

## RESEARCH ARTICLE

Editorial Process: Submission:12/07/2017 Acceptance:05/09/2018

# Psychometric Properties of the Persian Version of the Offspring Cancer Needs Instrument (OCNI)

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### Abstract

**Aim:** The offspring cancer needs instrument (OCNI) was developed specifically for assessing unmet psychosocial needs of adolescents and young adults who have a parent with cancer. The aim of this study is to examine the psychometric properties of the Persian version of this instrument. **Methods:** For this methodological study, translation of OCNI into Persian was conducted using translation and back-translation and revision in line with the developer of the instrument. Then, face and content validity, construct validity, internal consistency and stability of the Persian version of the instrument were examined with a population of 188 adolescents and young people having a parent with cancer in five hospitals in Tehran, Iran. Data were analyzed using SPSS version 16 and LISREL 8.5. **Results:** The final Persian version of the instrument demonstrated face and content validity proven by expert and participant reviews. Confirmatory factor analysis confirmed construct validity of the instrument and its seven subscales. Cronbach's alpha was 0.96 for the total instrument and 0.76-0.93 for its seven subscales. The intraclass correlation coefficient (ICC) calculated to evaluate the test-retest reliability, was 0.83. **Conclusions:** The Persian version of OCNI has acceptable psychometric properties. It can be used for measuring psychosocial unmet needs in adolescents and young adults in Persian language populations who have a parent with cancer.

**Keywords:** Psychometrics- cancer- adolescents- parents- young adults- needs assessment

*Asian Pac J Cancer Prev*, **19** (6), 1621-1626

### Introduction

Cancer is one of the most common challenging diseases, which is predicted to be more prevalent in the next few decades. Assuming a stable incidence rate, the estimated new cases of cancer could increase from 12.7 million in 2008 to 21.4 million by 2030 (Huang et al., 2014). In Iran, between 2005 and 2006, the estimated age-standardized incidence rate of cancers was 102.4 and 117.3 per 100,000 among females and males, respectively (Esmaeilzadeh et al., 2015). These statistics, along with the fact that almost 25% of cancers occur in the 21–55 years of age population which are the prime childbearing and parenting years, emphasize the importance of achieving more knowledge for young family members of patients dealing with cancer (Phillips, 2014).

The diagnosis of cancer is a family experience that can affect the lives of all its members, it can increase stress and bring many challenging situations (Woźniak and Izzycki, 2014). This might represent a potentially traumatic event for young members of a family and put them at the risk of improving psychosocial problems (Jeppesen et al., 2013). The increased risk of psychosocial issues such as anxiety/depression, confusion, sadness, anger, feelings of

uncertainty and loneliness in teenagers and young adults living with a parent with cancer, are evidenced (Jeppesen et al., 2016). Young people who have a parent with cancer often have elevated levels of distress and a high level of unmet needs (McDonald et al., 2016). A holistic, patient-family centered philosophy of care necessitates understanding the needs of all family members involved and is called to provide the best caring plan for all affected persons (Huang et al., 2014). Psychosocial needs is described as '...a desire or requirement for help that supports a person's emotional and psychological wellbeing' (Nicholls et al., 2017). Needs which for children who have a parent with cancer are reported to include honest communication, receiving information about the cancer, help in coping with emotions, the need for their friends to understand them, support from other young people who have had similar experiences, and the need to be able to continue with their regular interests and activities (Patterson et al., 2017).

The proper and accurate self-expressed assessment of psychosocial needs facilitate the tailoring of holistic health care programs for every person (Patterson et al., 2013). This assessment needs reliable and validated tools. These tools should be developed; or, in the case of tools

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that are designed for other cultures and in other languages, the latter can be translated and used. The provision of a demonstrable evidence of sound psychometric properties, such as validity and reliability of a translated tool, using a methodological process, should be evidenced (Bonevski et al., 2000). It is less costly and time-consuming to use existing instrument than developing a new one (Waltz et al., 2010).

For selecting the most appropriate instrument for study there may be a need to examine several instruments. When selecting an instrument for research, it is important to consider how the instrument was developed, how to use it and what the instrument exactly measures (Grove et al., 2012). Offspring Cancer Needs Instrument (OCNI), is the first tool developed specifically for examining unmet psychosocial needs of adolescents and young adults (AYAs) who have a parent with cancer, developed by Patterson et al. (Patterson et al., 2013). During a study for identifying psychosocial needs of AYAs whom have a parent with cancer on 2011, they took the first step for developing OCNI. This study was conducted in two phases, at the first part needs of target population in 8 themes identified. And at the second part, primary construct validity, face and content validity and internal consistency were also calculated for OCNI (Patterson et al., 2011). Later in 2013, the psychometric properties of the revised OCNI were established. Dimensional structure of the questionnaire determined by exploratory factor analyzes, and Rasch analysis. Construct validity and test-retest reliability (n=35) were also assessed. Rasch analysis results suggested that overall, respondents used the scale consistently. The retest correlation for the overall measure was 0.73. Support for construct validity was provided by the correlations between psychological distress and the OCNI domains. The lowest domain Cronbach alpha was 0.89. The final version of OCNI has 47 items and 7 subscales including: information, family issues, practical assistance, time out, feelings, support (from friends) and support (from other young people) (Patterson et al., 2013). Possible OCNI scores range from 47 to 188 with higher scores indicating greater levels of unmet need (Patterson et al., 2017). Because it is the only instrument which examines this concept in this specific age group and based on steps took place in developing and evaluating psychometrics properties of instrument, it is selected for this study. Also this instrument shown sound psychometric properties in using with other researchers. In a review which aimed to determine the availability of cancer caregiver instruments, a literature search was conducted using various databases from 1937 to 2013. The instruments were divided into different areas of caregiver distress and into adult versus pediatric populations and instrument psychometric data were evaluated. OCNI was the only instrument in area of needs of cancer patient's offspring, which reported with validity and reliability among all instrument which reviewed (Tanco et al., 2017). Also Nicholls et al (2017) used OCNI in a study that aimed to establish whether experiences of cancer illness are generalizable to young people with parents who have other chronic conditions, as the OCNI may be adapted for broader use in measuring unmet needs of these young

people. They undertook a qualitative study, employing interviews and interpretative phenomenological analysis (IPA). From this pilot qualitative work, it was concluded that the OCNI could be adapted and tested for suitability to measure unmet needs for young people who have parents with a chronic condition. Later in part 2 of study they tested the reliability and validity of the modified OCNI. They developed a short instrument with acceptable reliability and validity. Items from the original OCNI, when adapted to chronic condition experiences, are suitable to explore needs in this population (Nicholls et al., 2017).

## Materials and Methods

### *Setting and participants*

In this methodological study 188 AYAs, aged between 12-24 years, who have a living parent diagnosed with cancer in any stage and type within last 5 years were enrolled in this study. For confirmatory factor analysis sample size between 100 to 200 is medium and may be acceptable minimum sample size if the model is not too complex (Harrington, 2009). Inclusion criteria were those whom their parents are under treatments or follow up for cancer in one of the five selected educational referral hospitals in Tehran, the capital of Iran. Exclusion criteria are unawareness of parent or AYAs from type of illness and unwillingness for participation. The convenience sampling method was used.

### *Translation*

First, the permission to use and translate the OCNI was done through correspondence with its developer. The English version of the instrument was separately translated to Persian by two health professionals familiar with the concepts of the questionnaire, as well as the languages of origin and destination. An expert panel then evaluated the translations; and a single form was produced, based on the consensus on the best translation of each item. Then, this initial Persian form of tool was translated back-to English by two other qualified persons, evaluated by the same expert panel; and finalized as a single English form. Finally, the back translation form of tool was sent to the developer of the tool, to be reviewed for probable inadequacy of words and concepts. Consequently, the confirmed Persian version of the tool was used for this study.

### *Face and Content validity*

The Persian version of OCNI instrument was revised by a group of 15 nursing experts in mental health, family and community health, pediatric, and oncology, for its face and qualitative content validity. Eventually, a group of 20 AYAs of targeted population read the instrument and evaluated its clarity and simplicity.

### *Construct validity*

In this stage of the study, eligible AYAs were chosen. The study objectives and methods were explained and informed consent was obtained from the AYAs. The questionnaire including the "demographic information" of the participant, sick parent and family, and OCNI were

given to them to complete which took approximately 30 minutes. For investigating the construct validity of the tool and to determine the goodness of fit between a hypothesized model and the data obtained from the study samples, confirmatory factor analysis (CFA) using LISREL statistical software version 8.5 was done. For the best test of goodness of fit, more than one index should be used, so, along with the ratio of chi-square to degrees of freedom, root mean error of approximation (RMSEA), normal fit index (NFI), non-normal fit index (NNFI), comparative fit index (CFI) and goodness of fit index (GFI) were used.

#### Internal consistency

Cronbach's alpha coefficient was used to measure internal consistency of the Persian version of OCNI using SPSS v.16.

#### Test-retest reliability

To measure the stability of the instrument, 15 AYAs were randomly asked to fill the Persian version of OCNI for the second time after two weeks. Randomization here means all participant who were accessible in this period of time were equal for selecting and were chose by chance of meeting at time of sampling. Test-retest reliability was tested using Intraclass correlation coefficient (ICC) with 95% confidence interval. P-values less than 0.05 were considered significant.

#### Ethical considerations

A university ethics committee had approved the study and its method (ethical code: IR.SBMU.PHNM.1395.401). Permission for translation and using of instrument is granted by the developers by means of an email from. All participants and their parents were informed about the reason, methods and their role in study. Written informed consent was taken from all the participants and from the parents of the children younger than 18 years old. All the participants were already aware about the type of disease and volunteered to participate.

#### Results

A total of 188 questionnaires were analyzed. Demographic characteristics of the study sample are shown in Table 1. Face and content validity in this study evaluated qualitatively. Opinions and comments made by experts, AYAs and developer were limited to some changes in words and sentences to bring them closer adjust them to the concept and more understandable for the participants. Some changes in words were for example: openly vs. explicitly, upsetting vs. worrying, consultant vs. counsellor.

Confirmatory factor analysis was used to confirm belonging of the 47 items to the 7 dimensions which theoretically was determined. Table 2 shows the amount of indices for CFA of 7-dimensional OCNI in our Persian-language population.

Table 1. Demographics of AYAs with a Parent with Cancer

AYA demographics' information	AYA gender	AYA age	AYA education	AYA occupation status	AYA sequence in the family
	86 males (45.7%)	Early adolescences: 20 (10.63%) Middle adolescence: 43 (22.9%) Late adolescence: 64 (34.0%) Young adult: 61 (32.47%)	Primary: 7 (3.7%) Secondary: 26 (13.8%) High school: 71 (37.8%) University: 84 (44.7%)	Employed: 34 (18.1%) Unemployed: 39 (20.7%) Student: 115 (61.2%)	First: 76 (40.4%) Middle: 37 (19.7%) Last: 75 (39.9%)
	102 females (54.3%)				
Sick Parent demographics' information	Parent's gender	Parent's age	Parent's education	Parent's marriage status	Parent's occupation status
	48 males (25.5%)	<40: 20 (10.6%) 40-50: 103 (54.8%) 50-60: 53 (28.2%) >60: 12 (6.4%)	Primary, secondary or high school: 97 (51.6%) Finished high school: 66 (35.1%) Bachelor: 21 (11.2%) Master and upper: 4 (2.1%)	Main parents Living together: 173 (92.0%) Divorce: 6 (3.2%) Remarriage: 2 (1.1%) Other parent is died: 7 (3.7%)	Workless: 153 (81.4%) Working: 35 (18.6%)
	140 females (74.5%)				
Family information	Child number	Family financial status			
	1-2: 92 (48.9%) 3-5: 80 (42.6%) >5: 16 (8.5%)	Weak: 48 (25.5%) Moderate: 107 (56.9%) Good: 33 (17.6%)			
Parent's cancer information	Time from diagnosis (year)	Cancer diagnosis	Cancer type	Treatment status	Treatment type
	Less than 1 year: 118 (62.8%) 1-5 year: 70 (37.2%)	Primary: 145 (77.1%) Recurrent: 43 (22.9%)	Breast: 76 (40.4%) Colorectal: 21 (11.2%) Blood: 17 (9.0%) Lymph: 13 (6.9%)	Waiting to start: 13 (6.9%) Under treatment: 153 (81.4%) Finished: 22 (11.7%)	Chemotherapy: 66 (35.1%) Radiotherapy: 4 (2.1%) Surgery: 5 (2.7%) Combination of treatments: 103 (54.8%) Other treatments: 10 (5.3%)

Table 2. The Indices of Fitness of the Model of CFA

Fit index type	Observed value	Acceptable value
Chi-Square	1767.26 Df= Degrees of Freedom = 1013, (p=0.0)	p>0.05
Chi-square/df	1.77	<3
Root Mean Square Error of Approximation (RMSEA)	0.063	<0/08
Normed Fit Index (NFI)	0.94	>0/09
Non-Normed Fit Index (NNFI)	0.97	>0/09
Comparative Fit Index (CFI)	0.97	>0/09
Goodness of Fit Index (GFI)	0.91	>0.09

Table 3. Cronbach's Alpha and ICC Amounts for Persian Version of OCNI and Its Subscales

Domains	Number of items	Cronbach's alpha	ICC(single measures)	ICC (average measures)	Pvalue
Information	9	0.88	0.81	0.89	<000
Family issues	4	0.79	0.73	0.84	<000
Practical assistance	7	0.89	0.82	0.9	<000
Time out	5	0.82	0.72	0.84	<000
Feelings	13	0.93	0.74	0.85	<000
Support (friends)	4	0.84	0.81	0.89	<000
Support (other young people)	5	0.84	0.75	0.86	<000
Total	47	0.76	0.83	0.9	<000

Cronbach's alpha coefficient of the Persian version of the OCNI was 0.96. In addition, coefficients of Cronbach's alpha for all seven subscales were upper than 0.7 (Table 3).

The Intraclass Correlation Coefficient (ICC) was estimates and their 0.95 confident intervals were calculated based on a 2-way mixed-effects model. The amounts were 0.83 for the total tool and upper than 0.7 for all seven subscales (Table 3).

## Discussion

Aim of this study was translation and evaluation of psychometric properties of OCNI in Persian language for using in Iranian population. It is essential to evaluate psychometric properties of a translated tool in another culture, because it may not be appropriate in the new society (Michaeli Manee, 2011; Hillen et al., 2013).

Because there has been little research conducted into the needs of young people who have a parent with cancer, a qualitative exploratory method of data collection was first used for initial step in developing OCNI (Patterson et al., 2011). Data were collected from AYAs who had a parent with cancer and staffs who worked with this population and the instrument was developed based on this data. It is necessary to evaluate items and domains in same Persian population to explore if items and domain structure vary among this population or not. In Iranian society and with their differences in culture and family system, there might be some differences regarding parental cancer. As it was indicated in present study, most families are nuclear in Iran and religious status is also widely different which can have effects on levels of these needs. Symptoms identified for one disturbance in one culture are not always representative of that disturbance in another

culture (Ager, 2002). Also previous studies have shown that stage and severity of the parent's illness (Gazendam-Donofrio et al., 2011; Ellis et al., 2017), age, gender, the economic situation, employment status, and marital status of parents, number of children, place of residence, type of cancer (Syse et al., 2012) child's developmental stage (Gazendam-Donofrio et al., 2011), child's gender (Jeppesen et al., 2016; Ellis et al., 2017), time since diagnosis (McDonald et al., 2016), recurrence and more intensive treatment regimens (Osborn, 2007), and parent-child relationships (Phillips, 2014) may influence the adjustment or the experiencing of distress on with children in cases of parental cancer. In a recent qualitative research by Azarbarzin et al., (2016) on adolescents who have a parent with cancer in Iran, results shown that one aspect that the participants of this research were concerned with was supportive-educative needs which is close to domain of "information" in this instrument. In Azarbarzin et al., (2016) study, adolescents had feelings such as loneliness, loss of support, depression, lack of protection, disability, guilt, and identity disorder, bewilderment, emotional involvement, nervousness and thoughts of adolescents about parent's disease, impatience, changes in sleep pattern, changes in appetite, social isolation, aggression and other aspects of psychological problems' sign and symptoms, the fear of parent's death, fear of the future, stress about the disease and its progress, difficulties at their school because of their parents' disease and problem with teachers and the stuff of their schools, which are close to some of OCNI items in "family issues", "practical assistance", "time out" and "feelings" domains. Their participants also recognized "friends and close families" as "Affective and Helpful Supportive Agents" similar to support from other friends' domain.

In this study, face and content validity, construct validity, and reliability of this tool were assessed. Face and content validity which evaluated qualitatively were proven by experts' and participants' comments.

Confirmatory factor Analysis (CFA) was used to answer if the data of the study confirm the theoretical model of the developer of the tool. According to CFA results, the model for assuming the 47 items into seven factors which was theoretically determined, was confirmed. Fit indexes values shows the fitness of model. In addition the amounts of factor loading for all of the items were greater than 0.3 and significant (0.38- 0.72). The results of coefficients of Cronbach's alpha showed that the Persian version of the OCNI has an excellent internal consistency ( $\alpha=0.96$ ), means that the items of the tool have congruence and consistency. In addition, according to the results, it can be said that each of the subscales has similar structure and so that conceptual excursiveness is not seen between them. There are different reports about the acceptable values of alpha, ranging from 0.70 to 0.95. A low value of alpha could be due to a low number of questions, poor connectivity between the items or heterogeneous constructs (Tavakol and Dennick, 2011). In this study, Cronbach's alpha was higher than 0.7 for all 7 domains which means acceptable. "Feelings" got the highest grade and "family issues" the lowest. For test-retest reliability, Intraclass Correlation Coefficient (ICC) was calculated. It is an estimation of the amount of agreement between scores of two or more measurements for a quantitative variable. There are no standard values for acceptable reliability using ICC. A low ICC could not only reflect the low degree of rater or measurement agreement but can also relate to a lack of variability among the sampled subjects, the small number of subjects, and the small number of raters being tested. Based on the 95% confident interval of the ICC estimate, value less than 0.5, between 0.5 and 0.75, between 0.75 and 0.9, and more than 0.90 are indicative of poor, moderate, good, and excellent reliability, respectively (Koo and Li, 2016). According to the results we can describe ICC's values for all domains of the Persian version of OCNI as acceptable.

Based on this study's results, OCNI which shows sound psychometric properties in this Persian language population may be a useful and necessary tool for measuring, identifying and caring about adolescents' and young adults' psychosocial needs when a parent confronts with cancer diagnosis.

This Study is Subject to Certain Limitations. The accessibility to children was difficult because the majority of these children did not accompany their parents to the hospital and it wasn't possible to visit them personally. Most of the time we got contact them through their parents which added one step more for researchers. One limitation in this study was that the children and even the patient was kept unaware about the kind of disease. In many cases family hid the kind of disease, especially in younger children. In their mind this would protect them from the mental burden of the illness. Another barrier was the attitude of parents that completing the questionnaires may have an emotionally negative influence on their children and make them over think about the illness

and its consequences. Some of the parents and children were reluctant to cooperate possibly due to boredom and fatigue which has resulted from the disease and treatment. All these limited our sample size. Suggestion for further researches is evaluating this instrument in larger numbers of sample or in other chronic conditions of parent in Persian language population. Also exploratory researches may be useful for establishing probable extra domains which may exist for this concept in Iranian community.

In conclusion, the results of this study show that the Persian version of the "Offspring Cancer Needs Instrument" has a good validity and reliability and its seven-dimensional structure is confirmed. Therefore, it is applicable to assess unmet psychosocial needs of adolescents and young adults in Persian-language population.

#### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

#### Acknowledgements

The present article was extracted from the thesis written by first author derived from her MSc thesis in pediatric nursing approved by the Research Vice-chancellor of Shahid Beheshti University of Medical Sciences (95/4/26-66000899). The authors wish to acknowledge Ms. Catharina Huberta Schouten for critical editing of English grammar and syntax of the manuscript and Ms. Patterson and Ms. McDonald for their help and professional comments in the translation process. The researchers are grateful to participants and their parents recruiting in this study and companionships of staffs in Imam Khomeini Hospital Complex, Shohada Tajrish Hospital, Ayatollah Taleghani Hospital, Hazrat Rasoul Hospital, and Firoozgar Hospital which were study environment.

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