

## Research Article

# Effectiveness of Islamic Spiritual Care Education for Parents on Quality of Life and Chronic Pain of Children with Cancer

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**Aims:** Studies showed that spiritual care is a good mechanism of coping for parents with children suffering from cancer. The purpose of this study is to investigate the effect of parents' Islamic spiritual care on pediatric quality of life and chronic pain in children with cancer.

**Instrument and Methods:** A semi-experimental study was performed at Mahak Hospital in Tehran, Iran. Forty-five child-parent pairs were assigned into the experiments ( $n = 25$ ) and control groups ( $n = 20$ ). The parents of children with cancer in the intervention group received eight sessions of Islamic spiritual care of the child with cancer lasting between 80–90 minutes. The control group received only routine standard care. All parents completed the Spirituality & Spiritual Sare Rating Scale (SSRS) and all children with cancer completed the pediatric quality of life inventory and Oucherpain scale before and after the interventions. The data was analyzed in SPSS-21.

**Findings:** There was significant difference between attitudes of parents toward spirituality and spiritual care between two groups ( $F=10.02$ ;  $P<0.01$ ;  $\eta^2=0.48$ ). The mean of 'Spirituality' in the experimental group was 3.73 at pre-test, 4.11 post-test and 4.4three months after the sessions. Also, the results showed that spiritual care training of parents improved the pediatric quality of life. The mean children quality of life in experimental group was 3.39 at pre-test, 4.16 post-test and 4.22 three months later ( $F=12.46$ ;  $P<0.01$ ;  $\eta^2=0.41$ ) and hence a decreased pain perception in children with cancer during follow-up. The mean of pain perceived among children with cancer was 8.96 at per-test, 7.42 posttest and 4.89 at follow up. ( $F=15.33$ ;  $P<0.01$ ;  $\eta^2=0.33$ ).

**Conclusions:** The results showed that spiritual care training of parents increases their attitude toward spiritual care for their children. In this regard, the impact of current training increases pediatric quality of life and reduces the intensity of pain among children with cancer.

**Keywords:** Family education; Spirituality in healthcare; Health-related quality of life; Pain- childhood cancer

## Introduction

Due to the chronic nature of cancer patients have to undergo long-term treatments which has physical and psychosocial complications [1]. These mental and physical outcomes resulting from a cancer diagnosis cause an existential crisis in the person [2].

Children have spiritual life and when they could perceive various aspects of "self", they can perceive spirituality [3-4]. Children with cancer may ask questions about their disease. They wonder why they are inflicted and ask questions about the reason for the pain and suffering [5]. In fact, the first question they ask when they suffer is "why" them. They ask questions about God and about death and the reason why they are chosen by Him to suffer the pain and agony. Therefore, diseases accelerate the process of spiritual development in children [6]. Spiritual crisis in children manifest in them as a result of fear. This fear, that includes fear of sudden movements, loud noises, loss of supporters, darkness, being alone, and hell, is

indicative of spiritual crisis [7]. Therefore, they exhibit behaviors like aggression, cessation of interaction with others, crying, and regression. Spirituality as knowledge of connections with self, others, and the world [8]. Spiritual beliefs affect the person's interpretations of events and facilitate the process of coping with and accepting them [9]. Therefore, patients also need spiritual care in addition to clinical care [10].

Spiritual care encompasses religious support, communication skills, and empathic relationship with the patient [10]. Spirituality enhances psychological coping through providing support sources and indirectly through its effects on hope and improves mental health, quality of life and pain perception [11].

The quality of life in children and adolescents diagnosed with cancer is influenced by the internal environment (self) and immediate environments like family [12]. Children diagnosed with cancer regard their parents as the best source of support [13]. Spiritual care has a

great impact on children with chronic disease [14,15]. According to the American Cancer Society, family's support and spiritual care account for 35% of cancer survival [16]. Parents play an important role in spiritual support [17] which contributes towards helping the children remain calm and optimistic [18].

Researchers have found that spirituality and religious activities help children cope successfully with disease [5,19]. Children diagnosed with cancer need to cope with pain, through spiritual care along with parents' supports, which helps to relieve their pain easily by making them buoyant [3,14,20]. A review of the literature showed no relevant training in this regard for the parents of sick children. On the other hand, it is important to address the spiritual care of children and adolescents diagnosed with cancer from the perspective of Religious-Islamic and cultural teachings. Therefore, this study was conducted to investigate whether Islamic spiritual care by parents has any effects on the quality of life and pain perception of children diagnosed with cancer.

## Instrument and Methods

Using a quasi-experimental approach with pretest and posttest and follow-up, the effectiveness of a parents' Islamic spiritual care-training program was evaluated in children with cancer from September 2020 to May 2021. Approval of The Shahid Beheshti University was obtained for this study (ISO2709) and parents and children received a detailed explanation of the objectives of the study and informed consent was obtained from all of them. In order to observe the "confidentiality principle", the parents were assured that the collected data would be confidential and anonymous.

The inclusion criteria were a diagnosis of cancer and age 6-16 years. The included children had not received prior training or psychological intervention before the study. The parents who were recruited were primary and legitimate caregivers and had minimum literacy required for executing orders and completing questionnaires and home assignments.

Parents and children who were unable to attend the sessions regularly or do home assignments correctly were excluded from the study. A group of children cancer patients with the same mean age and radiotherapy method, who were on treatment at the same time, were selected.

The experimental and control group each included 45 child-parent pairs, selected by purposive sampling method from Mahak Charity Hospital and Mahak Welfare Center. After attrition, the experimental and control group included 25 and 20 parent-child pairs, respectively. The control group remained on a waiting list and received training similar to the experimental group after the follow up period was over, which was performed three months after completion of the intervention.

The participants were informed about the training session's group. The educational sessions were held in groups. The psycho educational sessions were held based on brainstorming, model presentation and group discussion. Each session was about 90 minutes offered once a week at Mahak Charity Hospital and Welfare Center. Pretest and posttest were performed before and after the educational sessions. Follow-up was done three months after the last session.

The spiritual care educational training package for parents of children with cancer was provided by Borjaliluetal [21] and used for the education component of the intervention which is primarily concerned with psychoeducational therapy. This package was designed based on the ASSET model (Actioning Spirituality and Spiritual Care Education and Training) [22,23] with regards to Islamic approaches.

The educational package encompassed subjects such as introduction to the concepts of spirituality, spiritual self-awareness, spiritual wellbeing with Islamic approach, spiritual development of children, spiritual needs of children, spiritual challenges of children diagnosed with cancer (for example, the meaning and cause of the disease and the pain and the concept of death), familiarity with effective relationships as a spiritual need (secure and insecure attachment patterns, attachment and exploration behaviors in child-parent interactions), recognition of solutions for promoting hope in children diagnosed with cancer (improving self-confidence, independence, and self-sufficiency) and prepare prayer conditions for child.

## Measurement Tools

**PedsQL™ Present Functioning Visual Analogue Scales:** Pediatric Quality of Life Inventory provides a child self-report measure of anxiety, sadness, anger, fatigue, and pain using six items. This measure can be used in children aged 5-18 years and is scored in a range of 0-100 mm line anchored happy face and sad face [24]. In this study, the Farsi version of this scale [25]. A higher score indicates a higher level of anxiety, sadness, anger, concern, and pain. The internal consistency of the instrument for the child version measured at an interval of 7 days was in the range of 0.65-0.73.

**Oucher Pain Scale:** This scale, which is in the form of a poster, is composed of two parts: a numeral scale (0-10 or 0-100) for specific children and a visual scale with six images on the right and numbers 0-10 on the left side of the images for specific children. In the numeral scale (0-10), the number selected by the child indicates the pain score. In the visual scale, the image selected by the child should be converted to an even number in the range of 0-10 (lowest image=0 and highest image=10) [26]. The Spanish version was also applied in this study [25]. The content validity of the Scale using the Kendall's Concordance Coefficient, assuming  $P < 0.001$ , was 0.75.

**Spirituality & Spiritual Care Rating Scale (SSCRS):** SSCRS was designed by McSherry et al [27] and it has four components: Existential Elements; Spiritual Care; Religiosity; and Personalized Care. SSCRS was rated on a 5-point Likert-type scale. Higher scores mean higher level of attitude towards spirituality or spiritual care. In this study, the Persian version was completed by parents [28]. The Cronbach's alpha for spirituality, spiritual care, religiosity and personalized care were 0.60, 0.67, 0.90 and 0.82, respectively.

## Findings

There were 25 children (mean age =10.71, SD=0.82) in the experimental group and 20 children (mean age=10.53, SD=0.65) in the control group. Also, 45 parents (mothers=18 or fathers=27) participated in this study (experimental group: mean age=36.86, SD=8.32; control group: mean age=31.94, SD=9.98).

**Table 1:** Demographic data of children with cancer and their parents.

Characteristics of the participants		Experimental group N or Mean	Control group N or Mean	P value
<b>Parent</b>		N=25	N=20	
Mean age of Parent		36.86	31.94	0.34
Parent sex	Male	17	10	0.41
	Female	10	8	
Education Level	Secondary school	7	8	0.34
	Diploma	10	5	
	University degree	8	7	
<b>Children</b>		N=25	N=20	
Mean age of children		10.71	10.53	0.25
Gender	Girls	15	12	0.16
	Boys	9	9	
Cancer Type	Leukemia (ALL + ANLL)	16	11	0.32
	Solid malignancies	9	9	
Mean Length of time since diagnosis, (months)		8.7	8.9	0.24

**Table 2:** Comparison of mean score Spirituality and Spiritual Care of experimental and control group among parents of child with cancer.

Pre: Post	Follow up		Post test		Pre-test		SSCRS
time effect	SD	M	SD	M	SD	M	
F=10.02;	0.011	4.41	0.14	4.11	0.023	3.37	Experimental Group
P<0.01;							Total score spiritual and spiritual care
$\eta^2=0.48$	0.021	3.45	0.017	3.52	0.021	3.41	Control Group

**Table 3:** Comparison of mean score Pediatric Quality of Life and Severity of Pain of experimental and control group among child with cancer.

Pre: Post	Follow up		Post test		Pre-test		Variables
Time effect	SD	M	SD	M	SD	M	
F=12.46;	0.037	4.22	0.04	4.16	0.038	3.39	Experimental Group
P<0.01;							Pediatric Quality of Life
$\eta^2=0.41$	0.033	3.35	0.035	3.35	0.034	3.5	Control Group
F=15.33;	1.137	4.89	1.44	7.42	1.131	8.96	Experimental Group
P<0.01;							Severity Of Pain
$\eta^2=0.33$	2.021	7.46	1.4	8.07	1.05	8.46	Control Group

In the experimental group, 16 children had leukemia and 9 children had solid malignancies (such as brain tumors, lymphoma, neuroblastoma, Wilms' tumor, osteosarcoma and rhabdomyosarcoma). The socio-demographic profile of the study population at experimental and controls were comparable with no significant differences (Table 1).

The mean and standard deviation scores on the total score spiritual and spiritual care Scale for the two groups over the three times are outlined in (Table 2). The table shows increase mean spiritual and spiritual care scores among pre (M=3.37), post-test (M=4.11) and follow up (4.41) in the experimental group. The mean difference between pre-versus posttest ( $t = 9.32, p < .05$ ) and pre- versus follow up ( $t = 9.43, p < .05$ ) showed improve significantly after training in the experimental group but there wasn't significantly difference among mean in the control group. Comparing the Spirituality and Spiritual Care of experimental and control groups in posttest, AVCOVA was

used.

There were no significant differences were observed based on interaction between groups and time. For comparison of the Pediatric Quality of Life and Severity of Pain of experimental and control groups in posttest, AVCOVA was used. Its results have reported in (Table 3).

The pediatric quality of life scores in the experimental group increased in the posttest and there was also an increased in trend scores relating to quality of life until 3 months after the program (the mean scores were 3.39 at pretest, 4.16 at posttest, and 4.22 three months after receiving education). The mean difference between pre-versus posttest ( $t = 5.46, p < .05$ ) and pre- versus follow up ( $t = 5.63, p < .05$ ) showed improve significantly after training in the experimental group but there wasn't significantly difference among mean in the control group.

Result showed that education program favorably affected quality of life of child cancer. In the control group, no significant differences were seen after interactions between groups and time.

The mean and standard deviation scores on the severity of pain Scale for the two groups over the three time are outlined in (Table 3). The table shows decreased mean severity of pain among pre ( $M=8.96$ ), post-test ( $M=7.42$ ) and follow up ( $4.89$ ) in the experimental group. The mean difference between pre-versus posttest ( $t = 5.71, p < .05$ ) and pre- versus follow up ( $t = 5.07, p < .05$ ) showed reduction significantly after training in the experimental group but there wasn't significantly difference among mean in the control group. Therefore, the severity of pain in the intervention group decreased in the posttest and there was a reduction in trend values of stress until 3 months after the program in the control group. No significant differences were noted in the control group based on interactions of groups and time.

## Discussion

This study was conducted to evaluate the effect of Islamic spiritual care by parents on the quality of life and pain perception of children diagnosed with cancer. Firstly, in the present study, spiritual care training for parents of children with cancer was accompanied by a change in parents' attitudes towards spirituality and spiritual care in the experimental group and these results were consistent with the follow-up period ( $P < .001$ ).

In the current study, the parents were empowered about spirituality and spiritual needs for raising their parents' spiritual awareness. For this reason, some topics of importance that were discussed were: paying attention to God or a supernatural authority and trusting in him, outlining the meaning and goals of life (being realistic Situation and plotting new goals in accordance with existing conditions), Courage and Hope (acceptance of new conditions of life and living in the present moment), letting go (all of things beyond their control), Relaxation (Creating a Private Environment for You, Seeing the Fun of Life, Smiling and Joking), Communication (related to oneself, others and nature), love and forgiveness. Studies showed that Religious coping is used as a coping strategy by the Muslim parents of children with cancer [29-31]. Parents of children with cancer use religious coping methods to modify their anxiety, and comfort themselves and others involved in the situation [32,33]. Reading the Qur'an and prayer is one of the most important activities of this period [34].

The results showed the positive effect of parents' Islamic spiritual care on the situation-related quality of life of children with cancer in the experimental group. Therefore, there is a link between spirituality and quality of life in these patients, because faith, tranquility, and meaning are among the determinants of health-related quality of life [35,36]. Studies showed that [37-39] spirituality, with giving a meaning to life, motivates the patients to fight the disease and raises their hope, and therefore improves their quality of life. Spiritual well-being is associated with the ability to enjoy life events. Spirituality helps people manage the pain and live with the disease. Therefore, spiritual and religious coping improves the patients' quality of life.

In this study, parents' spiritual care of children with cancer was based on the cognitive and behavioral domains, because the quality of life for children with cancer is a general feeling of well-being based

on the ability to participate in usual activities and interaction with others [40].

In this study, attention was paid to the parent-child communication skills as an aspect of spiritual care, which is a safe supportive source for children, that brings about improvement of their situation-related quality of life. On the other hand, a safe and secure attachment was produced for them in the hospital to decrease their fear and anxiety.

The effect of the parents' spiritual care on the children's pain perception showed a significant decrease in the mean score of pain severity in the experimental group compared to the control group ( $P < 0.01$ ). However, it was no significant difference in the pain severity between the two groups on follow-up. One of the most important objectives of spiritual care is to reduce the patients' pain and suffering [41]. In line with the cognitive-behavioral approach to the treatment of chronic pain [42], it seems that the parents play an active role in searching for and assessing the information related to a painful situation and the challenges presented by the chronic illness.

In this study, emphasis was placed on the child-parent communication skills as a spiritual need of the children to interact with others. It seems that one of the reasons for the children's decreased pain perception was that their parents provided a warm, safe, and responsive environment, because an intimate, warm, and responsive environment provided by parents is associated with a high threshold of pain and stress in the treatment process of children diagnosed with cancer [43].

On the other hand, cognitive factors, i.e. the ability to perceive and assess pain and its importance as well as personal interpretations of pain, affect pain perception [44]. According to the cognitive appraisals about chronic pains, some people may regard pain as a part of God's test of faith or penance for past sins; hence, religion is believed to be a strategy to endure chronic diseases and pain [45,46]. In this regard, spirituality and effective religious coping strategies result in internal tranquility and decrease pain through giving a meaning to the disease. It seems that one of the reasons for reduced pain perception by children in the present study was distraction. Cognitive distraction is the most powerful and efficient non-pharmacological treatment of pain in children and as a coping strategy for acute pain. It seems that parents in this study, by attention to the training, created a fun and enlivening environment as a spiritual need of the children [47-49], and that the children's attention had diverted from pain to playing and doing art activities to reduce their pain perception. But, according to the finding, the effects of the parental spiritual care on the pain perception in the experimental group did not last at the follow up stage. It seems that cancer treatment in children includes repetitive cycles of chemotherapy and diagnostic and treatment procedures associated with complications and side effects like pain, nausea, vomiting, etc. The pain associated with treatment further increases with advances in the treatment process [50,51].

Selecting a homogenous group of children diagnosed with cancer with a similar mean age and radiotherapy method was a challenge of the present study. Another limitation was the time constraint that the parents had for receiving the required training.



## Conclusion

Findings showed that empowering parents in spiritual care strengthened their spiritual beliefs and educated them on spiritual care skills. Due to the effect of parents' spiritual care on increasing pediatric quality of life and decreasing perceived pain in the children with cancer, it seems that spiritual care could be a complementary therapy in the pediatric cancer. In this sense, it would be important to expand the training of Muslim parents' knowledge and spiritual care skill for children with cancer in Muslim healthcare environment.

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## Conflict of Interests

The authors declare that they have no conflicts of interest.

## Ethical Approval and Consent to Participate

This study was approved by the Ethics Committee of Community Health Service Center of Shahid Beheshti University and all subjects provided informed consent.

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