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EVALUATING THE BARRIERS OF THE QUALITY OF LIFEAMONG THE MOTHERS OF CHILDREN WITH CANCER

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Introduction
The main purpose of family-centered nursing care is helping people to achieve the optimal health. This is not possible without attention to family and parents who are the most original and the best supporters of our community's children. This research was conducted to evaluate the barriers of the quality of life among the mothers of children with cancer.

Methods
This descriptive analytical study was performed cross-sectional in 2015 in the pediatric oncology ward of Shafa hospital of Ahwaz. 60 mothers of children with cancer were enrolled for sampling. Data collection tools were demographic data, quality of life sf26 inventory, and information on the quality of life barriers that its reliability and validity were assessed. Data analysis was performed by using SPSS16 software and T-test.

Results
Demographic characteristics of mothers indicate that 55% of them are in the range of 23 to 33 years old and 58% have a bachelor's degree. The physical health score with the mean and the standard deviation was 19.78 (7.21). In addition, mental health, social health, environmental health, and general quality of life score are, respectively, 17.60 (7.37), 14.01 (6.82), 20.91 (8.04), and 11.71 (7.83). Barriers to the quality of life in the physical, mental, and social dimensions are, respectively, 0.85, 0.71, and 0.55.

Conclusions
According to the findings, it is suggested to hold workshops for nurses and to optimize the position of the ward in order to improve the quality of life of mothers.

Key Words: Quality of Life, Mothers, Cancer, Children, Nurses.

1. Introduction

Cancer is the leading cause of disability and premature death, and it has allocated a large share of health care systems services all over the world (1). Cancer disease causes a wide range of physical, emotional, and functional disorders in patients and their families and end angers their quality of life (2). Currently, cancers are one of the major health issues in Iran and all over the world (3). In Iran, cancer is the third leading cause of death after heart diseases and accidents (4).In 2010, 10,700new cases of cancer have been reported in children under 15 years in America. In addition, 11,360 new cases of cancer have been reported in children in the range of 0 to 15 in 2013, and 1310 death from cancer have been reported in 2013 in this age group. According to the Association of Children's Blood and Cancer, the number of children with cancer in 2010 was 150 to 200 thousand children in the country. Cancer incidence rises one percent each year, and in contrary, the successful statistics of treatment has increased 1.4% each year (4). Annually, more than 17,500 children around the World are diagnosed with cancer from birth until about age 19 (5). In addition to its relatively high prevalence, this disease is considered as a stressful life event whose negative effects will have a significant impact on the quality of life of patients and their families (6).Modanloo et al (2014) conducted a descriptive study to evaluate the family function among parents of children with cancer. Results have shown that almost half of families with children with cancer have an unhealthy public performance and the most common disorders were in solving problems and emotional fusion (7). Khanjari et al (2013) examined the quality of life among parents of children with leukemia and related factors. Results have shown that the average of the quality of life score of participants in this study is less than 50% of the total score (8). Raisi Dehkordi et al (2014) in a study entitled "Identifying mental challenges in children with cancer and their mothers' experience" found that mothers and children are faced with aggression, anxiety, depression, inadequate knowledge, and care-related problems. The results showed that the lack of awareness and mental problems were the most important problems of patients and their mothers (9).As the incidence of cancer is rising, the disease and its treatment affect all aspects of patients' life. Improving the quality of life among the mothers, who are the important part of family and community, increases the quality of life and cohesiveness of the family structure (10).Identifying the factors associated with quality of life can help to prevent this problem. Since mothers have a major role in caring children and families to improve their quality of life, thus detection of mothers' problems is necessary for the fulfillment of this task to remove the barriers. The present study aims to evaluate the quality of life among the mothers of children with cancer from their perspective, barriers, and solutions.

2. Methods

The present study is a cross-sectional and descriptive study, which has been conducted in 2015 by selecting 60 mothers in the form of available sampling in Shafa hospital of Ahwaz that is the only chemotherapy hospital in the province. The research tools included demographic data, the World Health Organization Quality of Life inventory sf26 and the researcher-made questionnaire of evaluating the life quality barriers from the perspective of mothers.Sf26inventory has4 subscales of physical health, mental health, Social communications, and environmental health. The score of each option was calculated as never=5, rarely=4, sometimes=3, many times=2, and always=1. Initially, a raw score is achieved for each subscale, which is converted to a standard score from 0 to 100. A higher score indicates a higher quality of life. The score range of physical health subscale is from 7 to 35 and their differential is 28. The score range of mental health subscale is from 6 to 30 and their differential is 24. The score range of Social communications subscale is from 3 to 15 and their differential is 12, and the score range of environmental health subscale is from 8 to 40 and their differential is 32. The reliability of the inventory is obtained before by Nejat et al. (2006) through retest test for sub-scales (physical health 0.77, mental health 0.77, Social communications 0.75, and environmental health 0.84). The internal consistency was calculated using Cronbach's alpha (11). Mothers' quality of life barriers inventory was in physical, mental, and social dimensions, and each factor was in option yes=3, somewhat=2, and no=1. Data collection tools were prepared to prepare mothers' barriers inventory, in addition to studying the researched papers and texts, reviewing the research team views, and reviewing the relevant research results. Content validity method was used for the preparation of the scientific validity of data collection tools. In this way, these tools were presented to faculty members of Tarbiat Modarres University, and the corrective comments and proposals were collected. After introducing the researcher to authorities in the hospital and permission to carry out research, the researcher went to the pediatric ward. Demographic information, quality of life sf26, and barriers inventories were distributed among 60 mothers of children with cancer while obtaining the informed consent and participation in the exact answering the questions. After completion, the data were analyzed in SPSS16 software using descriptive statistical tests. The mean value of quality of life scores were compared with cut scores. Chi-square test was used to evaluate the relationship between the demographic characteristics of mothers and quality of life dimensions. Absolute and relative frequency of responses was calculated to analyze the barriers to women's quality of life.

Results

The findings showed that age had no effect on women's quality of life. The evaluation between education and the quality of life of women under diploma, undergraduate and graduated had indicated that the group in social health who had low literate education suffer from a lack of social health in their lives more than other groups. In mental health, the group who had a master's degree had more mental health problem more than other two groups. The quality life of mothers of children with cancer in three physical health, mental health, and environmental health dimensions is low. Other information is given in Table 1. Findings related to demographic data indicate that the majority of young mothers have diploma degree or higher. The relationship between demographic characteristics and quality of life dimensions are summarized in Tables 2 and 3.The findings in relation to the quality of life barriers were 0.85 for the physical health, 0.71 for the mental health, and 0.55 for the social health. The priority of barriers in the physical dimension is the costs of treatment and the need for extreme and continuous care of the child, obligation for continued presence beside the child were reported by mother regarding this problem. The priority of barriers in the mental health is stress and anxiety about the future of children, restrictions for going to travel due to child illness and not having comfort due to illness for children. The priority of barriers in the social dimension was the lack of enough time to participate in social activities, engaging with the child's disease, and not having enough time to communicate with family by mothers. Other barriers showed in Table 4.

Table 1: Comparing the Average Score of each Dimension of Quality of Life by cutting Score

Variable	Mean	cut-off point	t	p
Physical health	19.78	21	1.30	0.19
Mental health	60.17	18	3.63	0.03
Social Health	14.01	9	5.69	p<0.001
Environmental Health	20.91	21	0.8	0.93

Table 2: Determining the Relationship between Mothers' Education and Quality of Life Dimensions

Variable	Education	Number	Mean	f	p
Physical health	Under Diploma	16	2.91	1.78	0.23
	Diploma	35	3.4		
	Under graduate	9	3.44		

Mental health	Under Diploma	16	4.1	5.51	0.033
	Diploma	35	4.73		
	Under graduate	9	5.25		
Social Health	Under Diploma	16	52.34	6.64	0.013
	Diploma	35	3.37		
	Under graduate	9	4.88		
Environmental Health	Under Diploma	16	4.1	1.23	0.86
	Diploma	35	3.33		
	Under graduate	9	3.01		

Table 3: Determining the Relationship between Mothers' Age and Quality of Life Dimensions from the View of Mothers

Variable	Age	Number	Mean	f	p
Physical health	From 23 to 33	33	19.84	1.08	0.285
	From 34 to 44	27	17.10		
Mental health	From 23 to 33	33	18.21	0.421	0.67
	From 34 to 44	27	17.15		
Social Health	From 23 to 33	33	14.60	0.824	0.415
	From 34 to 44	27	12.50		
Environmental Health	From 23 to 33	33	20.27	0.252	0.80
	From 34 to 44	27	21.00		

Table 4: Absolute and Relative Frequency of Mothers' Quality of Life Barriers in Physical, Psychological, and Social Dimensions

No.		Questions	Mothers					
			Yes		Somewha		No	
			Absolute frequency	Relative Frequency	Absolute frequency	Relative Frequency	Absolute frequency	Relative Frequency
Physical dimension	1	I do not have enough time.	14	23	34	57	12	20
	2	I do not have enough motivation.	19	32	21	35	20	33
	3	I do not have enough patience.	18	30	23	38	19	32
	4	I do not have enough energy.	12	20	22	37	26	43
	5	I cannot tolerate emotional pain.	29	48	11	18	20	33
	6	My child needs a severe and persistent care.	50	**83**	7	12	3	5
	7	I had a constant presence alongside my child.	50	**83**	8	13	2	3
	8	Living costs for my child treatment is a priority.	51	**85**	7	12	2	3
	9	Access to sports facilities (e.g. swimming, gym ...) It costly for me.	39	65	10	17	11	18
	10	I do not have enough information about ways to keep my physical health.	16	26	20	33	24	40
Mental dimension	11	Environmental conditions of the ward are not conducive for maintaining my physical comfort.	17	28	27	45	16	26
	12	There is not enough training from nurses about physical health.	20	33	17	28	23	38
	13	There are restrictions on access to safe water (due to failure of the water purifier).	26	43	15	25	19	31

	14	I am not fully supported by the people.	22	36	15	25	23	38
	15	My wife does not understand me completely.	10	16	13	21	37	61
	16	I am not fully supported by children.	6	10	12	20	42	70
	17	Nurses do not pay enough attention to our emotional needs.	12	20	20	33	28	46
	18	I do not have mental comfort.	32	**53**	20	33	8	13
	19	I constantly stress about the future of my child.	43	**71**	10	16	7	11
	20	I am frustrated about the improvement of my	8	13	17	28	35	58
	21	I do not have enough time for communication and dialogue with others.	20	33	27	45	13	21
	22	Due to my child disease, I have restrictions to go to travel.	33	55	13	21	14	23
	23	I travel restrictions because of being costly.	29	48	13	21	18	30
	24	My life is monotonous.	31	51	16	26	13	21
	25	I do not have enough information about ways to maintain my mental health.	19	31	21	35	20	33
	26	I do not receive adequate training to cope with difficult situations.	19	31	24	40	17	28
	27	Due to the lack of understanding by others, I prefer to be alone.	20	33	13	21	27	45
Social communication dimension	28	I am faced with the mistaken expectations of those around.	22	36	16	26	22	36
	29	I feel lonely in solving my and my child's	26	**43**	12	20	22	36
	30	Engaging in my child disease prevents me from communicating with others.	30	**50**	15	25	15	25
	31	I do not have enough time to communicate with my husband.	18	30	21	35	21	35
	32	I do not have enough time to communicate with my children.	18	30	17	28	25	41
	33	I do not have the desire to communicate with other mothers.	14	23	16	26	30	50
	34	I do not like to participate in social activities(attending in periodic, family, friends meetings , and extra-curricular classes)	22	36	12	20	26	43
	35	I do not have enough time to participate in social activities(attending in periodic, family, friends meetings , and extra-curricular classes)	31	**51**	15	25	14	23

Discussion

The purpose of his study was to evaluate the barriers of the quality of life among the mothers of children with cancer. Results showed that the quality life among the mothers of children with cancer in three physical health, mental health, and environmental health dimensions is low. Khanjari et al (2013) study entitled the quality of life among the parents of children with leukemia and related factors showed that the average of the quality of life score of parents in this study is less than the total score and does not have a favorable situation (12).The findings show that mothers have problems in the quality of life dimensions that have no significant relationship with age. The results of this study were consistent with the results of Khanjari et al (2013). The results suggest that the mothers in all age groups are involved in the problems of children and they are concerned about their children's care and future. Therefore, these cases affect their quality of life in each group age. In this study, the differences of maternal education were significant in some aspects. Litzman et al. (2011) study entitled the quality of life among parents of children with leukemia and brain tumors showed that higher education in parents is associated with reduced quality of life because parents with higher education prefer to have an active role in their child care processes. This will increase stress and reduce their quality of life (13). Torkoglu et al. (2012) in their research to investigate the impact of the care burden on the quality of life of cancer patients obtained no relationship between these two variables

(14). In Khanjari et al (2013) study entitles the quality of life among parents of children with cancer and related factors; there was no relationship between education and mothers' quality of life (12).The findings of this study showed that mothers of children with cancer are faced with a variety of physical, psychological, and social problems. However, Valizadeh et al. (2014) showed that caretakers of cancer patients bear a significant burden of care, and they need to spend a lot of time and energy in child care (15).Khoury et al. (2013) explained the biological experience of the parents of children with cancer in Lebanon. They stated financial problems as the main barrier to enhance the quality of life (14). In the present study, 85% of mothers allocated the life costs priority to treat their child. In the present study, the mothers reported stress and anxiety about the future of their child and the lack of comfort and relaxation due to their child's illness as the main barriers to improving the quality of life in the mental dimension. Raisi Dehkordi et al (2014) stated the lack of awareness and mental problems in their study as the main barriers in this regard (9).In the present study, mothers were under pressure in all dimensions as the main caretakers. The results of Claassen (2011) showed that caretakers' pressure was the only factor that caused in mental, social, and physical health (17). Pollock (2013) also stated that parents of children with cancer have physical and psychological problems (18).In addition, Witt et al. (2010) concluded that the experience of caring for children with cancer is associated not only with the lower quality of life, but also is likely to increase stress levels, which in turn has a negative impact on their mental health and their quality of life, (19). In this regard, Castells (2010) believes that if parents' needs to be met and they well equipped and supported, they can have a better behavior and a higher quality of life (20).As one of the important members of the healthcare team, nurses have the most interaction with the mothers. Thus, they can provide an appropriate care planning depending on the mothers' circumstances by identifying the factors affecting their quality of life. In other words, by knowing the barriers to quality of life in mothers of children with cancer, it can be scheduled to act directly to improve the mothers' lifestyle and the child's quality of life in directly. Thus, the health enhancement, the sense of well-being, and improving the quality of life of families of children with cancer in the physical and psychosocial can be helped by adopting the first level prevention strategies.

This research was not faced with certain restrictions, except that maybe mental and personality moods of the individual affect her responding to questions, which was not controllable for the researcher.

Conclusion

Mothers are faced with barriers in all dimensions of life. Therefore, the nurse managers are expected to hold workshops and introduce personnel to the dimensions and the barriers to quality of life of mothers of children with diseases so that they can have a proper care planning with an exact knowledge for their work space and advising families to promote the quality of life in mother. Secondly, given the constant presence of mothers with children, they should try to enhance the quality of life among the mothers of children with cancer by optimizing the physical and emotional status to make breezy changes and providing a perfect opportunity to interact with nurses, mothers and other mothers to improve the quality of life of mothers of children with cancer.

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Compliance with Ethical Standards

Conflict of Interest: The authors declare that they have no conflict of interest.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

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