it*". The relation between the mother and the child had strengthened during the disease due to the child's condition. The participants asserted that the child's condition affects their mental status profoundly and vice versa. Participant #13 explained that: "Even if they take me to the Heavens, I won't feel peaceful. I get calm when my son is with me. I never left my son alone".

## Discussion

The aim of this study was to determine the experiences of parents of cancer children about predisposing factors in producing spiritual care.

After data analysis, the theme of "psychological limbo" with three categories of "projection", "mental concern", and "psychological pains" was emerged. The first category of the study was "projection" in which the participants imposed their internal feelings on the external environment. They manifested their sorrow and agony due to their child's cancer in the form of anger and violence towards others. They also sought the person guilty for their child's disease and tried to attribute the child's cancer to others to be able to reduce their anxiety and feeling of guilt. In the study by Hekmatpoor et al. carried out on parents with cancer children, the participants looked for the factor that was guilty in the child's cancer. They rendered themselves, others, or the medical team as guilty in this regard. This has led to feelings of sadness and scolding in them or in others. Ultimately, the parents announced that they had accepted the disease of the child and adapted themselves to it through confiding God and performing religious rituals (Hekmatpou et al., 2013). Additionally, in onestudy conducted on the attitudes of parents with cancer children, the parents announced in their interviews that at first they suffered from anger and agony (Darcy et al., 2014). Some participants in the

Hexem- kari et al. study said that have been experiencing anger toward God and he knew the culprit causing disease in your child and ask themselves, why it happened to us? what we've done wrong? (Hexem et al., 2011).

The second category extracted from the data of the study was "mental concern" in which the parents were involved in mental obsession with the child's disease. It manifested itself as fear of the disease, fear of losing the child, recurrence of the disease, negative imaginations about future of the child, and worrying and confounding thoughts such as intolerance of difficult conditions or committing suicide. In onestudythe parents asserted that they were not sure of their child's cancer and had feelings of insufficiency and inability (Darcy et al., 2014). Anxiety and fear of death reduce life quality in the families of cancer children (Soleimani et al., 2017), and spirituality reduces anxiety in patients with cancer and in mothers of children with cancer (Borjalilu et al., 2016). Spirituality causes adaptability and compatibility with the disease in patients with cancer. It creates a positive attitude towards life, enhances life quality, and induces tranquility and peace in patients (Akhbardeh, 2011). Spirituality furthermore leads to better decision-making in cancer patients and is introduced as a source of adaptation for them since it diminishes stress and lack of confidence (Vafae, 2015). In onestudy conducted on chronic patients, the participants stated that God has punished them for the sins they have committed in their life. This has culminated in their psychological pressures and strains. The use of spiritual beliefs has reduced their mental pressures and induced peace in them (Akhbardeh, 2011) Parents unsure about their children's future (Saifan et al., 2014). In another study, the participants postulated that cancer in their child meant equal to death for them. Fear of future and imagination of losing the child had terrified them. Nonetheless, they were able to overcome the problems, acquire optimism and hope via confiding God (Hekmatpou et al., 2013).

The third category of the study was "psychological pains" in which the participants were afflicted with various psychological conditions due to the child's cancer including sadness, disturbance, anxiety, disappointment, pessimism, lack of willingness for talking to others, preferring seclusion, and great dependence on the sick child. In a study conducted on the experiences of parents with cancer children, they declared that the diagnosis of cancer in their children was highly difficult so that they were shocked at first: also, they stated that this issue caused them much discomfort (Darcy et al., 2014). As mentioned earlier, the participants had no inclination for communicating with others and secluded themselves from the society. The study by Seifa et al., (2014) referred to this issue wherein the parents of cancer children asserted that they have no willingness to attend the community and spent most of their time with the affected child. The parents developed stress and anxiety due to their child's cancer and sustained much psychological pressure (Saifan et al., 2014). Furthermore, Cernvall et al., (2013) postulated, by studying parents of cancer children, that the diagnosis of this disease induces much stress in the parents, makes them depressed, and reduces their

life quality. Kumar et al., (2017) also reported in their study that spirituality induces tranquility and peace in cancer patients influencing their adaptability with cancer stressors. Additionally, Hamilton et al., (2016) referred to the role of religion in diminishing psychological symptoms like depression, discomfort, anxiety, worry, and fear among the cancer patients. The participants of the study by Hekmatpou et al., (2013) confessed that they felt disappointed with no inclination for explaining the disease to others or telling the truth about the disease to their children. They said that they acquired the ability to tolerate the disastrous problems and to adapt themselves to the disease. Faith in God decreased the negative impact of others for cancer patients and in addition reduces the negative issues such as anxiety and discomfort caused by the disease (Hamilton et al., 2015). This finding is consistent with our results. Thune-Boyle et al., (2013) found in their study on cancer patients that the application of religious and spiritual sources plays a central role in adaptation and decreasing anxiety in cancer patients. Sulsman et al., (2015) investigated the correlation between "religion and spirituality" and "mental health" of the cancer patients and concluded that mental health improved with increasing spirituality in cancer patients. Seeing that the calamity of affliction with cancer, sustaining difficult treatments, and the resulting fatigue influence the physical status, performance, and psycho-social condition of the patients and their families culminating in the manifestation of feeling of inability in them (Eyigor and Akdeniz, 2014), the present study also confirmed this point since our participants felt unable and exhausted. Akhbardeh (2011) completed a qualitative study to explore the role of spiritual beliefs in the mental health of chronic patients and found that spiritual beliefs both facilitate patients' coping with the negative mental effects of chronic diseases, decrease depression and anxiety, and increase their life satisfaction leading to tranquility in patients. Krause et al., (2016) concluded in their study that the higher the spirituality in individuals, the greater their ability to cope with stressful life events. Thus, their mental health improves with increasing spirituality. Lyon et al., (2014) investigated the "effect of spiritual care on anxiety, depression, and life quality of cancer teenagers" and found that anxiety and depression decreased significantly in these teenagers after spiritual intervention. Moreover, their life quality and spirituality improved after intervention and during the follow-up processes. Additionally, interviews performed with the families of these patients demonstrated that, in the viewpoints of the families and the main caregivers, spiritual beliefs and issues can effectively influence the life quality and mental health of the families and the patients themselves. Wood et al., (2016) carried out a study aiming at determining the effects of short-term psychotherapy training periods with an emphasis on the spiritual aspects of stress-coping and improvement. They suggested that a progressive course of improvement began immediately after interventions, so, dealing with spiritual affairs in the framework of treatment team has very good advantages for cancer patients. Goncalves et al., (2015) alconcluded that spirituality reduce stress and depression.

Other studies also indicated that uses of religious and spiritual sources are common in adapting cancer patients with their disease, especially life-threatening conditions. The religious-spiritual fight with cancer may also aid in various functions like maintaining self-confidence, exposition of a feeling or meaning, the goal of mental peace, and feeling of hopefulness. Spiritual beliefs and enjoying mental health play an important role in promoting general health (Raffay et al., 2016). Finally, Taylor et al., (2015) probed “spirituality and spiritual care in cancer adolescents and adults” and concluded that feelings of indecisiveness and seeking support were observed more than anything else in the patients and they suffered from some sort of spiritual shortage. They sought some type of spiritual welfare.

In conclusion, this study explored the experiences of parents with cancer children and clarified the point that parents sustain some violent psychological and mental reactions when they first receive the bad news of their children’s disease. This issue serves as a predisposing factor, which drives the cancer patients or parents to apply spirituality and religion in adapting themselves with the stubborn conditions, accepting the disease, creating hope, and producing tranquility in them. Consequently, given the social culture of the Muslim population of Iran, it is mandatory to pay due attention to spirituality and train parents of cancer children in the spiritual and religious issues to avoid the imposition of psychological problems on them and secure their mental health. The strength of this study were sampling from different regions of the country and choosing participants with various age, gender and experiences. This study is first research about predisposing factors of spirituality care process of parents with cancer children in Iran. This study, nevertheless, suffered from some limitations that limit the external validity of the findings. Since this study was conducted on Muslim participants, so the results may not be generalized to other conditions with non-Muslim patients. Hence, it is recommended that similar studies be conducted on minority religious ethnicities to attain externally more valid results.

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