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Psychosocial Risks among Iranian Parents of Children with Cancer

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ABSTRACT

Objective: Support of parents of children with cancer requires health care personnel to be knowledgeable about the prevalence psychosocial risks among Iranian parents of children with cancer. This study thus was conducted to fulfill this aim in South-East of Iran.
Method: Using the Psychosocial Assessment Tool- Revised (PAT-R) for parents of children with cancer, 200 parents of these children in two hospitals supervised by Kerman University of Medical Sciences was assessed. Result: The results indicated that parents who did not plan for future pregnancy, had more sibling problems (mean=0.18, p=0.00, SD=0.13) compared to those who planned for future pregnancy. Also more children parents have, the higher "child problems" (mean=0.42, p=0.04, SD=0.20). The means of categories of "child problems" (mean= 0.33, p=0.01, SD=0.17) and "family problems" (mean=0.25, p=0.001, SD=0.14) were lower among parents who had own car compared to others. The means of categories of "family problems" (mean=0.17, p=0.00, SD=0.11) and "parents' stress reactions" (mean=1.11, p=0.00, SD=0.64) were lower among parents who did not have financial difficulties compared to others. Conclusion: The results of following study revealed that there were association between socio-demographic data such as planning for pregnancy, number on children, financial difficulties and psychosocial risks. More study is needed to elucidate the Iranian parents' experience of having children with cancer.

Keywords: Financial difficult, Parents of children with cancer, Psychosocial Assessment Tool- Revised, Psychosocial risk, South-East of Iran

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INTRODUCTION

The number of children with cancer is rising, caused by increases not only in incidence but also in survival rates [1] Each year in the United States, approximately 13,500 children and adolescents 18 and under are diagnosed with cancer, that's more than a classroom of kids a day.[2] About 1,350 children younger than 15 years old are expected to die from cancer in 2014.[3] Childhood cancer is a stressful and potentially traumatic experience for both the patient and his/her family [4]. As pediatric patients and their parents learn of a cancer diagnosis and embark on an often lengthy and intensive course of treatment, they are at increased risk for new or exacerbated psychosocial difficulties [5]. Assessment of risk factors is critical to the delivery of psychosocial care matched to the needs of children and families across the course of treatment and reduces the likelihood of poorer child and family psychosocial outcomes [5].

According to American cancer society,[6] if our child has been diagnosed with cancer, how to pay for treatment is usually not the first thing that comes to mind, but

having health insurance coverage for cancer treatment and all of the needed follow-up care is critical. They go on that some people must work out money issues before their child can even start treatment and for others, it can become a problem after treatment begins [6]. The financial stress, employment loss, and overall negative economic impact on families with a critically ill child have been demonstrated [7]. As a consequence of childhood cancer, the household's income may be reduced, and this may negatively affect the family welfare [8]. Financial stress has a negative impact on how parents parent [9]. Low family income leads to the worst outcomes, even a short-term spell can have a significant effect on children [10]. Klassen et al.,[11] identified that five main areas were found to contribute to psychological health of the parents: family social and economic characteristics, child characteristics, caregiver demands, self-perception, and coping [11].

Chairman of the Cancer Research Center of Iran believes that about 50% of all pediatric cancers leading to death. However, the statistics in the world is about 30%. The direct cost of treating cancer is six billion dollars in annual, while the external costs of cancer are much more than this [12]. According to the Iranian Ministry of Health and the Children's Cancer Association, the incidence rate of cancer among children is 1500 to 2000 per year. Iran is located in the Eastern Mediterranean Region [13]. The majority of the people in Iran consider themselves as religious. Iranian families are nuclear and in some areas extended. Familial relations and sentiments are so strong that for instance incurable disease strikes not only the patient but the family as well [14]. The psychological health of family is an important factor influence health of children in every context. The assessment of psychosocial risks seems necessary to be done among parents of children with cancer. This may produce essential information for health care personnel and assist them to provide appropriate psychosocial care for such families. In the Iranian context no study was found to assess prevalence of psychosocial risks among parents of children with cancer. This study thus was conducted to fulfill this aim in South-East of Iran. This study also aimed to answer the question: is there correlation between demographic characteristics of parents of children with cancer and their PTSS?

BACKGROUND

Using Psychosocial Assessment Tool (PAT) some researchers in different countries assessed the psychosocial risks of parents of children with cancer.[15–17] MacCarty et al.,[15] assessed psychosocial risks in Australian parents of children with cancer. Parents completed the PAT at diagnosis (T1) and 6–8 months later (T2). They found that there were no significant differences between T1 and T2 participants with respect to parent age, education level, marital status and ethnicity, or patient gender, age and diagnosis [15]. Alderfer et al.,[16] evaluate 132 mothers and 72 fathers of children with cancer. Parents completed the PAT at diagnosis (T1) and 4 months later (T2). In this study changes in risk status across time were not associated significantly with race/ethnicity, socioeconomic status, patient sex, cancer diagnosis or intensity of cancer treatment [16].

Kazak et al.,[17] assessed the parents of 125 children with cancer, recruited from the Division of Oncology at the Children's Hospital of Philadelphia; they completed the PAT at diagnosis (t1) and 3 to 6 months later (t2). In this study the most commonly endorsed risk factors were financial difficulties (43.2%), followed by having more than three children living in the home (18.4%), a history of emotional problems in the family (18.4%), and single parenthood (17.6%). Also according to this

study understanding commonly endorsed psychosocial risk factors for families (i.e., financial difficulties, marital status, family size, and a family history of emotional problems) may aid in the development of targeted interventions for families of children with cancer [17].

MATERIALS AND METHODS

Study Design and Setting

This is a cross-sectional, descriptive study and was approved by Kerman University of Medical Sciences. There was also an approval from the heads of two hospitals supervised by Kerman University of Medical Sciences (KUM), prior to the collection of data. In Kerman, only these hospitals had pediatric oncology unit.

Instrument

Demographics

Socio-demographic characteristics in fallowing study were gender of parent, mother age, father age, gender of patient, patient age, diagnosis, duration of diagnosis, number of children, intrinsic religiosity, extrinsic religiosity, Education, marital status (Married/Separated/ other), device, planning for pregnancy, childcare/Parenting, emotional support, financial support, information, help with everyday tasks, patient's health coverage, and child know about cancer. Socio-demographic characteristics were developed base on previous researches and authors' experiences.

Psychosocial Assessment Tool-Revised (PAT-R)

The PAT was designed to examine psychosocial risks of parents of children with cancer. The PAT was created by a multidisciplinary work group at CHOP.[18] This instrument has seven subscales; family structure and resources, family social support, family problems, parent stress reactions, family beliefs, child problems and sibling problems. Subscales scores are created by calculating the proportion of items on the subscale endorsed as 'high-risk' (each individual item is scored dichotomously as risk or no risk). A total score (0–7) is created by summing the subscale scores.[19] Utilizing the PPPHM 3-tiered risk framework, a total PAT2.0 score of<1 represents the Universal (lowest risk) category, a score 1<PAT<2 is classified in the targeted (elevated risk) category and PAT>2 is classified as the clinical (highest risk) category.[15] The instrument used in several earlier researches to assess PTSS among parents of children with cancers in different contexts (15, 19, 20, 21). They reported good internal consistency and test–retest reliability and acceptable validity of the PAT. For example in one study,[21] Cronbach's alpha values were more than 0.80 and test–retest reliability was strong for mothers (r=0.78) and fathers (r=0.87).

Translation and Validation

For translation of the questionnaire from English into Persian, the standard forward–backward procedure was applied. The initial translation was done by one of the authors (S.I.) and one of faculty member in nursing department supervised by KUM. Both are nurse educators and clinically experienced in oncology wards. Their native language is Persian and their second language is English. A helpful reference at this stage was the Hajiiem English–Farsi dictionary. As the study aim was to use the questionnaire in oncology units, the items were discussed with two oncologists, and two physicians working in pediatric oncology. The translation was revised according to their comments.

A teacher of English at Razi Faculty of Nursing and Midwifery then translated the questionnaire back. Afterward, a pilot group of 20 parents from the study were asked to read the questionnaire and make their comments on it. Each item was discussed. All items, except items number

a, d, and g in category of "child problems", were straightforward and no major changes were made. Some parents in pilot group said that these items are difficult to understand, so an easier option might be better to replaced. They suggested some options, but those options deviates considerably from the original items. So it was decided to stick to the original version.

The validity of scale was assessed through a content validity. Ten faculty members at the Nursing and Midwifery School reviewed the content of the scales from cultural and religious perspectives. They agreed that PAT was a culturally and religiously appropriate questionnaire to be used in the research context. They suggested that the categories and method of scoring are not appropriate and should be changed. Therefore categories and scores were revised. In the revised questionnaire (Psychosocial Assessment tool- Revised {PAT-R}) the PAT-R contains subscales such as family problems (consist of 12 questions; Item Response Anchors are 0= no, 1= Yes), parent stress reactions (consist of 3 questions; 0=Not at All, 1= Sometimes, 2= Often, 3= Very Much), family beliefs (consist of 10 questions; 0=Not at all, 1= true Just a little bit true, 2= Pretty much true, 3= Very true), child Problems (consist of 17questions; 0=Never a Concern Sometimes, 1=a Concern Currently, 2= Receiving Help) and sibling Problems (consist of 17 questions; Item Response Anchors are 0= no, 1= Yes). To assess the reliability of the scale, internal consistency was calculated for the entire sample of 200. The value of Cronbach's α for PAT-R was 0.67. Also the value of Cronbach's α for subscales child problem, sibling problem, family problem, family belief and parents stress reaction was 0.70, 0.70, 0.73, 0.75, and 0.83 respectively. Therefore, the Persian version of PAT-R presented acceptable reliability.

Population and Data collection

Accompanied by a letter including some information about the aim of the study, the questionnaires were handed out by the second author to 213 parents of children with cancer (100 mothers and 100 fathers) who their child admitted during May 2014 to July 2014 in pediatric oncology wards. Convenience sampling was used. As 13 participants were not agreed to participate, finally 200 parents participated in the study. 200 questionnaires were distributed among participants with no drop-out. Participants were parents of children aged between 0–18 years and had cancer. After explaining the study to parents and emphasizing the confidentiality of the information, written consent was obtained from participants. The 100 mothers and 100 fathers were not parents of the same child in all cases.

Data Analysis

All analyses were performed using SPSS version 19 (SPSS Inc., Chicago, Illinois, United States). Descriptive statistics (frequency, percentage, mean, and standard deviation) were used to describe the study sample characteristics**.** A Kolmogorov-Smirnov test indicated that the data were sampled from a population with normal distribution. So, independent t-test was used to examine the correlation between PAT-R scores and some demographic factors including: gender of patient and planning for pregnancy. To check the association between PAT-R scores and other demographic factors, one way ANOVA was performed. The significance level was set at 0.05.

RESULT

Participant Demographics

The sample consisted of 200 participants (100 mothers and 100 fathers). A descriptive analysis of background information (Table 1) revealed that the mothers' age ranged between 22–55 years. The fathers were aged between 25-65 years. 60% of participants had

nonacademic education (Diploma and lower than diploma). All respondents were Muslim. The majority of participants (95%) stated that they always experienced the existence of God in their daily living. 85.5% of them claimed that they attended religious activities with varying regularity. 67% of participants had 2- 3 children. 81.5% of participants said that they are not willing to have more childe. 39.5% of participants did not receive financial support. 42% of participants received help from his/her wife to do their daily tasks. 51.5% of participants were using their personal car to do their daily tasks. 77% of parents stated that their cancerous child is under insurance. 26.5% of participants were experiencing financial problems most of the times. 43% of participants stated that they are not able to pay medical budgets.

Table 1. *Background characteristics of sample.*

Variable	n	%
Gender of patient		
Female	69	34.5
Male	131	65.5
Age of patient (year)		
0-1	9	4.5
1.1-3	25	12.5
3.1-6	57	28.5
6.1-12	66	33
12.1-18	43	21.5
Diagnosis		
All	146	73
Wilms tumor	24	12
Brain tumor	15	7.5
Other	15	7.5
Duration of cancer (year)		
0-1	97	48.5
1.1-3	83	41.5
3.1-6	15	7.5
6.1-10	5	2.5
Religious		
Islam	200	100
Intrinsic religiosity		
Always	190	95
Sometimes	9	4.5
Never	1	0.5
Extrinsic religiosity		
Daily	171	85.5
Few times per week	20	10
Few times per month	7	3.5
Few times per year	2	1
Never	0	0
Education		
Illiterate	12	6
Non academic	120	60
Academic	68	34
Mother age		
22-32	87	43.5
33-43	96	48
44-55	17	8.5
Father age		
25-35	90	45
36-46	90	45
47-57	14	7
58-65	6	3

Number of children		
1	43	21.5
2-3	134	67
>3	23	11.5
Planning for pregnancy		
Yes	37	18.5
No	163	81.5
State of relationship between parents		
Married	194	97
Separated	6	3
other	0	0
Childcare/Parenting		
Spouse/Partner	97	48.5
Patient's Grandparents	18	9
Extended family	53	26.5
Friends	30	15
Work Associates	1	0.5
Other (describe)	0	0
No One	1	0.5
Select more than one option	0	0
Emotional support		
Spouse/partner	51	25.5
Patient's grandparents	27	13.5
Extended family	53	26.5
Friends	8	4
Work Associates	1	0.5
Other (describe)	0	0
No one	12	6
Select more than one option	48	24
Financial support		
Spouse/partner	37	18.5
Patient's grandparents	20	10
Extended family	32	16
Friends	6	3
Work Associates	1	0.5
Other (describe)	8	4
No one	79	39.5
Select more than one option	17	8.5
Help with everyday tasks (ex: meals, errands, transportation)		
Spouse/partner	84	42
Patient's grandparents	11	5.5
Extended family	40	20
Friends	2	1
Work associates	0	0
Other (describe)	1	0.5
No one	43	21.5
Select more than one option	19	9.5
Device		
Own car	103	51.5
Public transportation	89	44.5
Rides from others	8	4
Patient's health coverage		
Insurance	154	77
Health assistance (Charities and government)	19	9.5
None	27	13.5
Financial difficulties		
No	20	10
Have some financial problems	75	37.5
Have many financial problems	53	26.5
Hard to meet our basic needs	52	26
Economic difficulties		
None	16	8
Phone/utility bills	4	2
Rent/mortgage	38	19
Buying food	10	5

Vehicle (upkeep/gas/insurance)	6	3
Medical exp	86	43
Select more than one option	40	20
Child know about cancer		
Yes	46	23
No, too young	94	47
No, opted to not tell him/her	60	30

Findings

In PAT-R, the total mean score was 0.56. Among all categories of the scale, the highest mean score belonged to the category of parent stress reaction (mean=1.75), and the lowest one belonged to the category of sibling problems (mean =0.16).

In this study, there was a correlation between category of “sibling problems” and planning for pregnancy. Parents who did not plan for future pregnancy, had more sibling problems (mean=0.18, p=0.00, SD=0.13) compared to those who planned for future pregnancy. It was found that category of "child problems" correlated with number of children. It means that the more children parents have, the higher "child problems" (mean=0.42, p=0.04, SD=0.20). There was a relationship between categories of "child problems" as well as "family problems" and own car. The means of categories of “child problems” (mean= 0.33, p=0.01, SD=0.17) and “family problems” (mean=0.25, p=0.001, SD=0.14) were lower among parents who had own car compared to others. Two categories of "family problems" and "parents' stress reaction" correlated with financial problems. The means of categories of "family problems" (mean=0.17, p=0.00, SD=0.11) and "parents' stress reactions" (mean=1.11, p=0.00, SD=0.64) were lower among parents who did not have financial difficulties compared to others. It was found that category of “family problems” correlated to financial problems (Table 2).

Table 2. *Correlation between PAT-R and demographic factors.*

	Child-P	**Sibling-P**	**Family-P**	**Parent stress reaction**	**Family belief**
Planning for pregnancy					
Mean					
Yes	0.37	0.10	0.25	1.63	1.55
No	0.35	**0.18**	0.30	1.78	1.56
Std. deviation					
Yes	0.19	0.14	0.11	0.80	0.31
No	0.17	**0.13**	0.16	0.79	0.33
Correlation					
Yes	p=0.75	p=0.05	p=0.07	p=0.30	p=0.98
No	p=0.73	**p=0.00**	p=0.15	p=0.29	p=0.98
	t=-0.34	**t=3.55**	t=1.41	t=1.04	t=0.24
Number of children					
Mean					
1	0.30	0.01	0.27	1.92	1.53
2-3	0.36	0.21	0.30	1.67	1.54
>3	**0.42**	0.18	0.26	1.91	1.62
Std. Deviation					
1	0.11	0.04	0.15	0.87	0.24
2-3	0.18	0.12	0.16	0.76	0.34
>3	**0.20**	0.08	0.10	0.73	0.36
Correlation					
1	**p=0.04**	p=0.07	p=0.37	p=0.11	p=0.6
2-3					
>3					

Device					
Mean					
Own Car	**0.33**	0.15	**0.25**	1.58	1.56
Public Transportation	0.40	0.17	0.33	1.93	1.55
Rides from others	0.38	0.22	0.27	1.91	1.35
Std. deviation					
Own car	**0.17**	0.131	**0.14**	0.71	0.30
Public transportation	0.18	0.138	0.16	0.84	0.32
Rides from others	0.15	0.15	0.10	0.72	0.57
Correlation					
Own car	**p=0.01**	p=0.33	**p=0.001**	p=0.07	p=0.20
Public transportation					
Rides from others					
Financial difficulties					
Mean					
No	0.40	0.17	**0.17**	**1.11**	1.51
Have some financial problems	0.32	0.16	0.28	1.64	1.57
Have many financial problems	0.35	0.14	0.29	1.76	1.58
Hard to meet our basic needs	0.40	0.19	0.36	2.15	1.50
Std. Deviation					
No	0.27	0.13	**0.11**	**0.64**	0.34
Have some financial problems	0.16	0.12	0.15	0.69	0.35
Have many financial problems	0.17	0.14	0.13	0.78	0.29
Hard to meet our basic needs	0.15	0.14	0.17	0.79	0.33
Correlation					
No	p=0.06	p=0.05	**p=0.000**	**p=0.000**	p=0.47
Have some financial problems					
Have many financial problems					
Hard to meet our basic needs					

DISCUSSION

The results of this study indicated that parents of cancerous child who did not plan for future pregnancy, had more sibling problems (mean=0.18, p=0.00, SD=0.13) compared to those who planned for future pregnancy. For example the items of child problem such as: "have difficulty making and keeping friends, act shy or cling to you/other familiar adults? and "have developmental concerns or delays" were correlated with planning for pregnancy. According to Nolbris, Enskar, & Hellstrom,[22] when a child develops a life threatening disease like cancer and needs treatment, the whole family becomes involved and this new situation often changes the pattern of life for the family and for the healthy siblings. They go on that the siblings felt difficulties to always be loyal with the brother or sister needs and demands from other interests.[22] According to Miedema, Easley, Fortin, Hamilton, & Mathews,[23] siblings have reported feeling lost and ignored by parents who are preoccupied with the sick child and who may be absent from home for extended periods of time accompanying a child receiving treatment out of town. They go on that these feelings can lead to behavioral challenges in the siblings left at home.[23] They reported that there is a relationship between the distance a family has to travel to the hospital for children with chronic illness and the quality of family relationships, because of the travel time and time spent away from home.[23] According to Walter,[24] one or both parents may be spending a lot of time at the hospital with the sick child. Siblings may be concerned about getting help with homework, transportation to and from school and activities, and how meals and food shopping will get done. He goes on that they may feel guilty about being healthy, about resenting the attention their sibling with cancer is getting and/or about their own needs for their parents' help and attention.[24] Being parents of cancerous child required them to devote more time and energy to address the needs of their

sick child. Therefore, they have limited opportunities to meet their personal affairs such as plan for future pregnancy and so on.

Base on the results, two categories of "family problems" and "parents' stress reaction" correlated with financial problems. For example the items of family problems and parents stress reaction such as: "have there been marital difficulties, conflict or discussion of separation", and "have you had bad dreams/ nightmares about your child being ill?" were correlated with financial problems. The means of categories of "family problems" (mean=0.17, p=0.00, SD=0.11) and "parents' stress reactions" (mean=1.11, p=0.00, SD=0.64) were lower among parents who did not have financial difficulties compared to the others. The financial stress, employment loss, and overall negative economic impact on families with a critically ill child particularly in families living with a cancer diagnosis have been demonstrated.[7] Cancer in a child may reduce incomes by interfering with work capabilities and opportunities.[8] Economic instability is directly tied to instability in other family domains (i.e., parental employment, family structure)[10] and has an adverse effect on marital relationships and increases couples argue more particularly over money.[9] Earlier studies indicated a positive association between job loss and subsequent divorce or separation as well as foreclosure and divorce [25]. Furthermore, family income is strongly associated with children's health [7]. Children's having Low-income are at risk of failure in school and more likely to experience grade retention, receive special education services, and drop out of high school.[26] Poverty and economic stress may lead to less effective parenting which, in turn, has adverse consequences for children's development and adjustment.[27] According to Sandstrom & Huerta,[10] families facing economic instability have trouble paying utility and food insecurity or a lack of reliable access to proper nutrition, and may cause adverse child outcomes. According to Kazak et al.,[19] perhaps most importantly, the wellbeing of children is closely linked to the psychosocial health of their families. They go on that the psychosocial risks associated with their families (many of which may not even be known to the child, such as parental emotional problems, financial difficulties, etc.) can impact the child's adjustment to treatment across treatment and afterwards (Kazak et al., 19).

Based on the results, category of "child problems" correlated with number of children. For example the items of child problem such as: "have difficulty making and keeping friends, act shy or cling to you/other familiar adults? and "have developmental concerns or delays" were correlated with number of children. It means that the more children parents have, the higher "child problems" occur (mean=0.42, p=0.04, SD=0.20). Probably by increasing the number of children, families have to tolerate more pressure to take care of children. According to Booth & Kee,[28] family size affect the production of child quality within a family and higher birth order children receive a lower share of family resources. They go on that those predicting negative effects relate to greater parental time endowments for lower birth order children; greater devolvement of responsibility to lower birth order children; and the simple fact that mothers are older when they have higher than lower birth order children.[28] The sheer presence of more children added to their stresses and made parenting more difficult; making it harder to cope and this can increase the chance of risk to the children in families where there are significant problems already.[29]

Based on the findings, a relationship was found between categories of "child problems" as well as "family problems" and own car. For example the items of family problems and child problems such as: "have there been marital difficulties, conflict or discussion of separation? and "have difficulty making and keeping friends, act shy or cling to you/other familiar adults?" were correlated with financial problems. The means of categories of "child problems" (mean=0.33, p=0.01, SD=0.17) and "family problems" (mean= 0.25, p=0.001, SD=0.14) were lower among parents who had own car compared to those who had not. Miedema et al.,[23] reported that, among other hardships, families with children who had cancer were required to travel 400 km on average (round trip) to receive treatment. They go on that a relationship between the distances a family has to travel to the hospital for children with chronic illness and the quality of family relationships, because of the travel time and time spent away from home.[23] The following study was conducted in Kerman, the center of Kerman Province. A large number of families of children with cancer who referred to the hospitals are not from Kerman. They come from small or large cities around. They had to travel a large distance to receive the treatment. Therefore, having own care may reduce the budgets they had to pay to come to the center. This may contributed to the findings that "child problems" and "family problems" were lower among parents who had own car compared to those who had not.

LIMITATIONS

Since data collection was done during children hospitalization in order to receive their medicines, parents may have stress due to the invasive procedure that was done on their own children. Their responses may have been affected by their current children status in hospital. Therefore, they asked to complete the questionnaire at home and returned it the next visit if they want. However, they may also share the items with others prior to answering.

CONCLUSION

The results of following study revealed that there were association between socio-demographic data such as planning for pregnancy, number on children and financial difficulties and psychosocial risks. In fact the results of this study indicate the relationship between economical situation and psychosocial risk of parents of children with cancer.

According to our study results when a family is on welfare and is financially supported, these families are able to effectively cope with the disease of their child and therefore have less stress and anxiety. In our country there is a charity organization that is called Mahak. This Institute provides financial and emotional support to families who have children with cancer. However, the institute has led the parents of children with cancer are more capable and they can better left behind their problems. So nurses are required to provide essential information to families about how to use such supportive services.

Creating a reflective narrative environment in which parents of children with cancer can express their own experiences and feelings about disease of their child, their sibling problems and how they cope with it seems to be as an effective approach to identify their psychosocial risks and its influential factors. Such meetings that conducted under supervision of expert nurses could be rich learning sources for parents and support their essential personal maturation. Since psychological risk is multidimensional and cultural base, it is suggested to conduct some appropriate

qualitative studies to explore psychological risks of parents of children with cancer in the context and then develop a valuable instrument in order to appropriately assess these risks.

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