Original Article

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Association of Health-related Quality of Life with Resilience among Mothers of Children with Cancer: a Cross-sectional Study

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Abstract

Background: Childhood cancer as a life-threatening illness has negative consequences for both the patients and their family. The aim of this study was to examine the impact of child cancer on their mother's quality of life and to assess the association of quality of life with resilience among mothers of children with cancer.

Materials and Methods: In this cross-sectional study, a total of 145 mothers of children with cancer participated. Data were collected by two questionnaires: (a) PedsQL™ Family Impact Module, (b) Connor-Davidson Resilience Scale. Datawere analyzed using SPSS version 13. Pearson correlation test was run for the analysis.

Results: The result showed that total scale score, HRQOL Summary score, and the Family Functioning Summary Score were 41.68±20.62, 43.10±22.40, and 45.06±24.30, respectively. The mean score of resilience among mothers of children with cancer was 86.80±19.08. There was a positive association between resilience and all dimensions of life quality (p<0.05).

Conclusion: Measuring HRQOL and resilience in a preventive strategy would help to address vulnerable mothers and to present psychosocial support for them. Designing and implementing family-oriented and parent-focused intervention strategies in health care systems are recommended for improving the quality of life of families with cancer children.

Key words: Cancer, Children, Mother, Resilience, Quality of Life

Introduction

Childhood cancer is the most common cause of death after the first birthday (1). Childhood cancer affects childern between 0 and 18 years old and stand for almost 0.5 to 3.0% of malignant tumours caused by abnormal and uncontrolled cell division (2). Chronic diseases such as cancer in childhood not only affects the patient's life, but also have significant and negative consequences on the whole family system (3). Moreover, the impact of paediatric chronic disease on the family functioning is the most important concern given prominence to the role of the family in coping with chronic disease (4). When a child is diagnosed with cancer, the entire family system faces with new stressors and demands; and experience a severe trauma (1). Prior studies have asserted that caregivers of children with chronic disease experience much more stress (5) and consume more time dealing with cancer child (6). A cancer diagnosis may bring about greater burden on the family (7) and increases the need for social support (8). These stresses continue through all period of a family's experience with cancer, including diagnosis, cancer management, relapse, and death (9, 10).

Additionally, role patterns and behaviour of parents are disturbed by the child illness and family members may change their social roles or even in some cases leave each other and take up new ones (11). Therefore, careful assessment of how children's disease affects their families is of both research and clinical importance (12).

The family's ability to cope with the various stressors and uncertainty associated with their child's diagnosis affects child's quality of life (2). Furthermore, health-related quality of life (HRQOL) is increasingly acknowledged as a crucial health related measure in health services and research (13). Research on the life quality of families with childhood cancer leads to the identification of families who need the special support or psychological intervention (2). Moreover, since a chronic disease always demands parental involvement and adaptation to the new condition, careful evaluation of parental psychosocial status and functioning seem necessary (3).

Recently, the concept of resilience has been proposed as a psychological factor in referring protective attributes in the adaptation of persons with cancer (14). Therefore, promotion of resilience among parent of child with cancer may help them to cope with the numerous problems related to the diagnosis and treatment of their child (15). Resilience is defined as dynamic capacity of individuals that enables a person to thrive in the face of life adversities or risks (16). Since the diagnosis of cancer has been perceived as a traumatic event, the level of resilience among parent of child might be altered due to numerous stresses and psychological problems (17). Moreover, promoting resilience mechanism which used by parent during cancer treatment may lead to better adaptation and other optimal psychosocial outcomes in the family system (18).

Consequently, identification of resilience among parents of child with cancer may provide an opportunity for addressing psychosocial outcomes related to adaptation with cancer in child and their parents (19).

The consequences of children's cancer and its related symptoms have been examined from children's view and limited knowledge of the parent's perceptions about their children illness is discovered (20). Moreover, previous studies have focused on child's life health quality from their own view (21-23). Between the parents, mother has a pivotal position in the family system and she has the positive effect on family adaptation to the crisis of cancer (24).

Few studies have focused on the impact of childhood cancer on their mother's quality of life and the relationships between resilience and life quality of mothers has not been investigated yet. Therefore, this study was attempted primarily to evaluate the life quality of mothers with cancer child and secondly to assess the resilience of these mothers, and finally to investigate the association between quality of life and resilience among mothers of children with cancer.

Materials and Methods

Using a cross-sectional research design, a random sample of 145 mothers with cancer children was selected. The study was done at a large, Tabriz pediatric hospital located in Tabriz (affiliated to Tabriz University of medical sciences, Tabriz, Iran) during February 2013 to December 2014. The inclusion criteria for mother selection includes questionnaires completion by mothers, the ability of mothers for providing informed consent, and having one cancer child aged between 1 to 18 years old whose cancer being diagnosed at least three months before this study. Reluctant and unstable mothers or mothers whose child suffered from other chronic diseases were excluded from this study. Demographic data included mothers and their children's age, marital status, educational level of the mothers, and the number of children in the family, child's gender, and the date of cancer diagnosis were collected.

Data were collected by two valid questionnaires: PedsQL™ Family Impact Module and Connor-Davidson Resilience Scale. PedsQL™ Family Impact Module has 36 items and is a parent–report numerical indicator designed to assess the impact of child chronic disease on parents and the family function (4). This questionnaire includes 6 subscales which measures parents' functioning: (a) Physical Functioning (6 items), (b) Emotional Functioning (5 items), (c) Social Functioning (4 items), (d) Cognitive Functioning (5 items), (e)Communication (3 items), and Worry (5 items); Moreover, it has 2 subscales measuring Family Functioning: Daily Activities (3 items) and Family Relationships (5 items).

The instrument has five-Likert response options indicating: 0 [never a problem], 1 [almost never a problem], 2 [sometimes a problem], 3 [often a problem] and 4 [almost always a problem]. Each item is then linearly transformed to a 0 to100 scale [0=100, 1=75, 2=50, 3=25, and 4=0). Higher scores denote better parent HRQOL (less negative impact) and better family functioning. Finally, three types of scores can be achieved: 1) Total Scale Score is calculated as the sum of the 36 items divided by the number of items responded; 2) the Parent HRQOL Summary Score is computed as the sum of the 20 item scores of Physical, Emotional, Social, Cognitive Functioning subscales calculated by dividing the number of items answered in these subscales; 3) the Family Functioning Summary Score is obtained from the sum of the 8 items of Daily Activities and Family Relationships subscales divided by the number of items answered in these subscales (4).

The following steps for the linguistic validation of the questionnaire were conducted according to the PedsQL™ Translation Methodology (25): 1) the forward translation from English to Persian was done by a nurse educator and a medical English teacher who were fluent users of English, 2) The backward translation from Persian version to English was done by another academic member who could speak Persian and English, 3) A comparison between the original form and the back translated form was performed by another translator who was fluent in English and his native language was Persian, and 4) the Persian version was tested on 20 parents. Internal consistency reliability of the instrument was checked using Cronbach's Alpha Coefficient for each subscale scores. All subscales achieved values ≥ 0.70 and were considered acceptable.

The second instrument for data collection was Connor-Davidson Resilience Scale. This questionnaire involves 25 items and is used for measuring resilience resources among parents of children with cancer. It has five Likert response options (0= strongly disagree; 4 = strongly agree). The sum of the responses on each item yields a total score from 0 to 100. The highest scores reflects greater resilience (26). The Persian version of this questionnaire which validated by Hashemi&Jokar in Iran was used for the current study (27).

Ethical considerations

This study was approved by the Research Ethic Committee of Tabriz University of Medical Sciences, Tabriz, Iran. All patients were informed by the researchers about the objective of the research. Participation in this study was completely voluntary and confidentiality of participants was respected. Informed consent form was obtained from all mothers.

Statistical analysis

Statistical analyses were performed using SPSS software (version 13.0). Descriptive statistics for participants' characteristics were used. To investigate the possible associations between HRQOL and resilience among mothers, Pearson correlation coefficient analysis were conducted. Coefficients <0.3 were considered as weak correlation, 0.3 to 0.5 moderate correlation, and >0.5 as strong correlation. Means and standard deviation were used for presenting normally distributed data.

Results

A total of 145 mothers of children aged between 1 to 18 years old completed the questionnaires. Table I demonstrates sample demographic information. The mean age of the mothers was 30.68±6 years. The majority of mothers were married (97.2%) and the educational level of 37.95% of mothers was diploma. The mean age of the children was 5.86±3.76 years, the majority were boys (56.56%), and 63.4% were in preschool period (Table I).

Table II summarizes the PedsQL™ Family Impact Module scores. The result showed that Total Scale Score, HRQOL Summary score, and the Family Functioning Summary Score was 41.68±20.62, 43.10±22.40, and 45.06±24.30, respectively. In this study, the mean score of resilience among mothers of children with cancer was 86.80±19.08 (Table III). The Pearson correlation analysis revealed a significant positive association between the resilience and each domain of PedsQL™ among mothers of children with cancer ($p<0/05$). However, no association between demographic characteristics and resilience was observed in this study including mothers age, education, marital status, number of child, child's sex, age, and cancer diagnosis duration ($p>0/05$).

Table I. Demographic Characteristics of the participants (n=145)

Variable		n (%)	Mean±SD	Range
Characteristics of mothers				
Age		145(100)	30.68±6	19-47
Marital status	Married	141(97.2)		
	Divorced	4(2.8)		
Educational level	Illiterate	18 (12.4)		
	Elementary	53(36.6)		
	Diploma	55(37.9)		
	University education	19(13.1)		
Number of children			1.88±1.06	1-8
Characteristics of Children				
Age			5.86±3.76	2-18
Gender	Boys	82(56.56)		
	Girls	63(43.44)		
Educational level	Preschool	92 (63.4)		
	Primary school	42(29.0)		
	School	9(6.2)		
	High school	2(1.4)		
Time since diagnosis of cancer (month)			10.01±12.42	1-60

Table II.PedsQL™ Family Impact Module scores among mothers of children with cancer (n=145)

Scores	Mean±SD
Total Impact	41.68±20.62
Parent HROQL	43.10±22.40
Physical functioning	287.46±148.50
Emotional functioning	194.31±127.67)
Social functioning	166.90±113.38
Cognitive functioning	213.23±138.46
Communication	144.67±79.45
Worry	134.66±124.83
Family functioning	45.06±24.30
Daily activities	32.30±24.03
Family relationships	52.72±29.18

Table III.Resilience score among mothers of children with cancer (n=145)

	Mean±SD	Minimum	Maximum
Resilience	86.80±19.08	38	162

Table IV. Association of PedsQL™ Family Impact Module scores with resilience among mothers of children with cancer (n=68)

Domains	Pearson correlation	p-value
Total Impact	0.47[*]	0/000
Parent HRQOL	0.44[*]	0/000
Physical functioning	0.41[*]	0/000
Emotional functioning	0.43[*]	0/000
Social functioning	0.38[*]	0/000
Cognitive functioning	0.28[**]	0/001
Communication	0.41[*]	0/000
Worry	0.43[*]	0/000
Family functioning	0.34[*]	0/000
Daily activities	0.25[**]	0.003
Family relationships	0.34[*]	0.000

[*] Moderate correlation, [**] Weak correlation

Discussion

The diagnosis of childhood cancer represents psychological and emotional challenges for patients' parents (28). Therefore, emotional support of these parents in order to cope with stress should be a usual task in pediatric oncology nursing care (29).

According to the results of the current study, health-related quality of life in mothers of children with cancer (41.68 ±20.62) was relatively low compared to Mano et al. (64.68±19.54) (30). Findings of this study are consistent with the result of Medrano et al. (12). They compared the life quality of parents with or without children suffered from chronic conditions. The result showed that the total score, parent HRQOL score, and family functioning score of parents of children with chronic conditions were significantly lower than the other group.

One of the most distressing life experiences for families is having a family member diagnosed with cancer (23, 31). In a previous study, the impact of child's health status on the family's functioning and well-being across several life domains, such as family health, family relationships, parental health or social activities was proved (3). Khoury et al. (23) examined Lebanese parents' experiences in a qualitative study and found that mothers experienced tired and felt guilty because of paying no attention to other siblings. Furthermore, mothers found managing problems created by the disease and planning family activities. Other studies have documented that mothers of child with cancer experience higher levels of distress compared to fathers (32, 33).

It seems that cancer diagnosis has a negative influence on the quality of life of parents children with cancer compared to other chronic conditions. In this regard, Goldbeck (3) discovered that maternal QoL score among families with a child suffering from cancer was significantly low compared to mothers of children with other problems such as diabetes, epilepsy, and healthy controls. Therefore, addressing mother's problem in managing her child's cancer gets prominence.

Cancer as a life-threatening illness has negative consequences for both the patients and their families which may even influence mothers resilience (34-36). Resilience is an optimistic view on life and is defined as the person's ability to undergo individual change enabling her/him to survive and thrive (37). The result of this study showed that the mean score of resilience among mothers of children with cancer was low. Mothers often are the main caretaker and have to focus on child's cancer process (38). In our country, mothers are more involved than fathers in the overall care of the children suffered from cancer (24). These results were somewhat expected, as it is culturally more acceptable in our country for mothers to deliver child care and to communicate with others regarding their child's condition. These results depicted a positive association between family relationships and resilience. In the US, Orbuch et al. found that children had more open and supportive relationships with mothers than with fathers. Similarly, they observed that children who had good relationships with their mothers had higher levels of well-being (10).

The findings demonstrated that high resilience was positively associated with high quality of life in all dimensions. These results are in line with Hjemdal et al (39) who found that persons with high resilience coped with distressing events more competently than those who had low resilience. Brody et al. (38) argued that mother often experiences the emotional and mental strains of their child's cancer in all phases of their life. In Korea, Shin et al (40) reported a definite relationship between the resilience of mothers of pediatric cancer patients and their cancer children.

Finally, no relationship between demographic characteristics and resilience was observed in this study. The results were in contrast with Shin et al. (40) who found high resilience in mothers who were employed.

Limitations

One of the limitations in the study was the selection of participants from one hospital. The other limitation concerns about lack of access to fathers of children participated to this study. Another limitation is related to nature of the current study which has some limitation due to its nature of being cross sectional. Therefore, further studies with larger population, with father involvement, and longitudinal nature are recommended.

Conclusion

Diagnosis of childhood cancer leaves negative psychological impact on quality of life of their mother. Measuring HRQOL and resilience in a preventive strategy would help to address vulnerable mothers and to present psychosocial support for them. Therefore, designing and implementing family-oriented and parent-focused intervention strategies by nurses or other medical professionals are recommended for promoting family health system along with interventions for increasing resilience among mothers of children with cancer.

Conflict of interest

There was no conflict of interest.

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