**RESEARCH ARTICLE**

**Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of Caregivers**

Somaieh Borjalilu1,*, Shahriar Shahidi1, Mohammad Ali Mazaheri1, Amir Hossein Emami2

**Abstract**

**Background:** The purpose of this study was to explore the effectiveness of a spiritual care training package in maternal caregivers of children with cancer. **Materials and Methods:** This study was a quasi-experimental study with pretest and posttest design consisting of a sample of 42 mothers of children diagnosed as having cancer. Participants were randomly assigned to either an experimental or a control group. The training package consisted of seven group training sessions offered in a children’s hospital in Tehran. All mothers completed the Spirituality & Spiritual Care Rating Scale (SSCRS) and the Depression, Anxiety and Stress Scale (DASS-21) at pre and post test and after a three month follow up. **Results:** There was significant difference between anxiety and spiritual, religious, Personalized care and total scores spiritual care between the intervention and control groups at follow-up (P<0.001). There was no statistically significant difference in stress and depression scores between the intervention and the control groups at follow-up. **Conclusions:** Findings show that spiritual care training program promotes spirituality, personalized care, religiosity and spiritual care as well as decreasing anxiety in mothers of children with cancer and decreases anxiety. It may be concluded that spiritual care training could be used effectively in reducing distressful spiritual challenges in mothers of children with cancer.

**Keywords:** Spiritual care training - mothers of children with cancer - quality of care - mental health - personalized care

**Introduction**

Childhood cancer is a chronic illness which claims millions of lives each year (Woodgate and Degner, 2003; Thomson, 2009). In Iran, depending on the region, the rate of childhood cancer is 48-112 and 51-114 per million in girls and boys, respectively. The rate of deaths from cancer is 42 in girls and 49 per million among boys (Mousavi et al., 2009).

Cancer is an unexpected and stressful event for children, adolescents and parents, which bring about challenges for both the patient and his / her family. Due to its chronic nature, cancer inflicts long-term treatment, physical disorders and mental distress on the patient (Cernvall et al., 2013; Kostak and Avci, 2013). Being diagnosed with cancer, therefore, sets off a state of crisis. Personal communications are disrupted because of uncertainty about the future and previous coping mechanisms seem insufficient. Also, hospitalization causes a despair phase in individuals and creates an emotion and spiritual crisis (Ebmeier et al., 1991; Highfield, 1992).

Spirituality refers to a universal human capacity for self-awareness, which is associated with a person’s search for identification, and acquisition of meaning and purpose (Benson, 2006; Pargament and Sweeney, 2011). Hay and Nay identified spirituality with ‘relational conscious’, an evolved human capacity for or an awareness of connections with self, others, the world and a transcendent power (Hay and Nye, 2006). Spiritual development is a lifelong process (Thomson, 2009). As such, children typically lead a strong spiritual life and once they are cognitively able to understand the different aspects of the ‘self’, they are able to grasp spirituality (Hart and Schneider, 1997; Woodgate and Degner, 2003).

When children are diagnosed with cancer, they may raise difficult questions to which they try to find the answer, such as why they are inflicted with the disease and why they suffer. Indeed, the first question that arises when a person suffers is ‘why’; therefore, he or she may make attempts to search for the meaning of their suffering (Brant, 2010). They may make enquiries about God and why He has caused them to suffer. Children may also ask questions about death and its nature. Therefore, diseases speed up children’s spiritual development (Shelly, 1982). In such cases, individuals need purpose to deal with crisis and the distress caused by these misfortunate events is rooted in one’s inability to find meaning and purpose of life. As such, spiritual crisis may lead to lack of energy, anxiety, depression, unexplained pains, sorrow, lack of control over thoughts and emotions, and a sense of...
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disengagement and isolation. Other consequences may include guilt feelings, anger, denial, helplessness and frustration (Shelly, 1982; Myers et al., 2014).

National Association for the Education of Young Children considers building interactions among family members as an effective strategy for promoting and supporting spiritual development in children (Heath et al., 2010). Parent’s role is, therefore, of utmost importance in nurturing spirituality in children. In this sense, spiritual care is yet another care parents could provide in time of chronic diseases. American Cancer Society reported that family and spiritual care accounted for 35% of cancer survival rate (Hufton, 2006). As for the role of family, admittedly childhood diseases cause caregiver stress in the family (Taft et al., 2012).

The official diagnosis of a cancer causes parents to experience a spiritual crisis and a high level of anxiety (Fortier and Wanlass, 1984). Typically, families go through this stage by feeling anger, depression, a sense of duality, loss and of pressure, loneliness, difficulty in decision making, and uncertainty (Anderzen et al., 2010). Most hospitalized children, however, need the involvement of their parents for supporting them in the face of adversity, regarding their parents as the best source of support (Taft et al., 2012). Undoubtedly, parents who have confidence in their supporting role exhibit wider participation in the care of their hospitalized children. Such parents convey a sense of confidence and safety to their children, thereby enhancing their children’s mental health and reducing the perception of pain (Kaplow and Hardin, 2007). Therefore, family members, particularly mothers, have a major role to play in supporting and providing emotional, social and spiritual needs of children (Woodgate and Degner, 2003; Abrams et al., 2007).

Spiritual care refers to supporting another person who is searching for meaning and purpose of life. It focuses on the individual who is anxious, in doubt or experiencing a sense of conflict. This care encompasses religious support (praying with the patient, talking to the patient about God, religious discussion with the patient, using religious texts), communication skills (establishing a real relationship with the patient, emotional support, making, and uncertainty (Anderzen et al., 2010). Most hospitalized children, however, need the involvement of their parents for supporting them in the face of adversity, regarding their parents as the best source of support (Taft et al., 2012). Undoubtedly, parents who have confidence in their supporting role exhibit wider participation in the care of their hospitalized children. Such parents convey a sense of confidence and safety to their children, thereby enhancing their children’s mental health and reducing the perception of pain (Kaplow and Hardin, 2007). Therefore, family members, particularly mothers, have a major role to play in supporting and providing emotional, social and spiritual needs of children (Woodgate and Degner, 2003; Abrams et al., 2007).

Materials and Methods

Study subjects

This study was a quasi-experimental study with pretest and posttest design. Participants consisted of 42 mothers of children with cancer residing in Tehran province. They were aged 21 to 52 years old (M=34.1, SD=9.45). The inclusion criteria included: age of the child (7 - 15 years), diagnosis of cancer by a pediatric oncologist, the child must have given radiotherapy for at least one month, the child should not be under any psychotropic medication, and that the mother should be the primary and legitimate caregiver. 42 mothers of child cancer were selected randomly by cluster sampling method from two children’s hospitals in Tehran. After coordination with officials in these hospitals, eligible participants were identified. Researchers then communicated with mothers, briefing them on the research purpose and the design. Finally, the participants gave their written consent to participate in the study. This study was conducted with the approval from the Faculty of Psychology and Education Ethics Committee in Shahid Beheshti University in Tehran. Ethics Committee’s approval letter number.

Intervention procedure

A total of 42 mothers were randomly assigned to a
control and an experimental group (n=21 in each group). The participants were then informed of the group training sessions. The training sessions were scheduled for March 2014 in three groups of seven participants. The entire training period lasted for two months. The control group remained on a waiting list and in accordance with requirements for research ethics, received training identical to the experimental group after the follow up period was over. The follow-up was performed three months after completion of the intervention.

The Educational aspect of the spiritual care training package for parents of children with cancer was provided by Borjalilu, Shahidi, Mazaheri and Fathabadi and used for the education component of the intervention (Borjalilu, 2014). This was based on the spiritual care training package, ASSET model (Actioning Spirituality and Spiritual Care Education and Training) (Narayanasamy, 2009). Major skills for spiritual care in this model are communication skills, encouragement and offering hope. The present model was, however, modified in conformity with local customs, beliefs and accepted norms. The package is primarily concerned with psycho-educational therapy which integrates psychotherapeutic and educational interventions (Lukens and McFarlane, 2006). The final version was then developed using expert judgments and opinions of some caregivers of children with cancer (Borjalilu, 2014). In each judgment session, the degree of agreement between experts and caregivers was over .8. Cohen’s kappa for the inter-rater agreement of the whole training package was 0.992. Table 1 summarizes the contents used in the training package.

This training package encompassed seven 90-minute sessions offered once a week. It involved questions and answers, brainstorming, model presentation and group discussion. Parents were assisted to think about the misfortune they faced. Both control and experimental groups were subjected to pre-test, a week before the treatment, and post-test, a week after the treatment, using SSCRs and DASS-21. The results were reanalyzed three months after completion of the intervention.

Data collection tools

Spirituality & Spiritual Care Rating Scale (SSCRs). Developed by Mc Sherry et al. (2002), it is an instrument investigating and measuring spirituality and spiritual care. The questionnaire was developed based on a 5-point Likert scale. Following the preliminary pilot of the questionnaire, some items were removed, making it a 17-item scale. The final scale consisted of four major factors of spirituality, spiritual care, religiosity and personalized care. Exploratory factor analysis was used to evaluate the reliability. Principal component analysis of the scale revealed that eigenvalues of the 4 factors were greater than 1 and that the cumulative percentage of variance accounted for by the current and all preceding principal components was 57% 0.32. Cranach’s Alpha for spirituality, spiritual care, religiosity and personalized care were 0.80, 0.67, 0.90 and 0.82, respectively. Test-retest reliability coefficients were 0.57, 0.77, 0.85 and 0.72 for spirituality, spiritual care, religiosity and personalized care, respectively (p<0.01).

Depression, Anxiety and Stress Scale (DASS-21). DASS (Lovibond and Lovibond, 1995) is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress. The short version, the DASS-21, is a 21-item questionnaire on a 4-point Likert scale. Acceptable estimates of reliability were obtained for the scale as a whole via internal consistency and test re-test reliability. Cranach’s Alpha for depression, anxiety and stress were 0.89, 0.85 and 0.83, respectively. Also, test-retest reliability coefficients were 0.80, 0.76 and 0.81 for depression, anxiety and stress respectively (p<0.01).

Statistical analysis

Statistical analyses mainly used the descriptive statistical analyses. Descriptive data were expressed as mean±SD (standard deviation). Analysis of variance (ANOVA) was used to ascertain the significance of differences between continuous variables and tested by repeated measures. Differences with P<0.01 were considered significant. Data were analyzed with SPSS version 17.0 for Windows (SPSS Inc., Chicago, IL).

Results

The 42 mothers (age range: 21-52 years) were asked to participate in this study, assigned in experimental group (M_1=36.8 years) and the control (M_2=31.9 years). For the compare the DASS-21 of experimental and control groups in posttest, AVCOVA was used. Its results have reported in Table 2.

Table 1. Spiritual Care Training Package Designed for Parents of Children with Cancer

<table>
<thead>
<tr>
<th>Session</th>
<th>Subject</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Spirituality</td>
<td>Introduction to concepts of spirituality and spiritual awareness and familiarity with religious coping strategies</td>
</tr>
<tr>
<td>2</td>
<td>Spirituality and children</td>
<td>Spirituality in children, familiarity with children’s spiritual needs, recognition of spiritual crisis in sick children and spiritual care</td>
</tr>
<tr>
<td>3</td>
<td>Relationship</td>
<td>Familiarity with secure and insecure attachment patterns and with attachment behavior. Exploration of mother-child interaction</td>
</tr>
<tr>
<td>4</td>
<td>Excitements</td>
<td>Familiarity with excitements, causes and behavioral manifestations, recognition of excitements of children with cancer, how to deal with these excitements in time of disease</td>
</tr>
<tr>
<td>5</td>
<td>Hope and future</td>
<td>Promoting self-confidence, sense of independence and self-sufficiency, familiarity with rules of the play as to create a fun and exhilarating environment for children</td>
</tr>
</tbody>
</table>
Table 2 shows the changes Depression, Anxiety and Stress scores of the intervention and control groups. The score of stress in the intervention group decreased in the post test and there was also a trend reduction in number of stress until 3 months after the program (the mean scores were 2.71 at pre-test, 2.37 post-test and 2.18 three months after receiving education). In the control group, significant differences were not identified during the 3-months follow up (corresponding scores were 2.67, 2.58 and 2.48 respectively). There were significant differences interaction between groups and time in pre and post test (F=18.01; P<0.001; η2=0.51), but no significant differences interaction between groups and time in 3-months follow up (F=2.64; P=0.114). In the control group, not significant differences interaction between groups and time.

The anxiety scores in the intervention group decreased in the post test and there was also a trend reduction in number of stress until 3 months after the program (the mean scores were 2.7 at pre test, 2.54 at post test, and 2.42 three months after receiving education). There were significant differences interaction between groups and time in pre and post test (F=4.009; P<0.001; η2=0.45) and significant differences interaction between groups and time in 3-months follow up (F=4.149; P<0.001; η2=0.35).

The score of depression in the intervention group decreased in the post test and there was also a trend reduction in number of stress until 3 months after the program (corresponding scores were 2.68, 2.47 and 2.4 respectively). There were significant differences interaction between groups and time in pre and post test (F=41.49; P<0.001; η2=0.35), but no significant differences interaction between groups and time in 3-months follow up (F=29.86; P=0.123). In the control group, significant differences were not significant differences interaction between groups and time.

Table 3 shows the changes Spirituality and Spiritual Care scores of the intervention and control groups. The score of Spirituality in the intervention group increased in the post test and there was also a trend increased in number of stress until 3 months after the program (the mean scores were 3.73 at pre-test, 3.93 post-test and 4.022 three months after receiving education). There were significant differences interaction between groups and time in pre and post test (F=9.09; P<0.00; η2=0.58), and significant differences interaction between groups and time.

Result showed that education program favorably affected anxiety of mother’s child cancer. In the control group, not significant differences interaction between groups and time.

The score of depression in the intervention group decreased in the post test and there was also a trend reduction in number of stress until 3 months after the program (corresponding scores were 2.68, 2.27 and 2.4 respectively). There were significant differences interaction between groups and time in pre and post test (F=41.49; P<0.001; η2=0.35), but no significant differences interaction between groups and time in 3-months follow up (F=29.86; P=0.123). In the control group, significant differences were not significant differences interaction between groups and time.

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The present research was concerned with exploring the effectiveness of educating mothers of children with cancer in spiritual care with the aim of improving their mental health and spiritual care skills. The results revealed that such training did indeed change mothers’ attitude towards spirituality and spiritual care in the experimental group and that this effect remained constant at follow-up. According to the ASSET model (Narayanasamy, 1999), teaching spiritual care on a personal level develops self-awareness (knowledge of spiritual attitudes and beliefs of the self) and spiritual health. Such training further raises awareness of spirituality and its domains, spiritual care, values and the concept of spirituality, and develops empowerment in recognizing and evaluating spiritual needs and establishing relationship with the patient (Chan, 2010; Foster et al., 2010b). The ASSET encourages caregivers to become sensitive to the patient’s spiritual needs, reduces spiritual stress and promotes the quality of spiritual care (Carson, 2011; Cone and Giske, 2013). As the most fundamental pillar in society, family is responsible for providing appropriate health care to the patient and her companions (Park, 2010). In providing care for the patient, the family needs a clear understanding of the disease and of the required care. With profound advances in hygiene, health care institutions have given way to family-centered care (Smith et al., 2015). In this sense, spiritual care has been regarded as a duty of caregivers in medical settings (Zollfrank et al., 2015)

Deborah and Elaine showed that diagnosis of a disease in the child causes mothers to feel guilty and experience a sense of isolation and punishment by God (because of past sins), thus developing resentment toward God and making attempts to search for the meaning of their children’s suffering (Allen and Marshall, 2010). Familiarity with the concepts of spirituality and self-awareness could encourage mothers to connect with a transcendent power (God), self (forgiveness) and others, hence experiencing peace of mind. Similarly, Hexem and her colleagues demonstrated that mothers believed that religiosity gave meaning to their lives and was a source of support, peace and relief; the source was believed to be God or a transcendent power (Hexem et al., 2011). Styling the needs of patients and caregivers, Taylor and Mamier found that patients and caregivers need time to relax and talk about spiritual resources (Taylor and Mamier, 2005).

In the present study, it was shown that the effect of spiritual care education in the experimental group was significantly different from that in the control group and that there was a significant difference between performance of experimental group and control group in the post-test.

In the proposed training program, mothers were initially familiarized with the concept of spirituality and spiritual needs as to promote self-awareness. Indeed, we intended to encourage mothers to embark on an introspection of the self, too look inside. Introductory sessions, therefore, targeted an assortment of issues: connection with God or a deity (Trusting God and soliciting help from Him), characterization meaning and life goals (a holistic perspective toward life, coming back to life, being realistic about the misfortune - the child’s disease - and setting new goals according to the current conditions), courage and hope (accepting the new conditions and living for the moment, giving up trying to control the uncontrollable, having faith, thinking positively and considering new possibilities), peace (creating a private self-enclosed environment, seizing the day and living life fully), exploring life beauties (appreciating nature and its beauties, art and music), respect and attention (unconditional acceptance, relationship with the self and others, expressing love and being dearly loved, and forgiveness). Covering these issues, we hoped to encourage the mothers to gain a new perspective on spirituality and personalized care.

The next step was the introduction of the following issues in the psycho education program: Children’s spiritual growth, spiritual needs, and recognition of spiritual crisis in children. This was done in order to empower mothers in providing spiritual care to their children. This was followed by a discussion on intellectual challenges.
children may face, such as the meaning of suffering, pain and the concept of death. The skills required for an effective mother-child relationship were also presented. Identifying emotions in children with cancer and how to deal with emotions were other issue discussed during the training session. Mothers were educated on strategies to raise hope in their children by improving their self-esteem and how to create a happy environment. In the light of the preparations offered in the training program, mothers gained a working knowledge on how to cope with the conditions of children with cancer; following the training program (post-test), mothers understanding was shown to be significantly different from that before the program (pre-test) (p<0.01).

Religiosity was yet another important issue considered in educating mothers on spiritual care, as it is a pivotal issue people reflect upon in adversity. According to the theory of stress and coping (Bambara et al., 2009), individuals adopt different coping strategies to deal with distress. Religion can serve as a support source to reduce adverse effects of stress (Lim and Zebrack, 2004). Whereas positive religious coping is characterized by a sense of spiritual connection with God (or a deity) and others and having meaning in life, negative religious coping represents weak connection with a deity and a pessimistic view of the world.

Caregivers’ coping strategies involve creating a philosophy for life, optimism and hope through religious teachings (Atkin and Ahmad, 2000; Rocha-Garcia et al., 2003). Religion, worship and faith serve an important support source for mothers (Patistea, 2005; Fletcher et al., 2010). A number of studies have shown that Muslim caregivers of children with cancer employed religious coping as a parental coping strategy (Sposito et al., 2015). Perricone and her colleagues found that mothers of children with cancer and chronic disease tried and controlled their distress by praying for their children (Banerjee et al., 2011; Perricone et al., 2013). Research suggests that adaptive caregivers exhibit a higher degree of positive religious coping and, expectedly, a lower degree of negative religious coping, compared to their maladaptive counterparts.

Another result in this study, it was showed effect of training spiritual care on mental health of mothers of child cancer. Therefore observed high scores of depression, anxiety and stress in mothers of children with cancer, because cancer in children is one of the most stressful events that mothers experience. (Masa’Deh et al., 2012; Naderi et al., 2012). Their children threatened with death and they feel that in this event they are unable to control affairs. (McCarthy et al., 2009; Witt et al., 2010).

As the results showed in the experimental group of mothers, spiritual care training had a significant effect in reducing of anxiety, depression and stress. As mentioned before, one of the objectives of Training courses was consciousness. Mothers rely on their own beliefs and values; browse more of their religious and spiritual. This led to reduce the anxiety; depression and stress in the mothers’ experimental group, because spirituality and religion are as a resource for coping with challenges and difficulties (Jim et al., 2006; Park, 2010) and also there is a relationship between the search for the meaning of life and mental health.

In the present study the aspects of cognitive, behavioral and spiritual experience of mothers of children with cancer were given. The cognitive aspect of the search for meaning and purpose of life was considered. In Experimental aspects, feeling of hope, love, and connection was considered, and in a Behavioral aspect was praying (Holder et al., 2010).

It seems that the spiritual care training in the field of Cognitive by some mechanisms such as Let’s go (Nash et al., 2013) thinking about the present that was emphasized in training sessions, cause To reduce the unpleasant feeling of anxiety, threaten and impacted. So the mothers were encouraged that to attend present time and have paid all their efforts for their child. Thinking about Today’s events and activities can make a distance to thinking of anxiety field.

On the other hand, one of the factors to reduce stress, anxiety and depression in mothers of children with cancer, was activation of spiritual coping strategies such as trust, patience, leaving the problem to God that are in our Islamic teachings, because when human is sure about near God Trust and belief in His wisdom created. In the Quran, God describes believers “I will submit my work to God, the Lord is aware of servants”. So the delegation of the affairs is leaving the affairs to God without cause, the official man submit to the will of God. Acceptance of God’s will, create a kind of friendship and love between God and human that man was resistant to accept the suffering of life (Bonab and Koohsar, 2011; Mousavi et al., 2015). Therefore, they will free from any threat, fear and stress and feel comfortable (Gaudette and Jankowski, 2013).

As the results show that education is the cause of reducing depression in the experimental group. Hospitalization for sick children in hospitals are often self-blames their mothers. These mothers often are less optimistic about future (Wray et al., 2011; Krattenmacher et al., 2014). This phenomenon is very important in chronic diseases such as cancer. Because, as mentioned earlier their children threatened to death and mothers feel powerless. (Kudubes et al., 2013). All subjects said confirm the high score on the depression test in two experimental and control groups of the present study. But it seems that the use of cognitive skills against spiritual such as drawing goals for the future (improved patient child and support family members), Trying to achieve the stated objectives, forgive yourself and others and to avoid self-blame, led reform in these maternal negative emotional responses and are reduced feelings of sadness, helplessness and hopelessness (Koons, 2012). On the one hand, it seems that according to Islamic teachings, such as the hope for divine mercy and healing in their children reduced a sense of emptiness. Have a positive outlook help mothers to improve their hope (Hanh et al., 2009; Garzini et al., 2013).

But the lack of significant stress and depression during the follow-up can be because of stress occurs essentially against the existence of some external conditions, such as disease, and as long as these conditions persist, there may also be stress. Also spiritual care for mothers is a short
term that has positive impact but external conditions, the existence of child illness, still exist. This post-treatment period also causing stress and depression may be deeply rooted in the people.

Religion provides individuals with a systematic approach for coping with stressors in life. Admittedly, religious coping strategies may be considered to be largely culture specific (Jim et al., 2015). This is vividly observable in the socio-cultural context of Iran. In this study, prior to the performance of psycho educational intervention, religious beliefs and practices in the experimental group was assessed (Pargament, 2001). Drawing on the approach, we tried to carry out a religious evaluation in order to adjust and reconstruct a stressful event. The experiences of mothers were also used to discuss spiritual coping strategies, such as faith, patience, and submission to God’s will. Accordingly, they were assisted to participate in religious practices, such as visiting holy places, prayer or worship; as to keep stressors away and to solicit God’s help.

The results showed that empowering mothers in spiritual care strengthened their spiritual beliefs and educated them on spiritual care skills. Though intrigued by the psycho educational program, the majority of mothers failed to attend the program, as the process of cancer diagnosis and treatment requires around the clock care by mothers. As such, empowering mothers of children with cancer calls for modern techniques of training, such as distance education. Examples include designing educational CDs and taking advantage of the cyberspace. Most countries offer online assistance for educating mothers of children diagnosed with cancer, so mothers could benefit from the available information and also share their experiences. Therefore, there are increasing calls for such new techniques in educating mothers of children with chronic and oncological disease.

References


