

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

Vahid Pakpour PhD<sup>1</sup>, Mansour Ghafourifard PhD<sup>2,\*</sup>, Zahra Sadri MSc<sup>3</sup>

1 PhD candidate in nursing education, Hematology and Oncology Research Center, department of community health nursing, Tabriz University of Medical Sciences, Tabriz, Iran.

2 PhD candidate in nursing education, Student Research Committee, department of medical surgical nursing, Tabriz faculty of nursing and midwifery, Tabriz, Iran. (Corresponding author)

3. Hematology and Oncology Research Center, Shahid Sadoughi University of Medical Sciences, Yazd, Iran.

\*Corresponding author: Mansour Ghafourifard, Department of medical surgical nursing, Tabriz faculty of nursing and midwifery, Shariartijonoobi St., Tabriz, Iran. E-mail: [m.ghafori@yahoo.com](mailto:m.ghafori@yahoo.com).

Received: 20 August 2015

Accepted: 12 May 2016

### 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. Data were 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  $41.68 \pm 20.62$ ,  $43.10 \pm 22.40$ , and  $45.06 \pm 24.30$ , respectively. The mean score of resilience among mothers of children with cancer was  $86.80 \pm 19.08$ . 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 children 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 to 100 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  $\geq 0.70$  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  $30.68\pm 6$  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  $5.86\pm 3.76$  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  $41.68\pm 20.62$ ,  $43.10\pm 22.40$ , and  $45.06\pm 24.30$ , respectively. In this study, the mean score of resilience among mothers of children with cancer was  $86.80\pm 19.08$  (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
<b>Characteristics of mothers</b>				
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
<b>Characteristics of Children</b>				
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
<b>Total Impact</b>	41.68±20.62
<b>Parent HROQL</b>	43.10±22.40
<b>Physical functioning</b>	287.46±148.50
<b>Emotional functioning</b>	194.31±127.67
<b>Social functioning</b>	166.90±113.38
<b>Cognitive functioning</b>	213.23±138.46
<b>Communication</b>	144.67±79.45
<b>Worry</b>	134.66±124.83
<b>Family functioning</b>	45.06±24.30
<b>Daily activities</b>	32.30±24.03
<b>Family relationships</b>	52.72±29.18

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

	Mean±SD	Minimum	Maximum
<b>Resilience</b>	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
<b>Total Impact</b>	0.47*	0/000
<b>Parent HRQOL</b>	0.44*	0/000
<b>Physical functioning</b>	0.41*	0/000
<b>Emotional functioning</b>	0.43*	0/000
<b>Social functioning</b>	0.38*	0/000
<b>Cognitive functioning</b>	0.28**	0/001
<b>Communication</b>	0.41*	0/000
<b>Worry</b>	0.43*	0/000
<b>Family functioning</b>	0.34*	0/000
<b>Daily activities</b>	0.25**	0.003
<b>Family relationships</b>	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 ( $41.68 \pm 20.62$ ) was relatively low compared to Mano et al. ( $64.68 \pm 19.54$ ) (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.

### References

1. Björk M, Wiebe T, Hallström I. An Everyday Struggle—Swedish Families' Lived Experiences During a Child's Cancer Treatment. *J Pediatr Nurs*. 2009;24(5):423-32.
2. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory™(PedsQL™) family impact module: reliability and validity of the Brazilian version. *Health Qual Life Outcomes*. 2008;6(1):35.
3. Goldbeck L. The impact of newly diagnosed chronic paediatric conditions on parental quality of life. *Qual Life Res*. 2006;15(7):1121-31.
4. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. *Health and quality of life outcomes*. 2004;2(1):55.
5. Lawoko S, Soares JJ. Quality of life among parents of children with congenital heart disease, parents of children with other diseases and parents of healthy children. *Qual Life Res*. 2003;12(6):655-66.
6. Moskowitz JT, Butensky E, Harmatz P, Vichinsky E, Heyman MB, Acree M, et al. Caregiving time in sickle cell disease: psychological effects in maternal caregivers. *Pediatr Blood Cancer*. 2007;48(1):64-71.
7. Sales E. Family burden and quality of life. *Qual Life Res*. 2003;12(1):33-41.
8. Helgeson VS. Social support and quality of life. *Qual Life Res*. 2003;12(1):25-31.
9. Zebrack BJ, Chesler MA. Quality of life in childhood cancer survivors. *Psycho-Oncology*. 2002;11(2):132-41.
10. Orbuch TL, Parry C, Chesler M, Fritz J, Repetto P. Parent-child relationships and quality of life: Resilience among childhood cancer survivors. *Family Relations*. 2005;54(2):171-83.
11. Siemińska M, Greszta E. The family of a child with cancer—changes within the family system. *Pol Psychol Bul*. 2008;39(4):192-201.
12. Medrano GR, Berlin KS, Hobart Davies W. Utility of the PedsQL family impact module: assessing the psychometric properties in a community sample. *Qual Life Res*. 2013;22(10):2899-907.
13. Ji Y, Chen S, Li K, Xiao N, Yang X, Zheng S, et al. Measuring health-related quality of life in children with cancer living in mainland China: feasibility, reliability and validity of the Chinese mandarin version of PedsQL 4.0 Generic

- Core Scales and 3.0 Cancer Module. *Health Qual Life Outcomes*. 2011;9:103.
14. Rowland JH, Baker F. Introduction: resilience of cancer survivors across the lifespan. *Cancer*. 2005;104(S11):2543-8.
  15. Rosenberg AR, Baker KS, Syrjala KL, Back AL, Wolfe J. Promoting resilience among parents and caregivers of children with cancer. *J Palliat Med*. 2013;16(6):645-52.
  16. Min J-A, Yoon S, Lee C-U, Chae J-H, Lee C, Song K-Y, et al. Psychological resilience contributes to low emotional distress in cancer patients. *Support Care Cancer*. 2013;21(9):2469-76.
  17. Golden-Kreutz DM, Thornton LM, Wells-Di Gregorio S, Frierson GM, Jim HS, Carpenter KM, et al. Traumatic stress, perceived global stress, and life events: prospectively predicting quality of life in breast cancer patients. *Health Psychol*. 2005;24(3):288.
  18. Molina Y, Jean CY, Martinez-Gutierrez J, Reding KW, Joyce P, Rosenberg AR. Resilience among patients across the cancer continuum: diverse perspectives. *Clin J Oncol Nurs*. 2014;18(1):93.
  19. Rosenberg A, Wolfe J, Syrjala K, Yi-Frazier J, Curtis JR, Baker S. The Impact of Personal Resilience Resources on Psychosocial Outcomes in Parents of Children with Cancer (SA509-C). *J Pain Symptom Manage*. 2014;47(2):451-2.
  20. Pöder U, Ljungman G, von Essen L. Parents' Perceptions of Their Children's Cancer-Related Symptoms During Treatment: A Prospective, Longitudinal Study. *J Pain Symptom Manage*. 2010;40(5):661-70.
  21. Abu-Saad Huijer H, Sagherian K, Tamim H. Quality of life and symptom prevalence as reported by children with cancer in Lebanon. *Eur J Oncol Nurs*. 2013;17(6):704-10.
  22. Matziou V, Perdikaris P, Feloni D, Moshovi M, Tsoumakas K, Merkouris A. Cancer in childhood: Children's and parents' aspects for quality of life. *Eur J Oncol Nurs*. 2008;12(3):209-16.
  23. Khoury MN, Huijer HA-S, Doumit MAA. Lebanese parents' experiences with a child with cancer. *Eur J Oncol Nurs*. 2013;17(1):16-21.
  24. Dolgin MJ, Phipps S, Fairclough DL, Sahler OJZ, Askins M, Noll RB, et al. Trajectories of adjustment in mothers of children with newly diagnosed cancer: A natural history investigation. *J Pediatr Psychol*. 2007;32(7):771-82.
  25. Varni J. PedsQL™ translation methodology. 1998.
  26. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety*. 2003;18(2):76-82.
  27. Hashemi L, Jowkar B. Study of relationship between spiritual transcendence and resilience *Journal of Educational Psychology Studies*. 2011;8(13):123-42.
  28. Lindahl Norberg A, Pöder U, von Essen L. Early avoidance of disease- and treatment-related distress predicts post-traumatic stress in parents of children with cancer. *Eur J Oncol Nurs*. 2011;15(1):80-4.
  29. Ringnér A, Karlsson S, Hällgren Graneheim U. A person-centred intervention for providing information to parents of children with cancer. Experiences and effects. *Eur J Oncol Nurs*. 2015;19(3):318-24.
  30. Mano KE, Khan KA, Ladwig RJ, Weisman SJ. The impact of pediatric chronic pain on parents' health-related quality of life and family functioning: Reliability and validity of the PedsQL 4.0 Family Impact Module. *J Pediatr Psychol*. 2009;jsp099.
  31. Doumit MA, Huijer HA-S, Kelley JH, Nassar N. The lived experience of Lebanese family caregivers of cancer patients. *Cancer Nurs*. 2008;31(4):E36-E42.
  32. Sloper P. Predictors of distress in parents of children with cancer: A

- prospective study. *J Pediatr Psychol*. 2000;25(2):79-91.
33. Frank NC, Brown RT, Blount RL, Bunke V. Predictors of affective responses of mothers and fathers of children with cancer. *Psychooncology*. 2001;10(4):293-304.
34. Van Humbeeck L, Dillen L, Piers R, Deveugele M, Grypdonck M, Verhaeghe S, et al. Tightrope walkers suffering in silence: A qualitative study into the experiences of older parents who have an adult child with cancer. *Int J Nurs Stud*. 2015;52(9):1445-53.
35. Williams A-l. Psychosocial burden of family caregivers to adults with cancer. *Recent Results Cancer Res*. 2014;197:73-85.
36. Goren A, Gilloteau I, Lees M, daCosta DiBonaventura M. Quantifying the burden of informal caregiving for patients with cancer in Europe. *Support Care Cancer*. 2014;22(6):1637-46.
37. McGee EM. The healing circle: resiliency in nurses. *Issues Ment Health Nurs*. 2006;27(1):43-57.
38. Brody AC, Simmons LA. Family resiliency during childhood cancer: The father's perspective. *J Pediatr Oncol Nurs*. 2007;24(3):152-65.
39. Hjemdal O, Friborg O, Stiles TC, Rosenvinge JH, Martinussen M. Resilience predicting psychiatric symptoms: A prospective study of protective factors and their role in adjustment to stressful life events. *Clin Psychol Psychother*. 2006;13(3):194-201.
40. Shin H, Lee JH. A correlation study on the resilience of children with cancer and their mothers. *J Korean Oncol Nurs*. 2008;8(1):24-31.