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Translational cultural adaptation and psychometric study of the Persian version of pediatric inventory for parents

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Abstract:

BACKGROUND: Cancer, as a life-threatening disease in children, poses several challenges for parents. It is necessary to have a tool that can comprehensively examine the stressful events for parents of children with cancer. The aim of this present study was to study the Persian version of pediatric inventory for parents (PIP).

MATERIALS AND METHODS: The study was conducted based on methodological research design. Four hundred and fifteen parents of children with cancer referring to Alia Asghar Children's Hospital and Children's Medical Centre in Tehran answered the Persian version of PIP questionnaire in 2019. A confirmatory factor analysis was carried out using LISREL (software version 8.8) to test the construct validity of PIP. The two tools of parental stress scale and state-trait anxiety inventory (STAI-Y) were used for concurrent validity purposes.

RESULTS: The results showed that the overall score of the questionnaire was higher than the average and related to emotional distress. The internal correlation coefficient (Cronbach's alpha) in both parts of the PIP was between 0.808 and 0.957 and acceptable. Concurrent validity analysis indicated positive and significant correlation of this tool in the difficulty section of the scale with both Parental Stress Scale and STAI-Y. The results of confirmatory factor analysis indicated that the factor loads of all items except three items in the frequency section were more than 0.3 and were appropriate.

CONCLUSION: The Persian version of PIP can be available to health and family experts as a valid and reliable tool to assess stressful events of parents of children with cancer.

Keywords:

Cultural adaptation, pediatric inventory for parents, psychometric study

Introduction

Cancer is the second-most common cause of death among children aged 1–14 and its overall incidence has slightly increased compared to 1975. Instead, rate of cancer deaths has declined in recent decades, from 6.5/100,000 in 1970 to 2.3/100,000 in 2016, down about 65%.^[1] In the new era, it is estimated that more than 80% of children with childhood cancer can

survive 5 years.^[2] However, the survival rate from cancer in poor countries is lower than that of developed countries.^[3] The incidence of fatality from cancer is about 75% in low-income countries, about 64% in middle-income countries, and about 46% in high-income countries.^[4] The incidence of childhood cancer in Iran was between 48 and 112 and 51 to 144 per million for the Iranian girls and boys. Mortality rates of childhood cancers in Iran are 42 and 49 per million for girls and boys.^[5] Some

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factors such as young age, multidisciplinary treatment approach, and lack of family history of cancer could reduce the risk of death from childhood cancer.^[6]

One of the challenges of parents of children with cancer is fear of disease progression.^[7] Parental stress is positively associated with the number of hospitalizations and the increase in the number of medical visits.^[8] Reducing of child's social activities and behavioral and social problems following the diseases is another contributing factor to parental stress.^[9] Children's hospitalization for surgery and long-term hospitalizations after surgery, in turn, is stressful for the parents of these children.^[10]

Childhood cancer as a family disease affects all aspects of life and the world of children and their families.^[11] Psychological distress in parents has a significantly negative relationship with health related quality of life (QoL) in children surviving cancer and has an adverse effect on treatment outcomes.^[12] Another concern is the mutual effect of parents' stress, especially that of the mother on the child's psychological problems.^[13] These results highlight the importance of knowing the factors influencing the stress, adaptability, and QoL of caring parents.^[14]

In general, it is important to study the stress of these parents and it is necessary to have a suitable tool for it. The pediatric inventory for parents (PIP) has been designed to study parental stress in parents of children with serious disease.^[15] It has been examined to assess parental stress in children with sickle cell anemia,^[16] chronic pain,^[17] Crohn's disease,^[18] inflammatory bowel disease,^[19] and type 1 diabetes.^[20] The PIPs were translated to Spanish,^[21] Dutch,^[22] and Swedish.^[23] The present study was done with the aim of psychometric study of the Persian version of the PIP.

Materials and Methods

This study was conducted based on methodological research with the aim of investigating the validity and reliability of the Persian version of PIP.

Continuous sampling was performed among those who referred to Alia Asghar Children's Hospital and Children's Medical Centre in Tehran from August 2017 to June 2018. The inclusion criteria were: (1) having a child with different types of cancer, (2) having a child under the age of eighteen, (3) ability to read and speak in Persian, (3) Iranian nationality, and (5) not having a history of psychiatric or neuropsychological disorder. Finally, 415 parents participated in the study according to recommendation of 10 samples for each item of the scale.^[24] Among this sample, 315 parents answered the demographic questionnaire and PIP and 100 parents

answered demographic, PIP, PSS, and state-trait anxiety inventory (STAI-Y), simultaneously [Table 1].

Instrumentation

Demographic information questionnaire

This questionnaire included information about parent, i.e., sex, educational background, occupation, marital status, and insurance coverage, as well as information about the child, i.e., sex, age, and duration of illness from the time of diagnosis to the time of responding to the questionnaire.

Pediatric inventory for parents

The original version of PIP was designed^[15] to investigate the stressful situations of parents of children with cancer. To develop this tool, review of texts, clinical experiences, panel of pediatric psychologists, and transactional model of stress and coping have been used.^[25] The PIP has shown extensive psychometric support, indicating internal consistency, as well as content, and concurrent

Table 1: Characteristic of the participants

Demographics	n (%)
Sex of parent	
Female	322 (75.99)
Male	93 (22.40)
Educational level	
Elementary	16 (3.85)
Lower diploma	128 (30.84)
Diploma	154 (37.10)
Higher education	117 (28.19)
Occupation	
Unemployed	29 (6.98)
Employed	382 (92.04)
Retired	4 (0.96)
Single-parent family	
Yes	29 (6.98)
No	386 (93.01)
Cover of insurance	
Yes	90.12 (374)
No	9.78 (41)
Sex of child	
Female	214 (51.56)
Male	201 (48.43)
Age of child	
≤ 1	23 (5.54)
1- 3	79 (19.03)
3- 6	119 (26.42)
6- 12	139 (33.49)
≥ 12	55 (13.25)
Duration of disease diagnosis (months)	
≤ 1	102 (24.57)
1- 6	138 (33.25)
6- 12	82 (19.75)
12- 24	41 (9.87)
24- 48	34 (8.19)
≥ 48	18 (4.33)

validity.^[15] The PIP questionnaire contains 42 items were classified into four categories or latent variables including communications with nine items, emotional suffering with fourteen items, medical care with eight items, and role performance with ten items. Each item is answered with two response patterns including the frequency of exposure to stressful events of the last week (PIP-F) and difficulty of dealing with them (PIP-D), which is answered with the 5-Part Likert scoring range Model with one to five score. Two overall scores were obtained including event frequency (PIP-F) and event difficulty (PIP-D). Responses are provided using a five-point Likert scale, ranging from 1 (“never/not at all”) to 5 (“very often/extremely”). Higher scores indicate higher levels of stress.

Parent stress scale

This scale designed to assess the stress levels of parents with disabled children by Berry and Jones.^[26] The PSS is an 18-item scale with a 5-part Likert response pattern with high required reliability and whole correlation of 0.43 and positive and significant correlation between the group of mothers ($r = 0.46$ and $P < 0.01$) and fathers ($r = 0.53$ and $P < 0.01$). The tool has undergone psychometrics and has been translated into several languages including Chinese,^[27] Spanish,^[28] Danish,^[29] and Persian.^[30]

State-trait anxiety inventory

Spielberger^[31] designed STAI-Y in American English. Cronbach’s alpha was between 0.82 and 0.95. The Spanish and English versions also had a high correlation between 0.83 and 0.94. The assumption of this tool is that anxiety is an emotional state that is manifested by emotions including tension and anxiety and increased activity of the nervous system. Anxiety, on the other hand, can be an individual characteristic or a personality characteristic. The Spielberger tool consists of 40 items (20 questions about anxiety state and 20 questions about anxiety trait) that are answered on a 4-Part Likert scale. This tool has undergone psychometrics and has been translated into Spanish,^[31] Portuguese,^[32] and Persian.^[33]

Procedure

Face and content validity in the expert panel, some revisions were made, after the translation and validation procedures. Then, performed a confirmatory factor analysis (CFA) in order to evaluate the factor structure of the PIP, concurrent validity was assessed using the PSS and STAI-Y.

Translation process

To translate PIP, having obtained permission from the original developer of the PIP, two fluent English and Persian translators translated it simultaneously and separately. The research team compared the two translated versions and examined them in terms

of cultural adjustment with Persian language and Iranian culture. After combining and integrating the original translations into a single translation, the two other English and Persian translators rendered the questionnaire to the original language.^[34] In the final step, the back-translated version was sent to the original designer and she suggested some changes to take place: For example, in item No. 13 “*while doing*” was suggested instead of “*during*”, and in item No. 23, “*health needs*” was suggested instead of “*hygiene needs.*” Finally, according to her points, the final Persian version was designed with little changes in the Persian text. For example, because most Iranian mothers do not have a job outside home and are homemakers, the phrase “*work at home*” was added to the item No. 5 (being unable to go to work/job).

Face and content validity

The final Persian version of the questionnaire was provided to 15 parents of children with cancer in order for them to assess qualitative face validity. Based on the parents’ comments, the items were re-examined and the appropriate changes were made.

In the second step, the questionnaire was given to 15 professors or graduates of pediatric nursing to calculate content and face validity coefficients. Content validity index (CVI) was calculated based on the number of specialists who have given the item a score of three or four (completely relevant, and very relevant) the relevancy of each item, divided by the total number of experts.^[35] Item-CVI index 0.78 and above indicates good content validity.^[36] In the present study, items 11, 22, and 35 did not obtain the CVI of 0.78 and were therefore not acceptable, but based on the decision of the research team and the importance of the items; they were not removed.

In the third step, the questionnaire was given to 415 parents of children with cancer to examine the construct validity by CFA and the reliability of internal correlation (Cronbach’s alpha). To examine concurrent validity, the two tools of parental stress scale (PSS) and STAI-Y were used. All participants received the questionnaires in print and in person and answered it at the outpatient clinic or oncology ward.

Statistical analysis SPSS-22 and LISREL 8.08 software

The reliability and validity of the questionnaire was calculated by Cronbach’s alpha and concurrent validity by the correlation coefficient and the significance of the relationship were examined using SPSS software version 22.0 (SPSS Inc., Chicago, IL, USA).

The models obtained from (PIP-D, PIP-F) were drawn separately in the LISREL 8.53 software to obtain CFA. Factor loadings, standardized factor loads, and independent *t*-values were reported. In order to have validity, there must be a significant correlation between construct and dimension as well as between the dimension and indicator.^[30] Significant numbers, or *t*-values, indicate the degree of significance of each parameter, and if the value is >1.96, the model parameters are significant. Structural equation modeling method, known as model fit has some indicators including $\chi^2/df \leq 5$, Root Mean Square Error of Approximation (RMSEA) <0.08, Confirmatory Fit Index (CFI) >0.90, Normal Fit Index (NFI) >0.9, GFI >0.91, and Incremental Fit Index (IFI) >0.90 as good model fitness.^[37]

Ethical considerations

The present study was confirmed and supported by Iran University of Medical Sciences with ethical code of IR.IUMS.REC 1395.95.03-123-29430 and followed the Helsinki Convention.^[38] The information letter contained the study purpose, its confidentiality and all participants signed a written informed consent.

Results

Participants

Totally, 322 mothers (59.77%) and 93 fathers (40.22%) of children with cancer diagnosed with various malignancies including leukemia, Wilms' tumor, neuroblastoma, brain tumor, hepatoblastoma, rhabdomyosarcoma, osteosarcoma, and unknown malignancy, with the age of under 18 participated in the study. The average age ranges of the mothers and fathers were (33.25 ± 6.38) and (38.59 ± 6.94), respectively [Table 1].

Distribution of items, descriptive statistics of PIP

The skewness and kurtosis degree were -0.5 and -0.24 respectively in the PIP-D and -0.3 and -0.17 in the PIP-F and were acceptable.^[39] Therefore, all subscales of the questionnaire had a normal distribution^[40] and consequently, the effect of ceiling and floor was not observed in this study.^[41] The average overall scores obtained in both sections (PIP-D and PIP-F) were higher than average (PIP-D: 155.10 ± 29.41 and PIP-F: 149 ± 25.55) and were related to the construct

of emotional distress (PIP-D: 55 ± 10.20 and PIP-F: 54.45 ± 9.79). The highest average was related to item of 36 (fear that my child's illness becomes more severe or dies) and the lowest average was related to the construct of medical care (30 ± 7.96) in the PIP-D and communication (29.38 ± 6.08) in the PIP-F and item of 22 (opposing a member of the medical care team).

The reliability of the questionnaire

The Cronbach's alpha range was 0.834–0.890 in the PIP-D and 0.808–0.890 in the PIP-F and was acceptable. The lowest alpha in the PIP-D (0.834) was related to medical care and the highest alpha (0.890) was related to emotional distress. The lowest alpha in the PIP-F (0.808) was related to role function and the highest alpha (0.863) was related to medical care [Table 2].

Concurrent validity

Pearson's correlation coefficient between the scores of four factors of PIP-D and two other tools (PSS and STAI) was calculated. The correlation test results indicated that the overall score of the PIP-D has a positive and significant relationship with overall score of the PSS ($r = 0.33, P < 0.001$). There were significant and positive relationships between the scores of every factors of PIP-D and the overall PSS score (0.14, 0.33, 0.28, and 0.36 with $P < 0.000$). There was a positive and significant relationship between the overall score of the PIP-D and the overall score of STAI ($r = 0.50, P < 0.000$). Results showed that there were positive and significant correlations between the scores of four factors of the PIP-D and the overall score of STAI-Y (0.415, 0.529, 0.275, and 0.484 with $P < 0.01$) [Table 3].

Construct validity

The results of CFA for both sections (PIP-D and PIP-F) indicated that the ratio of χ^2/df was 3.48 and <0.5. The RMSEA was = 0.778 and <0.88. CFI, IFI and NFI were >0.9 and Good Fit Index (GFI) was slightly <0.9. In general, according to the calculated indicators, the optimal fit of the model can be concluded [Table 4]. In addition, results of CFA indicated that the factor loadings of all items except three items in the PIP were more than 0.3 and were appropriate. The other items with factor loadings lower than 0.3 were not deleted due to the importance of these items in the questionnaire and by

Table 2: Means, standard deviations, and internal consistency of the pediatric inventory for parents

Variables	PIP-frequency		PIP-difficulty	
	Mean±SD	Cronach's alpha	Mean±SD	Cronbach's alpha
Communication (9- 45)	29.38±6.08	0.854	31.75±7.57	0.864
Emotional distress (15- 75)	54.45±9.79	0.856	59.42±10.75	0.890
Medical care (8- 40)	29.76±5.47	0.863	30.31±6.23	0.834
Role function (10- 50)	35.85±7.29	0.808	37.84±7.95	0.841
Total) 42- 210)	149.47±25.55	0.946	159.34±29.92	0.957

*Higher scores indicate higher stress. PIP=Pediatric inventory for parents, SD: Standard deviation

Table 3: Correlation coefficients between the total scores of the pediatric inventory for parents - event difficulty, parent stress scale, and state-trait anxiety inventory in parents of children with cancer (n=100)

Subscales' scores	Communication	Emotional distress	Medical care	Role function	PIP.D	PSS. total	State. total	Trait. total	STAI. total
Communication	1								
Emotional distress	0.75	1							
Medical care	0.66	0.67	1						
Role function	0.64	0.71	0.56	1					
PIP.D	0.86	0.93	0.81	0.84	1				
PSS. total	0.14	0.33	0.28	0.36	0.33	1			
State. total	0.39	0.52	0.25	0.45	0.49	0.39	1		
Trait. total	0.41	0.50	0.28	0.48	0.49	0.31	0.89	1	
STAI. total	0.41	0.52	0.27	0.48	0.50	0.36	0.97	0.96	1

*Hint: Correlation is significant at the 0.01 level (two-tailed). PIP=Pediatric inventory for parents, PSS=Parent stress scale, STAI=State-trait anxiety inventory

Table 4: Results of confirmatory factor analysis by LISREL

Fitness indicators models	χ^2/df	RMSEA	NFI	CFI	IFI	GFI
PIP-D (first-order)	3.52	0.078	0.95	0.96	0.96	0.76
PIP-D (second-order)	3.51	0.078	0.95	0.96	0.96	0.76
PIP-F (first-order)	3.48	0.078	0.94	0.96	0.96	0.78
PIP-D (second-order)	3.50	0.078	0.94	0.96	0.96	0.78

CFI=Confirmatory fit index, NFI=Normal Fit Index, IFI=Incremental Fit Index, GFI=Good Fit Index, PIP=Pediatric inventory for parents

judging the merits of them^[42] [Table 5].

Discussion

In the present study, the stress scores of parents of children with cancer were higher than the average in both sections of the PIP (PIP-F and PIP-D). Parallel to a recent study,^[43] it was found that about 70% of parents of children with cancer experience moderate to high levels of anxiety and symptoms of depression. Psychological distress in children with cancer and in their parents highlights the need for psychological support to reduce the manifestations of distress on them and to increase their QoL.^[44,45]

Similar to the results of psychometric study of the Dutch version of PIP^[22] and the Swedish version^[23] of it, the highest average was related to emotional distress factor. Distressing factors for parents of children with cancer maybe included three general categories: Factors related to the disease and its course, individual characteristics, and family factors. One of the disease-related factors include the length of time that has elapsed since the diagnosis and the other one include active treatment process, which is associated with symptoms of distress, depression, anxiety, and more posttraumatic stress disorder. Complex types of cancer, complex therapies, and psychomotor limitations are other factors influencing parental emotional distress.^[46] Parents' emotional distress increases stress and anxiety in the child, so that anxious parents create an atmosphere of frequent, constant, and uncontrolled stress at home that not only makes the child anxious, it will also disrupt the outcome of treatment.^[47]

As expected, the scores of PIP in the difficulty section (PIP-D) and its subscales had positive and significant relationships with the PSS. In the initial study of instrument development, in which the tool of PSI-SF (Parenting Stress Index-Short Form) was used, it was found that PIP instrument has a weak but significant and positive relationship with PSF-SF.^[15] In the psychometric study of the Dutch version of PIP, weak but significant correlation was observed between PSF-SF and the difficulty section of PIP.^[22]

There was significant relationship between the PIP-D and the trait and state sections of the STAI-Y. In the initial study of the validity and reliability of the PIP, there was a strong and significant relationship between PIP and Spielberger's state anxiety score.^[15] In the Dutch psychometric study of the PIP, there was a positive and significant relationship between the PIP-D and both trait anxiety and state anxiety sections of Spielberger's tool.^[22]

The Persian version of PIP has an acceptable fit in both PIP-F and PIP-D which is similar to the findings of the study of the Swedish version^[23] and the Dutch version,^[22] but the advantage of the present study is the greater number of samples for construct validity. In the present study, no one of the five items with unacceptable factor loadings had not been removed, but in the Spanish version of the PIP tool, several steps of exploratory, and CFA were performed and therefore the items were reduced up to 12 items.^[48]

Conclusion

Based on the results this study, it can be claimed that the Persian version of the PIP is a valid and reliable questionnaire and there is no need to delete or change the questionnaire items. The PIP questionnaire is in parallel to the PSS and the STAI-Y scales, and can properly examine the stress of parents of children with serious illnesses, especially cancer. The Persian version of this questionnaire fits well with the Iranian parent population and can be used in various studies in the Iranian population.

Table 5: Factor loadings in pediatric inventory for parents -D and Pediatric inventory for parents -F

Latent factors	Item	PIP-D		PIP-F	
		t	Standardized factor loadings	t	Standardized factor loadings
Communication	2. Arguing	-	0.57	-	0.58
	7. Speaking with doctor	10.56	0.66	11.42	0.68
	12. Feeling confused	10.36	0.64	10.46	0.66
	17. Talking with the nurse	9.91	0.60	10.16	0.64
	22. Disagreeing*	10.44	0.65	4.36	0.23
	27. Feeling misunderstood	10.31	0.64	10.49	0.67
	32. Speaking with child*	10.06	0.62	3.86	0.21
	37. Speaking with family	10.67	0.67	10.72	0.69
Emotional distress	40. Worrying	10.68	0.67	10.89	0.71
	1. Difficulty sleeping	-	0.53	-	0.53
	4. Learning upsetting news	9.67	0.63	9.16	0.58
	6. Seeing mood change	9.35	0.60	8.03	0.48
	9. Waiting for test results	9.57	0.62	6.02	0.33
	11. Trying not to think/ difficulties*	9.22	0.58	3.43	0.18
	14. Knowing/hurting	9.33	0.60	8.67	0.54
	16. Seeing child sad	9.39	0.60	9.17	0.58
	19. Thinking about/isolated	10.15	0.68	9.84	0.65
	21. Feeling numb inside	9.67	0.63	9.14	0.58
	24. Worrying about/impact	8.86	0.55	8.52	0.52
	26. Feeling helpless	9.92	0.66	9.56	0.62
	29. Feeling uncertain	9.43	0.61	8.72	0.54
	31. Thinking about/other ill	9.33	0.60	8.99	0.57
	34. Having my heart beat fast	9.12	0.57	7.33	0.48
Medical care	36. Feeling scared	6.41	0.36	9.05	0.57
	3. Bringing my child to the clinic	-	0.62	-	0.65
	8. Watching/eating	12.75	0.64	12.64	0.59
	13. Being with my child	11.25	0.64	12.33	0.71
	18. Making decisions	9.81	0.54	10.95	0.62
	23. Helping/hygiene needs	9.83	0.54	12.26	0.71
	28. Handling changes	11.35	0.65	11.81	0.63
	33. Helping/procedures	11.06	0.63	12.07	0.69
Role function	38. Watching/procedures	11.12	0.63	11.51	0.65
	5. Being unable to go to work	-	0.63	-	0.52
	10. Having money	10.02	0.56	8.61	0.54
	15. Trying to attend/other	9.32	0.51	6.66	0.35
	20. Being far away from family	10.91	0.61	8.52	0.53
	25. Having little time	9.68	0.53	8.27	0.51
	30. Being in the hospital	10.78	0.60	8.78	0.56
	35. Feeling uncertain	9.24	0.50	8.61	0.54
	39. Missing important events	10.32	0.57	9.05	0.59
	41. Noticing a change	10.64	0.59	8.45	0.53
42. Spending a great deal of time	11.81	0.67	9.26	0.61	

*Items with Factor Loadings lower than 0.3. PIP=Pediatric inventory for parents

Limitations

The study has been some limitations, for example, participants were only selected from the group of mothers or fathers, while parental stress also applies to people who care for sick children as caregivers such as grandmother or other people except parents who care for the children. Future psychometric studies of this tool should also consider this group.

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Conflicts of interest

There are no conflicts of interest.

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