

## **Psychometric properties of the Arabic version of the PedsQL™ Family Impact Scale**

### **Abstract**

Treatment of childhood cancer and its side effects can exert a negative impact on patients' parents. A valid and reliable instrument to measure family functioning in Arabic families was considered to be a vital resource. The PedsQL Family Impact Scale and the PedsQL Healthcare Satisfaction Hematology/Oncology Scale - Parent report were completed by 113 Jordanian parents of children with cancer. Cronbach's alpha coefficient was found to be excellent at 0.93 for the total PedsQL Family Impact Scale, which correlated significantly with the PedsQL Healthcare Satisfaction Hematology/Oncology Scale - Parent report, demonstrating good construct validity. The Arabic version of the PedsQL Family Impact Scale is both valid and reliable for use with parents of children with cancer.

**Key words:** Arabic translation; family impact; parents; Jordan; instrument-development.

## Introduction

Having a child with cancer is likely to exert a negative impact on parental functioning. Despite improvements in treatment and increased survival rate, the impact on the family from diagnosis into survivorship is often physically demanding and psychologically traumatic.

Research from Australia, the USA, the UK and Japan has shown that parents' experiences of living and caring for the child with cancer can include anxiety (Link & Fortier, 2016), fatigue (Tong et al., 2008) stress and depression (Muscara et al., 2015; Ozono et al, 2010). It can result in the adoption of inappropriate coping strategies (Turner-Sack et al., 2016; Stoppelbein et al., 2013), altered family functioning (Al Gamal et al., 2009; Long & Marsland, 2011), and occupational and financial impairment (Wakefield et al., 2014). Healthcare providers should assess family functioning when a child has received a diagnosis of cancer and provide support for the parents as well as for the patient.

Several questionnaires measure family functioning, such as the Family Environment Scale (Moos & Moos, 1986), the Impact on Family Scale (Stein & Jessop, 2003) and the PedsQL™ Family Impact Scale (Varni et al, 2004a). The PedsQL Family Impact Scale is multidimensional in scope, measuring varied aspects of family functioning: physical functioning - 6 items, emotional functioning - 5 items, social functioning - 4 items, cognitive functioning - 5 items, communication - 3 items, worry - 5 items, daily activities - 3 items, and family relationships - 5 items (Varni et al, 2004a). **Its validity and reliability in the measurement of functioning in families of children with complex chronic health conditions have been established by the originator** (Varni et al, 2004a), in Canada (Panepinto et al., 2009), and in China (Chen et al., 2011).

The availability of a reliable and valid version of the instrument to assess the functioning of Arabic families of children with cancer was thought to be important. Such a tool could help healthcare providers to assess family functioning in those populations in order to provide appropriate screening and interventions. To the authors' knowledge, the psychometric properties of the Arabic version of The PedsQL Family Impact Scale have not been established with parents of children with cancer. The aim of this study was to develop this Arabic version and to test its reliability and validity with a sample of Arabic parents of children with cancer in Jordan. Arabic is the first language of Jordan.

## **Method**

### **Design**

A cross-sectional design was used, and data were collected in 2015.

### **Participants**

One hundred and thirteen parents participated in the study. The inclusion criteria for the parents were that they had to be a Jordanian parent of a child with any type of cancer, they had to be able to speak Arabic, and they had to live with the child so that they could report validly on the impact of this relationship. Parents of children for whom curative treatment had failed or who were receiving palliative care were excluded since the instrument would not be appropriate and because of the researchers' reluctance to add to their burden.

## **Measures**

### **Instruments**

#### ***The Demographic Questionnaire***

The demographic characteristics which were included were (the parent's) age, sex, level of education, and socioeconomic background.

**The PedsQL™ Family Impact Scale** is a 36-item module from the PedsQL suite focused on the parent-reported impact of caring for a child. It provides summary parent functioning scores (physical, emotional, social, cognitive, worry, communication) and summary family functioning scores for daily activities and for relationships (Varni *et al*, 2004a). The Total Scale Score is established by summing all 36 items and dividing by the number of items completed. Internal consistency reliability of the original total scale was excellent ( $\alpha=0.97$ ). The internal consistency reliability of the subscales was  $\alpha=0.91$  for physical functioning subscale,  $\alpha= 0.90$  for emotional functioning subscale,  $\alpha= 0.88$  for social functioning subscale,  $\alpha=0.93$  for cognitive functioning subscale,  $\alpha=0.88$  for communication subscale,  $\alpha=0.82$  for worry subscale,  $\alpha=0.91$  for daily activities subscale, and  $\alpha=0.97$  for family relationships subscale. Construct validity for the PedsQL™ Family Impact Module was determined utilizing the known-groups method. The PedsQL™ Family Impact Module distinguished between families with children in a long-term care facility and families whose children resided at home. A 5-point response scale is presented throughout scored from 0 (never a problem) to 4 (always a problem). Scores are transformed to a 5-point 0–100 scale. Higher scores relate to reduced negative impact (and therefore better family functioning). The Parent HRQOL Summary Score ( $\alpha=0.96$ ), which is based on 20 items, is derived from summation of the scores divided by the number of responses provided in the physical, emotional, social, and cognitive functioning scales. The Family Functioning Summary Score ( $\alpha=0.90$ ) (derived from the remaining eight items) is calculated by dividing the sum of the item scores by the number of responses in the daily activities and family relationships scales.

### ***The PedsQL Healthcare Satisfaction Hematology/Oncology Scale - Parent report***

This 25-item questionnaire is designed to elicit satisfaction in the fields of General Satisfaction, Information, Inclusion of Family, Communication, Technical Skills, and Emotional Needs (Varni et al 2004b). Cronbach's alpha ranged from 0.82 to 0.96 for all domains which confirmed good internal consistency. **Construct validity was assured using intercorrelations with related scales.** The 5-point (0–4) Likert-type scales for the response categories were linearly transformed into a 0 to 100 scale to facilitate interpretation of the results, with higher scores indicating greater satisfaction. This instrument was translated to Arabic with permission from Mapi Trust

#### **Translation and piloting**

Approval to use the PedsQL instruments was gained from the Mapi Trust. **Data collection was undertaken using Arabic versions of the above instruments, the PedsQL instruments being subjected to a standard back-translation process devised by Brislin (1986). The following process was performed: the bilingual, bicultural expert translated the instruments from English into Arabic, and then a second bilingual, bicultural expert blindly (without access to the original language version) translated them back to the source language (that is, back-translation). Finally, the original English versions were compared with the back-translated English versions by a linguistic educator specializing in English language. No inconsistencies, mistranslated sentences or vague words were found.** Expert review of the acceptability, appropriateness, and comprehensiveness of the revised instrument was undertaken by two family mental health professionals to establish face validity. They scrutinized individual items in detail as well as the integrity of the whole instrument. No objection was made to any item, and the questionnaire's applicability to the target population was confirmed. A pilot test was

carried out with ten parents who were caring for a child with cancer. These found the proposed instrument and the process for administration to be acceptable. It was concluded that data collection could proceed with the translated version.

### **Ethical approval**

The University of Jordan Research Ethics Committee and that of the healthcare facility where data would be collected reviewed and approved the study. The voluntary nature of participation was emphasized to study participants via a printed information sheet and verbally, and parents were told that their data would be used only for the stated purposes of the study. To protect participants' privacy, study identification numbers were used, and personal details were not associated with the questionnaires. Hard copy and electronic data were stored securely with access restricted to the main researcher. In the light of the potentially emotionally upsetting context of the study, participants were assured that they could discontinue the data collection encounter at any time should they become distressed.

### **Data Collection**

Data collection was carried out in a private room in an out-patient clinic suite and a hospital ward in one Jordanian hospital in which most of the country's oncology treatment is provided. The oncology nurse coordinator assisted in the identification of potential participants from eligible parents and in making the first approach to explain the study to them. Parents who agreed were introduced to the researcher. Unsurprisingly in this culture, parents wished to continue immediately to data collection. Before commencing completion of the questionnaires, the researcher checked that the participants had understood the information and the consent form was signed by the parent and the researcher.

## **Data analysis**

Data analyses were carried out using IBM SPSS version 21 for Windows. Descriptive statistics were applied to summarise the sample characteristics. Two techniques were used to assess internal consistency: item-scale correlations (using Pearson correlation coefficients) and calculation of Cronbach's alpha. Cronbach's alpha was computed for the total PedsQL Family Impact Scale as well as for each subscale. In accordance with common convention, Cronbach's alpha coefficient equal to or greater than 0.70 was set as the level to be considered satisfactory. Convergent construct validity with the PedsQL Healthcare Satisfaction Hematology/Oncology Scale-Parent report was analyzed using Pearson's Product-Moment Correlation. Statistical significance was set at  $p < 0.05$ .

## **Results**

### **Demographic characteristics of parents**

The mean age of the parents was 39 years (SD=7.0) with a range of 24–56 years. Of these, 82 (72.6%) were women and 31 (27.4%) were men. The sample was predominantly Muslim (n=107, 95%), with 6 (5%) Christians. Most parents had completed secondary school (50.9%). Nine percent had completed preparatory school, 13% had completed primary school, 16% had completed a diploma and 11% had completed a BSc or a Master degree. Moreover 58.7% of the participants were housewives. Twenty six percent were in full-time employment, 4% worked part-time, and 10% were retired.

### **Means and standard deviations**

The mean PedsQL Family Impact Scale total score was 52.1 (SD=18.60). The means and standard deviations of the total score and subscales scores are presented in Table 1.

**[Insert Table 1 here]**

The mean PedsQL Healthcare Satisfaction Scale total was 71.7 (SD=16.8). The result showed that satisfaction with Technical skills (M= 75, SD=18.4) was ranked as the highest in the scale. Emotional needs was ranked as the lowest (M=64.9, SD=26.3)

### **Internal consistency and reliability**

Item-total scale correlations ranged from 0.30 to 0.73. Item-subscale correlations were all statistically significant ( $p < 0.01$ ), and are detailed in Table 2.

**[Insert Table 2 here]**

A Pearson Product Moment Correlation matrix determined correlations between the subscales scores and total score. **Statistically significant correlations were established between total score and all subscales scores: (physical functioning  $r = 0.757$ ,  $p = 0.005$ ; emotional functioning  $r = 0.749$ ,  $p = 0.005$ ; social functioning  $r = 0.682$ ,  $p = 0.005$ ; cognitive functioning  $r = 0.721$ ,  $p = 0.005$ ; communication  $r = 0.545$ ,  $p = 0.005$ ; worry  $r = 0.713$ ,  $p = 0.005$ ; daily activities  $r = 0.780$ ,  $p = 0.005$ ; family relationships  $r = 0.664$ ,  $p = 0.005$ ).** Cronbach's alpha for the total scale was 0.93. Cronbach's alpha for all subscales is presented in Table 3.

**[Insert Table 3 here]**

### **Construct validity**

The PedsQL™ Family Impact Scale total score was significantly positively associated with the total parent satisfaction scale score of the PedsQL Healthcare Satisfaction Hematology/Oncology Scale ( $p = 0.05$ ). The results indicated that the parents who were satisfied with the care that provided by the staff for their children and family more likely to experience good family functioning.



## Discussion

The lack of an Arabic version of the PedsQL™ Family Impact Scale to measure family functioning in parents of children with cancer may limit nursing assessment and intervention for such families. The stress burden on such parents and families can be greatly increased in comparison with not facing such challenges (Eiser et al 2005, Fotiadou et al 2008, Hovén et al 2008, Klassen et al 2011, Othman et al 2011, Whitney et al 2010, Yamazaki et al 2005). The effect may present as clinically diagnosed depression or post-traumatic stress (Jones 2012, Kohlsdorf & Costa 2012). These studies, conducted in Europe, North America, Malaysia and Japan indicate this to be a world-wide phenomenon, but the issue has not been addressed so well in the Gulf region.

The results of the current study confirm the appropriateness of the PedsQL Family Impact Scale (Arabic version) for this purpose. In this version, excellent internal consistency reliability was found for the total PedsQL™ Family Impact Scale as well as its subscales. Cronbach's alpha score was above 0.93 for the total PedsQL Family Impact Scale, in line with recent studies in children (Varni et al, 2004, Chin et al, 2013). Studies by Al-Gamal et al (2009), Al-Gamal and Long (2010) and Masa'Deh et al (2012) in Jordan, and by Almaqrami M & Shuwail A (2004) and Alyahri A & Goodman R (2006) in Yemen indicate that standard questionnaires designed in Western countries can be adapted successfully both linguistically and culturally for application in the Middle East.

There is strong evidence from The Netherlands (Vrijmoet-Wiersma et al 2005) and from Australia (Wakefield et al 2010) that both physical and psychological impacts of having a child

diagnosed with cancer can persist for years after the completion of treatment regimes. This highlights the importance of rigorous nursing assessment periodically to identify those in need of support so that nurses can intervene both in the hospital and at home after discharge. Pursuing better health in the parents might, of course, be expected to improve the health and wellbeing on the child for who they are caring. Such integrated family care is a core aspect of child health, mental health and community nursing. Peek and Mazurek Melnyk (2010) indicate a raft of supportive intervention for parents with cancer from a review of studies in the US, Iceland, Malaysia, Israel and The Netherlands. These include teaching strategies to avoid accepting additional burdens, formal psychological support, and expressive therapy to allow parents the opportunity to recognise and share their worries. Teaching other standard coping strategies and stress-reduction activities could be included in nursing interventions.

Construct validity of the PedsQL™ Family Impact Scale was assured as it converged well with the validated The PedsQL Healthcare Satisfaction Hematology/Oncology Scale. The positive correlation coefficients indicated that parents who were satisfied with the care provided by the staff for their children were more likely to experience good family functioning and greater positive impact on the family. This could be considered as additional evidence to suggest that the PedsQL Family Impact Scale (Arabic version) is a valid instrument.

This study had some limitations. The sample size in this study prevented the application of confirmatory factor analysis (CFA) to estimate construct validity. Tabachnick & Fidell (1996) recommend at least 300 cases for factor analysis. Such absolute rules have become contested (Myers et al, 2011), but even so, the researchers were not satisfied that CFA could be applied in this case. However, Cronbach alpha for the PedsQL Family Impact Scale,

together with those of its subscales, were good, indicating reasonable internal consistency. This study was necessarily limited to parents of Arabic children with cancer and the results cannot be applicable to other populations. Replication of this study with patients from other countries and cultures is needed.

## Conclusion

The PedsQL Family Impact Scale (Arabic version) has been shown to be a valid and reliable instrument to measure family functioning among Arabic parents of children with cancer. It could help nurses and other health professionals in the Middle East, particularly, but also in countries with Arabic-speaking minorities to identify deficits in parental HRQOL and family functioning, to apply interventions aimed at reducing negative impacts in a timely manner and to gauge the effectiveness of the interventions. **In particular, help with adopting more positive coping strategies would benefit parents, as would nurses teaching stress-reduction or avoidance techniques.**

## References

- Al-Gamal E, Long T. Anticipatory grieving among parents living with a child with cancer. *J Adv Nurs*; 2010; **66**(9), 1980-1990. DOI: 10.1111/j.1365-2648.2010.05381.x
- Al-Gamal E, Long T, Livesley J. Development of a modified instrument to measure anticipatory grieving in Jordanian parents of children diagnosed with cancer: the MM-CGI Childhood Cancer. *Cancer Nursing*; 2009; **32**(3) 211-219. DOI: 10.1097/NCC.0b013e31819a2ae4
- Almaqami M, Shuwail A. Validity of the self-report version of the strengths and difficulties questionnaire in Yemen. *Saudi Med J* 2004; **25**(5), 592-601.
- Alyahri A, Goodman R. Validation of the Arabic Strengths and Difficulties Questionnaire and the Development and Well-being Assessment. *East Mediterr Health J*; 2006; **12**(2) Supplement 2 S136-146.

Brislin RW. *The wording and translation of research instruments*. In: Lonner WJ, Berry JW (eds.), *Field Methods In Cross-cultural Research*. Beverly Hills, CA: Sage Publications, 1996; 137-164.

Chen R, Hao Y, Feng L, Zhang Y, Huang Z. The Chinese version of the Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module: cross-cultural adaptation and psychometric evaluation. *Health Qual Life Outcomes*. 2011; **23**: 9-16.

Landgraf JM, Abetz L, Ware JE. *The CHQ User's Manual 1st edition*. Boston: The Health Institute, New England Medical Center, 1996.

Link CJ, Fortier MA. The relationship between parent trait anxiety and parent-reported pain, solicitous behaviors, and quality of life impairment in children with cancer. *J Pediatr Hematol Oncol*. 2016 **38**(1): 58-62.

Long K, Marsland A. Family adjustment to childhood cancer: a systematic review. *Clinical Child Fam Psychol Rev*, 2011; **14**(1): 57-88.

Moos RH, Moos BS: *Family Environment Scale Manual. 2<sup>nd</sup> edition*. Palo Alto, CA: Consulting Psychologists Press, 1986.

Muscara F, McCarthy MC, Woolf C, Hearps SJ, Burke K, Anderson VA. Early psychological reactions in parents of children with a life-threatening illness within a pediatric hospital setting. *Eur Psychiatry*. 2015; **30**(5): 555-61.

Myers ND, Ahn S, Jin Y. Sample size and power estimates for a confirmatory factor analytic model in exercise and sport: A Monte Carlo approach. *Res Q Exerc Sport*; 2011; **82**(3): 412-423. DOI:10.1080/02701367.2011.10599773

Ozono S, Saeki T, Mantani T, *et al*. Psychological distress related to patterns of family functioning among Japanese childhood cancer survivors and their parents. *Psychol*; 2010; **19**(5): 545-52.

Pai AL, Greenley RN, Lewandowski A, Drotar D, Youngstrom E, Peterson CC. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *J Fam Psychol*; 2007; **21**(3): 407-15.

Panepinto J, Hoffmann R, Pajewski N. A psychometric evaluation of the PedsQL™ Family Impact Module in parents of children with sickle cell disease. *Health Qual Life Outcomes*; 2009; **7**: 32-38.

Peek G, Mazurek Melnyk B. Coping interventions for parents of children newly diagnosed with cancer: an evidence review with implications for clinical practice and future research. *Pediatr Nurs*; 2010; **36**(6):306-313.

Stein RE, Jessop DJ: The Impact on Family Scale revisited: Further psychometric data. *J Dev Behav Pediatr*; 2003; **24**: 9-16.

Stoppelbein L, Greening L, Wells H. Parental coping and posttraumatic stress symptoms among pediatric cancer populations: tests of competing models. *Psychooncology*; 2013; **22**(12): 2815-2822.

Tabachnick B, Fidell L. *Using Multivariate Statistics (5th edition)*. New York: Pearson Education, Inc., 2007.

Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*; 2008; **121**(2): 349-60

Turner-Sack AM, Menna R, Setchell SR, Maan C, Cataudella D. Psychological functioning, post-traumatic growth, and coping in parents and siblings of adolescent cancer survivors. *Oncol Nurs Forum*; 2016; **43**(1): 48-56.

Varni J, Sherman S, Burwinkle T, Dickinson P, Dixon P: The PedsQL™ Family Impact Module: Preliminary reliability and validity. *Health Qual Life Outcomes*; 2004a; **2**: 55. doi:10.1186/1477-7525-2-55

Varni J et al. Evaluation of the built environment at a children's convalescent hospital: development of the Pediatric Quality of Life Inventory parent & staff satisfaction measures. *J Dev Behav Pediatr*. 2004b; **25**:10-20

Vrijmoet-Wiersma CMJ, van Klink JMM, Kolk AM, Koopman HM, Ball LM, Egeler RM. Assessment of parental psychological stress in pediatric cancer: a review. *J Pediatr Psychol* 2008; **33**(7), 694-706.

Wakefield CE, McLoone JK, Butow P, Lenthén K, Cohn RJ. Parental adjustment to the completion of their child's cancer treatment. *Pediatr Blood Cancer*; 2010; **56**, 524-531.

Wakefield CE, McLoone JK, Evans NT, Ellis SJ, Cohn RJ. It's more than dollars and cents: the impact of childhood cancer on parents' occupational and financial health. *Psychosoc Oncol*; 2014; **32**(5): 602-621.

**Table 1 Means and Standard Deviations of the PedsQL Family Impact Scale**

<b>Scale</b>	<b>Mean</b>	<b>SD</b>
Physical Functioning	45.5	24.1
Emotional Functioning	47.8	24.1
Social Functioning	54.3	26.5
Cognitive Functioning	52.0	29.4
Communication	51.9	28.0
Worry	48.2	26.6
Daily Activities	38.5	28.0
Family Relationships	70.4	24.7
<b>Parent HRQOL Summary Score</b>	49.2	20.9
<b>Family Functioning Summary Score</b>	58.7	22.0
<b>Total Impact Score</b>	52.1	18.6

**Table 2: Item-total scale correlation and item-subscales correlations (n=70).**

<b>Subscales/item number</b>	<b>Item-subscale correlation</b>	<b>Item-total scales correlation</b>
<b>Physical Functioning Subscale</b>		
1 I feel tired during the day.	0.729**	0.574**
2 I feel tired when I wake up in the morning	0.730**	0.623**
3 I feel too tired to do the things I like to do	0.685**	0.554**
4 I get headaches	0.766**	0.495**
5-I feel physically weak	0.790**	0.664**
6- I feel sick to my stomach	0.660**	0.436**
<b>Emotional functioning subscale</b>		
1 I feel anxious	0.740**	0.614**
2 I feel sad	0.711**	0.484**
3 I feel angry	0.734**	0.498**
4 I feel frustrated	0.819**	0.635**
5 I feel helpless or hopeless	0.697**	0.554**
<b>Social functioning subscale</b>		
1 I feel isolated from others.	0.742**	0.503**
2 I have trouble getting support from others	0.629**	0.566**
3 It is hard to find time for social activities	0.849**	0.549**
4 I do not have enough energy for social activities	0.829**	0.509**
<b>Cognitive Functioning</b>		
1 It is hard for me to keep my attention on things	0.801**	0.671**
2 It is hard for me to remember what people tell me	0.883**	0.618**
3 It is hard for me to remember what I just heard	0.863**	0.615**
4 It is hard for me to think quickly	0.820**	0.551**
5 I have trouble remembering what I was just thinking	0.899**	0.651**
<b>Communication</b>		
1 I feel that others do not understand my family's situation	0.708**	0.446**
2 It is hard for me to talk about my child's health with others	0.795**	0.308**
3 It is hard for me to tell doctors and nurses how I feel	0.785**	0.485**
<b>Worry</b>		
1 I worry about whether or not my child's medical treatments are working	0.779**	0.619**
2 I worry about the side effects of my child's medications/medical treatments.	0.757**	0.579**
3 I worry about how others will react to my child's condition.	0.737**	0.469**
4 I worry about how my child's illness is affecting other family members	0.656**	0.450**
5 I worry about my child's future	0.795**	0.612**
<b>Daily Activities</b>		
1 Family activities taking more time and effort	0.814**	0.590**

2	Difficulty finding time to finish household tasks	0.877**	0.661**
3	Feeling too tired to finish household tasks	0.857**	0.734**
<b>Family Relationships</b>			
1	Lack of communication between family members	0.702**	0.468**
2	Conflicts between family members	0.802**	0.485**
3	Difficulty making decisions together as a family	0.836**	0.570**
4	Difficulty solving family problems together.	0.869**	0.529**
5	Stress or tension between family members	0.788**	0.581**



**Table 3: Internal consistency reliability for the PedsQL™ Family Impact Scale**

<b>Scale</b>	<b>Number of items</b>	<b>Reliability (Cronbach alpha)</b>
Physical Functioning	6	0.82
Emotional Functioning	5	0.80
Social Functioning	4	0.76
Cognitive Functioning	5	0.90
Communication	3	0.64
Worry	5	0.79
Daily Activities	3	0.80
Family Relationships	5	0.86
<b>Parent HRQOL Summary</b>	20	0.91
<b>Family Functioning Summary</b>	8	0.84
<b>Total Impact Score</b>	36	0.93