

Translation and Psychometric properties of the Persian Version of the “Kendall Chronic Sorrow Instrument” in Mothers of Children with Cancer

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Abstract

Introduction: The aim of this study was to translate and evaluate the psychometric properties of the Kendall Chronic Sorrow Instrument (KCSI) in Iranian mothers of children with cancer.

Methods: In this methodological study, Kendall Chronic Sorrow Instrument (KCSI) was translated and back translated. Its content and face validity were determined by 15 faculty members specialized in different fields of nursing and psychology. Among mothers of children with cancer, 264 mothers were selected by convenient sampling and completed the Persian instrument. Construct validity and internal consistency reliability were investigated by exploratory factor analysis and Cronbach's alpha was determined. To determine stability, the test-retest method was used for 20 participants during a 2-week interval.

Results: Factor analysis confirmed the presence of 3 factors that explained 49.92% of the instrument variance. Cronbach's alpha for the total instrument ($\alpha=0.84$) indicated its internal consistency. Pearson correlation coefficient of $r=0.86$ ($p<0.001$) confirmed the stability of the instrument. Chronic sorrow mean score of the participants in this study was 76.39 (SD=15.81).

Conclusions: The Persian version of the Kendall Chronic Sorrow Instrument (KCSI) can be used as a valid and reliable instrument to measure chronic sorrow in mothers of children with cancer.

INTRODUCTION

Chronic sorrow was introduced by Olshansky (1962) for the first time as a kind of progressive, ongoing, and endless grief experienced by parents, especially mothers of newborns with congenital anomalies. Also, other studies have reported this phenomenon in parents of children with mental or physical disability as well as with chronic and severe diseases [1-6]. This concept is defined as recurrent, unpredictable, and periodic sadness, which is permanent and progressive, and is triggered by internal or external events reminding the loss [7]. The recurrent pattern of chronic sorrow might have a non-linear and spiral design in the process of treatment, improvement or control of the disease; sorrow and severe grief may recur at a high level periodically at certain stages of the

disease. There was no specific time pattern for each stage of chronic sorrow, which occurs at times of relapse, and grief is experienced separately and periodically. Due to the cyclical nature of chronic sorrow, grief periods are replaced by happiness and satisfaction periods that prevent frustration caused by grief [8]. Chronic sorrow can be one of the experiences of cancer patients and their family caregivers [7]. Cancer is among diseases of children whose incidence has been reported as 160000 per year and it is still considered as the second leading cause of death in 1- to 14-year-old children [9, 10]. The incidence of cancer in Iranian children is 176 per 1 million children under fifteen years [9]. Despite improvements in survival rates, cancer is still a life-threatening condition

and could cause many challenges for children and families. In such circumstances, the world is not as safe and secure as before [11, 12].

Given the increasing emphasis on the importance of holistic care in enhancing the quality of life for children and families, paying attention to the psychological aspects of care for children with cancer and their families is among fundamental issues important for nursing care of children [13]. Nursing researchers, in an effort to identify and measure chronic sorrow, to a great extent have conducted different studies to explore and detect the concept in parents of children with chronic conditions [14-17]. Although cancer in children is one of the most commonly discussed areas in pediatric nursing care, there is little evidence regarding the description of chronic sorrow concept in families of these children. There are some qualitative and quantitative methods of assessing chronic sorrow [17]. Kendall Chronic Sorrow Instrument (KCSI) has been designed for the evaluation and measurement of chronic sorrow in females with ongoing loss. Questionnaire items were designed by in-depth interviews with 96 females with ongoing loss. The questionnaire had eighteen 7-point Likert scale items, in which participants were asked to determine their experience about each item from "almost always" to "never". Scores were summed, and total score of 0 to 38 was considered as no chronic sorrow, 39 to 82 was considered as probability of chronic sorrow, and 83 to 108 was considered as chronic sorrow. In determining instrument reliability, Cronbach's Alpha of 0.91 confirmed its high internal consistency. The simultaneous conduction with "Center of Epidemiologic Studies-Depression Scale (CES-DS)" and "General Wellbeing Scale (GWBS)" and the positive and negative significant correlation with the first and second instrument confirmed the construct validity of the instrument [18].

This questionnaire was used for mothers of children with cerebral palsy and autism, yet, it should also be tested for parents of children with other chronic disorders [6, 18]. In most Islamic societies, including Iran, the primary caregiver of the child is his/her mother. Some studies have reported gender differences in the incidence of chronic grief and its higher prevalence in mothers [19, 20]. Further studies are needed to assess the impact of race and culture on the incidence and prevalence of chronic sorrow [21]. In order to provide high quality care for the child and his family, nurses should be familiar with implications related to chronic diseases, such as chronic sorrow, and instruments should be designed to measure these concepts. Given no instrument has been provided to measure this psychometric concept in Persian language societies, the purpose of this study was to perform translation and psychometric evaluation of the Persian version of the Kendall Chronic Sorrow Instrument in mothers of children with cancer.

METHODS

Study Design

This study used a methodological design.

Setting and Sample

Overall, 288 mothers of children with cancer, who had re-

ferred to one of the 3 children's specialized hospitals of Tehran were selected by convenient sampling based on inclusion criteria to investigate instrument's psychometric properties. The samples were mothers, whose children had been diagnosed with cancer of any type for six months, and had no history of any psychiatric disorder, such as depression, and their children had no other important health problem other than cancer. If children were in the acute phase or end stage of the disease, their mothers were excluded.

Ethical Consideration

The study plan was approved by the ethics committee of Shahid Beheshti University of Medical Sciences and Health Services (project No. 7172/12/25/P); written consent, including study objectives, the right to participate in the study voluntarily, and data confidentiality was received from the participants before taking part in the study.

Instrument

In this research, based on the Wilde et al. (2005) method, after obtaining permission of the instrument designer via e-mail and asking her for assistance in instrument translation, a group of people with relevant experience was invited to cooperate [22]. Kendall Chronic Sorrow Instrument was translated from English to Persian, by two independent experts. Both versions were reviewed, revised, and edited by researchers and then retranslated to English by another expert. After matching both instrument English versions (the original and translated versions) by researchers, the final version was sent for the instrument designer and after the final version was approved by her, the Persian version was completed by 5 mothers of children with cancer, who met the inclusion criteria and were Persian speakers. The items that were mentioned as cases of misunderstanding were edited and the participants did not mention any case that had discrepancy with the cultural context. To determine content and face validity, Persian translation was sent to 15 experts in the field of pediatric nursing, psychiatric nursing, cancer nursing, general and clinical psychometric and psychology. These experts were chosen based on their experience in practice and research in cancer, family and children psychology, and nursing fields. After editing the Persian version, according to the experts' opinions, it was filled again by 10 mothers, who were qualified for inclusion, and the final version was approved by the researchers and the instruction was written by them. It should be noted that the original version of the instrument was designed to assess chronic sorrow in adults; therefore, according to the fact that its items were used for mothers, they were changed from a focus on the individual's disease to a focus on the child's illness. Therefore, in review of content validity, it was approved by the instrument designer as well as the relevant experts. For example, the phrase "I feel saddened when I think of loss" was changed to "I feel saddened when I think of my child's disease" and these changes were approved by teams that investigated the content and face validity of the instrument.

Data Collection

Medical records of all children were reviewed by the re-

searcher to ensure that they were diagnosed with cancer. For each hospital, a questioner was selected among clinical nurses, who knew the mothers, and they were briefed on how to fill the questionnaires.

After ensuring the participants had the inclusion criteria, they were given the questionnaires by colleague nurses, and mothers filled the questionnaires in the presence of questioners. For illiterate or low-literacy participants, nurses read the questionnaire for them and recorded their responses. Twenty mothers participating in the study were asked to fill the questionnaire again 2 weeks later to evaluate consistency and stability of the instrument. Most researchers have advised from 2 days to 2 weeks for applying a test re-test reliability; this time frame seems a reasonable compromise between recollection bias and unwanted change [23].

Data Analysis

After entering the data, statistical analysis was performed by the Statistical Package for Social Sciences (SPSS) software, version 16. Due to the fact that the main instrument was de-

termined as one factor by the instrument designer, exploratory factor analysis was conducted to determine factors. Before conducting exploratory factor analysis, sample adequacy for factor analysis was evaluated by Kaiser-Meyer-Olkin (KMO) and Bartlett test of sphericity [24, 25]. "Scree plot" and Eigenvalue of > 1 were used as a criterion for determining the number of factors. Construct validity and internal consistency reliability were investigated by exploratory factor analysis, and Cronbach's alpha and *t* test of mean among the scores were obtained by two tests [23].

RESULTS

Data from 264 mothers participating in the study were used and other cases (24 cases) were excluded due to failure in completing the questionnaire. The mean age of the mothers participating in the study was 29.8 (8) years and over 90% of participants had elementary education and more than 50% had high school diploma. Most of their children (70.8%) had leukemia. Demographic characteristics of the participants are given in Table 1.

Demographics	%	n
Age (yr.)		
18- 25	10.6	28
26- 35	58.7	155
34-45	27.3	72
≥ 46	3.4	9
Marital status		
Married	245	92.8
Divorced	15	5.7
Widow	4	1.5
Number of children		
One	75	29.5
2-3	160	60.6
4-5	53	8.7
≥ 6	3	1.1
Education		
Low literacy	18	6.8
Basic school	109	41.3
High school	100	37.9
Bachelor	34	13.3
Master degree	2	8
Disease of child		
Leukemia	187	70.8
Brain tumor	3	1.1
Lymphoma (any kind)	18	6.8
Rhabdomyosarcoma	10	3.8
Wilms Tumor	10	3.8
Other	36	13.6
Time passed from initial diagnosis (yr.)		
<1	31.1	82
1-3	48.1	127
4-6	12.1	32
≥ 7	8.7	23

Table 2: Rotated Matrix of Items of Persian Kendall Chronic Sorrow Instrument (N = 264)

Item	First factor	Second factor	Third factor
The changes in my life because of my child's disorder are unfair.	0.754		
I believe that life is unfair.	0.736		
I feel my life is not the same as I had hoped or dreamed it could be because of my child's disorder.	0.703		
I feel alone during the times that I feel sadness related my child's disorder.	0.634		
I think about what my life might have or could have been when I am reminded that my child has autism.	0.606		
I feel older than my age because of my child's disorder.	0.535		
I feel that I have to give up things in my life because of my child's disorder.	0.509		
I feel saddened by things that other people see as unimportant or minor.	0.497		
When I think about the time which my child's disease happened, I feel sad.		0.752	
I feel sadness when I am reminded that my child has disease		0.747	
Remembering the disease of my child in any situation make me sad.		0.653	
I feel like crying when something reminds me that my child has disease.		0.567	
I feel full of sorrow		0.541	
I feel just as sad when I think of the disorder as I did when my child was first diagnosed		0.537	
I feel that the sadness related to my child's disorder comes and goes.		0.476	
I feel that I have control over my life situation			0.779
I feel that I have enough energy to deal with my life.			0.698
I think about the loss as if it had just happened			0.636

Table 3: Results of Paired T-Test for Test Re-Test Performance of Persian Kendall Chronic Sorrow Instrument on 20 Mothers of Children with Cancer)

	Mean	St Deviation	Correlation	t	df
Test 1	81.75	13.12	(P < 0.001) 0.94	1.263	1.9
Test 2	80.55	12.53	(P < 0.001) 0.94	1.263	1.9

The factor, titled "sadness", included 7 items that explained 18.60% of the variance and its Cronbach's alpha was $\alpha=0.80$, and the third factor titled "get along" included 3 items that explained 9.52% of the variance and its Cronbach's alpha was $\alpha = 0.53$. For the third factor, removing each item, did not result in an increase in Cronbach's alpha (Table 2).

Cronbach's alpha coefficient of the total questionnaire was computed ($\alpha = 0.84$). Sample adequacy was evaluated by the KMO test and Bartlett test of sphericity (KMO index = 0.86 and $\chi^2 = 1540.182$, $P < 0.000$). Exploratory factor analysis was performed by considering Eigen value of 1, factor loading of 0.4 and greater, and three factors were extracted with 49.92% variance. The first factor, titled "disparity", included 8 items that explained 21.8% of the variance and its Cronbach's alpha was $\alpha = 0.82$. The mean scores for test and re-test were 81.75 and 80.55, respectively; the difference was not statistically significant. The correlation between the two mean scores was 0.95 ($P < 0.001$).

Pearson's correlation coefficient was calculated to determine test-retest reliability for 20 participants, which was statistically significant ($r = 0.86$ and $P < 0.001$). To determine stability

of the instrument using test re-test exam, the paired t test disease-related factors was used (type of cancer, stage of cancer and elapsed time since onset of disease); no significant relationship was observed with chronic sorrow scores.

DISCUSSION

Since culture plays an important role in evaluating a concept by a valid instrument, it is essential for the instrument's validity and reliability to be studied in a population with cultural and ethnic background different from a population in which the main instrument is developed [26]. This study aimed to translate and assess psychometric properties of the Persian version of the Kendall Chronic Sorrow Instrument in mothers of children with cancer. The results showed that the Persian Version of Kendall Chronic Sorrow instrument is valid and reliable for investigating the concept in mothers of children with cancer in Persian language populations. Content and face validity of the instrument was approved by 15 experts. The panel suggested that some items should be added to the questionnaire as the original instrument had been

designed for adults with no specified ongoing loss, thus it cannot cover all aspects of the concept of chronic sorrow in mothers of children with cancer.

The review of the first factor items showed that all of these items were about conflicting perceptions of the individual with chronic sorrow regarding the reality of their life and what they had expected. Such a phenomenon is characterized by chronic sorrow and it is an ongoing conflict between reality and expectations of the individual and not their ongoing loss that makes them feel that life is unfair and have imaginative vision of life without the presence of disease in the individual or family [3, 14, 27]. This phenomenon is known as “disparity” amongst researchers. Disparity between the expectations and standards of living and what occurs in events related to chronic illness and life-threatening conditions should be taken into account in cultural, religious, and climatic backgrounds, as these factors could affect parental roles, family structure and functions, and parental expectations of having a healthy child and how to manage this sense of ongoing loss. Also, culture could affect parental attitudes towards the child’s illness and disability [6, 8, 14].

Regarding the second factor items, all items describe the feeling of sadness of the individual as they are due to ongoing and endless loss in life. Widespread grief or sadness, internally and externally, reminds the individual of their losses, fears and despairs that could be intensified even years after the initial feeling of loss and is one of the main characteristics and underlying assumptions of chronic sorrow [28, 29]. This factor was termed “sadness” by researchers. Olshansky believes that the way parents perceive this sorrow does not depend on the parents’ character, socioeconomic class, religion, and ethnicity [6]. However, researchers believe that cultural, religious, and ethnic backgrounds are effective in ways of understanding and methods for coping with this grief [30]. In the Islamic culture, the child’s sickness is interpreted as atonement for parents, so for some parents this attitude could be associated with spiritual purification following abundant grief and sorrow due to their child’s disease [31]. In this case, further ethnographic and exploratory studies are needed. The third factor is composed of only three items, all of which emphasize on living normalization by an individual with chronic sorrow in intervals of intense sorrow due to loss reminders. For mothers of children with chronic conditions, it brings about the feeling of joy due to the presence of their children despite their disability and permanent illness [28, 29]. This factor is known as “getting along” by researchers. Facing the reality of loss is necessary and in chronic sorrow, the individual, facing the loss factor in intensifying events such as hospitalization, reaches a new structure of “self” that is necessary for accepting expectations and relationships in life despite of their wishes [18].

In this study, Cronbach’s alpha value was close to the value obtained in the original instrument for the 18-item instrument. This method has widely been used to determine the internal consistency, and values close to 1 indicate higher internal consistency. In inter-group comparisons, values that are greater than 0.8, are considered very desirable [32]. The instrument’s Cronbach’s alpha value for mothers of children with autism was 0.91 [17]. For the internal consistency of each of the three factors, only the third factor had a relatively low Cronbach’s alpha value ($\alpha = 0.53$). The low number of items in this factor could be the major reason of low internal

consistency. However, the correlation of each of these statements of this factor with the entire test showed high levels over 0.8. All three items emphasized on a positive attitude in personal life despite the disease (statements such as “I have enough energy in my life”, “I have full control over my life situations”, and “my child disease is what happened and I had no control over it”). The theoretical concept of chronic sorrow represents the cyclical and recurring grief and natural condition of the individual’s life in the interval between grief periodical attacks, which is the base of discrimination between chronic sorrow and other forms of grief with the linear model [30, 32]. Therefore, the researchers decided to keep the statements.

As a limitation, researchers accepted no depression in participants only with their oral confirmation, hence considering that depression could be a part of the families of children with cancer, participation of depressed participants could be effective in response to these statements due to its impact on the natural process of individual’s life. In this regard, it is suggested for a research to be performed to investigate the relationship between depression and chronic sorrow in mothers of children with cancer. Instrument’s repeatability by the test-retest method showed that the Persian version had high internal and external stability in the population of mothers of children with cancer in Iran. As a minor finding, chronic sorrow mean score in this study was more than in other studies conducted on mothers of children with autism 18. In other words, mothers of children with cancer, compared with mothers of children with autism experienced higher chronic sorrow. Nature of cancer due to its higher correlation with death, the risk of recurrence, and frequent hospitalizations 33, in contrast to the relatively constant trend of autism could explain this difference. Frequent hospitalizations due to progressive chronic and life-threatening conditions act like a stimuli and intensify the feeling of constant conflict between the norms of life and what has been expected, which could increase the chronic sorrow experience. These stimuli, in theoretical framework of chronic sorrow have a very close relationship with the disparity they cause [7, 33]. In this study, no significant relationship was found between the individual characteristics of mothers, characteristics related to the children, and disease-related characteristics. Also in another study, no significant relationship was found between child’s age at time of diagnosis and type of epilepsy (resistant or nonresistant to treatment) and health problems associated with the amount of chronic sorrow observed in the parents of children with epilepsy [4]. The researchers emphasized on the lack of relationship between the disease variables and the occurrence and amount of chronic grief. In another study, a significant relationship was found between the number of children as well as severity of autism and chronic sorrow [17]. Researchers believed that the presence of other healthy children in the family was a supportive factor for parents. Although the relationship between depression and the incidence of chronic sorrow is supported [17], and Olshansky emphasizes the lack of parents’ individual impact on amount and incidence of chronic sorrow, there is a focus on the need for further studies to investigate the relationships between other variables such as socio-economic class and race and individuals’ way of coping with chronic sorrow [19].

In summary, the findings of this research support the applicability of the Persian version of Kendall Chronic Sorrow

Instrument to measure chronic grief in mothers of children with cancer. This instrument could be used by nurses and other health care professionals in Persian language societies and helps them detect a better understanding of the chronic sorrow concept in families with children affected by cancer. Nurses should be aware of the cyclical and pervasive form of sorrow, which is experienced by mothers of children with cancer and chronic sorrow as a need to be measured by valid and reliable instruments. There is a lack of knowledge about the extent of chronic sorrow and its relationship with other variables in mothers of children with cancer. Introducing a valid and reliable instrument for measuring chronic sorrow in this population could help practical nurses identify affected people for more supportive interventions.

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CONFLICT OF INTEREST

The author declares no conflicts of interest.

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