

Research Article

The Persian Version of the Scale of “Information and Support Needs of the Primary Relatives of Individuals with Breast Cancer”

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Keywords

- Breast cancer
- Information
- Support needs
- Primary relatives
- ISNQ
- Persian

Abstract

Primary relatives of individuals with breast cancer need information and support due to genetic transmission and fatal consequences of breast cancer.

Aim: The purpose of this study was to translate and culturally adapt the “Information and Support Needs of the Primary Relatives of Individuals with Breast Cancer Questionnaire” (ISNQ) into Persian language.

Materials and Methods: Study was carried out in Noor Nejat Hospital’s Breast Polyclinic and Radiation Oncology Department. In validity and reliability study carried out totally 145 women who had immediate relatives with breast cancer were reached. The 29-item ISNQ was translated to Persian language, back translated, and tested. In the validity studies of the scale, language, content, construct validity, reliability and time consistency and internal consistency analyzes were carried out.

Results: In this study, as a result of the explanatory factor analysis, the KMO value of the scale was calculated as 0.57 in the information part and 0.70 in the support needs part. The eight factors all together explained 77.8% of the variance. It was the first factor (concerns of supporting information) explaining the biggest part of variance. In the internal consistency analysis, Cronbach’s Alpha value was calculated as 0.86 for the Information part and 0.92 for the support needs part.

Conclusions: The reliability and validity of the Persian adapted version of the ISNQ was shown to be satisfactory. Thus, it can be used to investigate the information and support needs of Iranian women with first-degree relatives of breast cancer.

INTRODUCTION

Breast cancer is the most frequent cancer among women, impacting 2.1 million women each year, and also causes the greatest number of cancer-related deaths among women. In 2018, it is estimated that 627,000 women died from breast cancer – that is approximately 15% of all cancer deaths among women. While breast cancer rates are higher among women in more developed regions, rates are increasing in nearly every region globally [1]. Similarly, in Iran, breast cancer is one of the most frequent malignancies in women. Its peak incidence age in Iranian women is in the fourth and fifth decades of life [2-5]. Family history and genetic mutations are important risk factors for breast cancer [6]. Studies have shown that many women with breast cancer and their first degree relatives experience high levels of stress, anxiety, and depression during time (related to breast cancer diagnosis, treatment, and relapse) [7-11]. Women who have one or several first-degree relatives with breast cancer fall into high-risk group, so they are right to worry. However, to date there are studies of the information and support needs of women who have a family history of breast cancer [12-17]. There is a need for valid and reliable scales to be used in descriptive and

intervention researches regarding these women’s information and support needs in Iran.

In the literature, it has been reported that women with a history of breast cancer need to be informed and supported about breast cancer in order to prevent the development of breast cancer or to detect the disease at an early stage [12-16]. It is known that women with first-degree relatives who have breast cancer need information and support regarding disease, treatment and recovery [18]. Information and support are very important to make it easier for the individual and family to deal with the stressors brought by breast cancer. Women who have breast cancer in their first degree relapse and therefore are at high risk for breast cancer should be informed by health professionals such as doctors, nurses and midwives about breast cancer screening behavior, risk factors, symptoms and ways of protection and genetic counseling [19]. In one study, they reported that education given to high-risk women with first degree breast cancer decreased their anxiety and depression symptoms [7]. Although many studies and questionnaire have been conducted on the needs of individuals women with breast cancer [20,21], there are few studies focused on the information and support needs of women with a first-degree relative with a

history of breast cancer [14,16,17]. "Information and Support Needs of Women with Primary Relatives with Breast Cancer Questionnaire: ISNQ" was developed by Chalmers et al. in 2001. Validity and reliability study of Turkish versions were done in 2006 and 2007 as thesis work [16,17]. So far, no studies have been conducted on psychometrics of Information and support needs of women with primary relatives with breast cancer questionnaire in Iran. In this context, the study was carried out to determine the Persian version of "Information and Support Needs of the Primary Relatives of Individuals with Breast Cancer" (ISNQ) which was developed by Chalmers & Thomson as a methodological scale, and to contribute to studies to be planned for Iranian women.

MATERIALS AND METHODS

In this methodological study, psychometric properties of ISNQ of the Primary Relatives of Individuals with Breast Cancer were analyzed. Sampling was conducted in continuous method. The data in Noor Nejat Hospital's Breast Polyclinic and Radiation Oncology Department was carried out in Iran 2014-2015. After Ethical Committee's approval was obtained researcher was present on site, and after obtaining written consents, issued the questionnaire to those that met the study inclusion criteria by conducting face to face interviews.

After a review of related literature, sample size was estimated at 145 women. Study inclusion criteria were: being the first-degree relative of a woman with breast cancer (mother, daughter, sister), to communicate in Persian, volunteering to participate in the research.

The women included in the research sample were asked questions prepared in the light of the literature, in order to determine the socio-demographic characteristics. Demographic details of the participants such as age, marital status, education level, number of children, occupation of spouse, rate of income, housing status, place of residence, and type of insurance, the degree of closeness of their relatives with breast cancer were investigated at the beginning of the questionnaire.

The "ISNQ", whose validity and reliability of the Persian version has been tested, consists of 29 items. Chalmers and Thomson first conducted this scale in 1996, and then they reorganized the same questionnaire in 2001. In this study, the last version of the information and support requirements scale, which was organized in 2001, was used [14]. In addition, the Turkish validity and reliability study of scales were performed [16,17]. Likert-type scaling method was used in the scale. "4" ranging from "0" (the most important [4], important [3], somewhat important [2], junk [1], is not suitable (0) ratings are based on the information requirements, the results are evaluated. Support the requirements to be met, ranging from "0" from the "4" to (completely (4), fairly (3), little (2), no (1), is not suitable (0) ratings are based on the results evaluated [14]. Comprising a total of 29 items, 18 items of this scale are for information needs and 11 items are for support needs.

Psychometric testing

Translation procedure: First, the permission of the designer to use the questionnaire from English to Persian and translate

was obtained. The questionnaire was translated from English to Persian by the researcher. The translated version was checked for content validity against. The English version by a professor at the Department of Midwifery of Tarboyat Modars University School of Medicine and who knew both languages (Persian, English), a faculty member working in the Department of Midwifery, Breast Diseases and Breast Cancer Early Diagnosis and Treatment Center were reviewed by the researches and a comprehensive version was produced in accordance with the original version. After the translation was done, appropriate phrases were selected and, finally, the Persian version of the questionnaire was translated back to English by a language specialist (Backward translation). ISNQ was compared with the original and necessary corrections were made. The prepared scale was applied to 10 women who agreed to participate in the pre-application.

Validity of the scale: Content validity was determined by the Lawshe technique by taking the opinions of 10 experts. According to this, Scale General Expert Opinion Scope Validity Index is above 0.80 and it is decided that the scale will be suitable for application. An Explanatory Factor Analysis was performed for both information and support needs in determining the construct validity of the ISNQ. The adequacy of the sample taken before the statistical analysis was evaluated using Kaiser-Meyer Olkin (KMO) value and Barlett Sphericity (sphericity) analysis.

Reliability of the scale: In the study to measure stability, test-retest method was used with a two-week interval. Test-retest application was analyzed with 'Paired samples t test' in order to examine the consistency of scale items against time. Independent Samples t test was used for comparison of quantitative data. The results were evaluated bilaterally at 95% confidence interval and at $p < 0.05$ significance level. The relationship between the scores obtained in the first and second application of the scale was analyzed using Pearson Correlation Analysis. Cronbach Alpha reliability coefficient was calculated in both the first and second application of the scale in order to determine the internal consistency. Gutman Split-half reliability coefficient was calculated for both applications by separating the first half and last half of the scale, the Spearman-Brown reliability coefficient scale into odd and even numbers, and separately for both halves.

RESULTS

In this study, totally 145 women who had immediate relatives with breast cancer, with mean age 37.7 ± 8.91 (min: 20, max: 68) years participated. It was determined that 32.4% of the women participating in the study are university or high school graduates, 77.9% are not employed (housewives). 89.7% of women stated that their income is sufficient to expenses. It was determined that the relatives with breast cancer participating in the study were 60.0% mothers, 29.7% were sisters and 10.3% were daughters. Participants' details were presented in Table 1.

The values calculated for the content validity ratio of each item were found higher than in the Lawshe table; therefore, no items were eliminated. In terms of the content validity index was found as 0.9793.

In factor analysis, factors with one or more Eigenvalues were taken. Sample sufficiency value according to Kaiser- Meyer-Olkin

Table 1: Women’s Demographic Details.

Participants’ details (145 women)	Number %
Age range	
20-29	32 (22.1)
30-39	63 (43.5)
40-49	29 (20.0)
50-59	16 (8.9)
60-69	8(5.5)
Education level	
Literate	20(13.8)
Elementary	12 (8.3)
Middle school	25 (17.2)
High school diploma	41 (28.3)
Bachelor’s	47 (32.4)
Occupational status	
Employed	27 (18.7)
Unemployed (Hausewife)	113 (77.9)
Retired	5 (3.4)
Income	
Sufficient	134 (92.4)
Insufficient	11 (7.6)
Degree of relatives	
Mothers	87 (60.0)
Sisters	43 (29.7)
Daughters	15 (10.3)

value of the scale was determined as 0.574 in the information part and 0.709 in the support needs part, it was indicated sufficiency of sampling for factor analysis. Barlett sphericity test values were significant determined as $X^2 = 3932.177$, $p < 0.001$ for Barlett spherical test values and $X^2 = 3855.191$, $p < 0.001$ for support needs section. According to the explanatory factor analysis result: the first factor (concerns about the supportive information), with 8 factors that have an eigenvalue above 29 items, 11,367% of the total variance; The second factor (concerns about breast cancer) is 11,084%; The third factor is 10,610% (concerns about breast cancer risk); The fourth factor (support concerns) is 10,365%; fifth factor (concerns about risk) is 10,274%; sixth factor (emotional worries) of 9,762%; the seventh factor of 7,446% (concerns about going to control); while the eighth factor (predictive concerns) explained 6,935%, it is seen that 77,843% of the total variance was explained with eight factors. The status of factor structures is shown in Figure 1 for information needs and in Figure 2 for the support needs. In addition to the study; the distribution of the items that constitute 7 and 8 factors in the original structure of the scale was evaluated. For this, when determining which factor the items have strong correlation, the rotated components matrix is used. The rotated components matrix of the scale for Information needs is given in Table 2; the rotated components matrix of the scale for Support needs is given in Table 3.

For the invariance test against time, the scale was carried out for the second time by applying the scale again to 30 women who agreed to re-apply after two weeks under similar conditions. While the reliability was 111.73 in the first measurement, it was 110.97 in the second measurement. When the relationship between the scores obtained from the first and second application

of the scale was examined (Pearson Correlation Analysis), it was determined that the reliability coefficient was $r = 0.993$, $p < 0.001$ and the scale did not change against time.

In the analysis made for the internal consistency of the ISNQ, Cronbach Alpha analysis and item total correlation were evaluated. Cronbach’s Alpha value of 29 items that make up this scale was found 0.863 in the Information section and 0.925 in the Support section. Total Scale Correlation Coefficients of the sub-dimensions of the ISNQ was determined as $r = 0.052$ and 0.873. Sub-dimension total score reliability coefficients vary from item to item. There is no item with sub-dimension total score correlation (r) value below 0.052. Half-test reliability results were calculated Guttman Split-Half 0.76; Spearman-Brown 0.76. First Half Cronbach Alpha Value 0,80; Second Half Cronbach Alpha Value 0.75; The Correlation Between the Two Halves was 0.61.

DISCUSSION

In this study, researchers evaluated the validity and

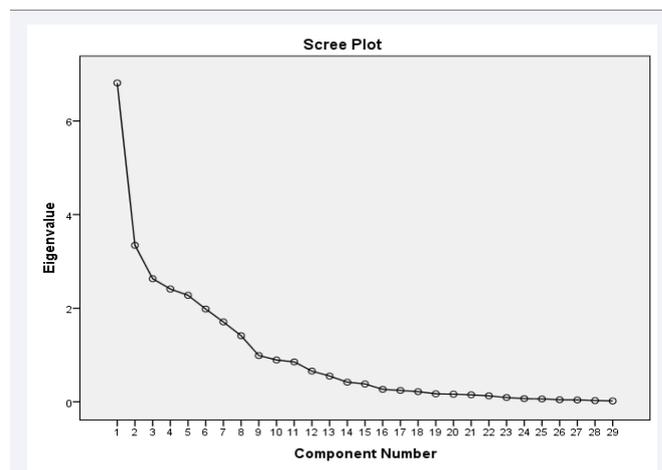


Figure 1 Slope Graph of Information Needs Scale of Women with First-Degree Relatives of Breast Cancer (n=145).

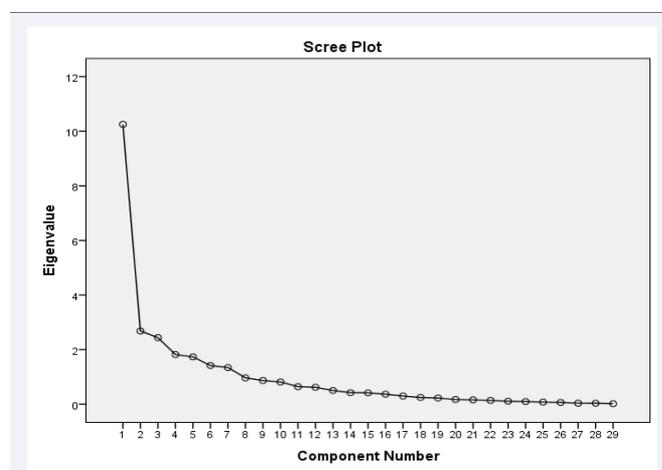


Figure 2 Slope Graph of Support Needs Scale of Women with First-Degree Relatives of Breast Cancer (n=145).

Table 2: Rotated Components Matrix of Information and Support Requirements Scale of Women with First-Degree Relatives of Breast Cancer (Information needs).

Items	Factors							
	Faktör1	Faktör2	Faktör3	Faktör4	Faktör5	Faktör6	Faktör7	Faktör8
13	,749	,333	,202	-,212	,016	,084	,083	,000
16	,743	,238	,126	,200	-,101	,068	,028	,383
21	,715	-,102	,083	-,022	,217	,099	,427	,081
22	,628	,020	,151	,583	,188	,163	-,041	,038
25	,533	-,105	-,046	,057	-,019	,038	-,101	-,095
4	-,044	,821	-,083	-,014	,047	,241	,003	-,077
2	,011	,770	,040	,445	,009	-,254	,076	-,016
1	,332	,734	,052	-,042	,103	,356	-,044	,114
18	,001	,689	,184	,298	,006	,223	-,013	,159
5	-,061	,081	,845	,012	,122	,364	-,034	-,043
29	-,108	-,001	,803	,430	-,065	-,208	-,120	,016
14	,434	-,081	,746	-,117	-,012	-,013	,055	-,012
7	,001	,047	,729	-,018	,045	,531	,196	-,021
12	,356	,126	,574	-,224	,038	-,062	,080	,099
26	,065	,401	,033	,835	-,103	,054	,000	,078
23	,077	,320	,006	,692	,407	,135	,150	,003
15	-,113	-,040	,057	,607	-,129	,463	,325	,005
27	,007	-,026	-,126	,587	,255	-,088	,183	-,012
9	-,065	,027	,012	,163	,874	,389	-,048	,031
11	,010	-,107	-,080	,073	,861	-,078	,024	,278
10	,393	,107	,298	,006	,774	,108	,006	-,111
17	-,071	,399	-,011	,100	,549	-,225	,264	,050
3	,225	,361	,070	,046	,047	,769	-,127	-,060
20	,335	,076	,133	,098	,026	,754	,316	,103
6	-,161	,296	,106	,058	,358	,600	-,012	,328
24	-,152	-,068	-,029	,142	-,064	,119	,904	-,004
8	,330	,138	,109	,181	,118	-,009	,817	,051
28	-,055	-,032	-,044	-,098	,054	-,014	-,095	,926
19	,199	,120	,049	,178	,185	,154	,206	,842

Table 3: Rotated Components Matrix of Information and Support Requirements Scale of Women with First-Degree Relatives of Breast Cancer (Support needs).

Maddeler	Bileşenler						
	Faktör 1	Faktör 2	Faktör 3	Faktör 4	Faktör 5	Faktör 6	Faktör 7
20	,666	,197	,304				
18	,661	,278	,374	,131	,345	,182	
1	,640	,286	,330	,365	,167	,126	,130
2	,603	,259			,112	,112	
23	,599	-,255	,128	,205	,135		,339
17	,566	-,121	,530	,325	,421	,154	
11	,425	-,158	,170	,136	,241	,173	,360
5	,264	,795					
7	-,115	,752		,398	,210		
3	,321	,685	,304	,183			,217
12	,185	,682	,418	,110			
13		,631	,610			,330	
6	,569	,580		-,262			
4	,425	,474	,437	-,117	,169	,235	,183
14	,368	,111	,709				
16	,142	,229	,671		,272	,238	
22	,341	,153	,554	,411	,119	,309	,281
29		,284			,836		
27	,154				,678	-,106	
25			,434		,224		
26	,603	,205			,627	,234	,167
					,607	-,247	,102

24	,164						
21		,116	,555	,195	,928		,177
8	,416	,418			,658		,132
15	,207		,356	,100	,653	,353	-,134
28					,581		
19	,404	,123	,310			,929	,135
9						,770	
10	,132	,247	,105	,342			,918
							,831

reliability of a translated Persian version of "Information and Support Needs of the Primary Relatives of Individuals with Breast Cancer (ISNQ)" in Iranian women. The scale consisted of 8 subscales with 29 items. The results revealed that this scale is suitable for a sample of Iranian women, the scale can be evaluate their information and support needs of the primary relatives of individuals with breast cancer. It has been observed that the Persian form of the ISNQ Scale, the original version and the Turkish versions show a level of compliance similar to validity and reliability studies [14,16,17].

As a result of the explanatory factor analysis in the study, the first factor (concerns about the supportive information) was 11,367% of the total variance with 8 factors whose eigenvalue was higher than one for 29 items; the second factor (concerns about breast cancer) is 11,084%; the third factor is 10,610% (concerns about breast cancer risk); the fourth factor (support concerns) is 10,365%; fifth factor (concerns about risk) is 10,274%; sixth factor (emotional worries) of 9,762%; the seventh factor of 7,446% (concerns about not going to control); eighth factor (predictive concerns) was disclosed 6,935%. It was seen that 77.843% of the total variance was explained with 8 factors. In the study, it was observed that the eight-factor structure was supported in the Persian form of the scale as in the original version of the scale [14]. The results are similar to the Turkish versions of the scale [16,17].

In literature it is stated that high-risk women with breast cancer experience emotions such as fear, anxiety, anger, uncertainty and helplessness in their family history [7-11]. While women worry about the health of their relatives with breast cancer, they also worry about their health and need information and support. It is known that there are few attempts for early diagnosis compared to women who do not have a history of breast cancer in their first degree relatives [12-16,19,22,23]. Therefore, women with first-degree relatives of breast cancer need more information and support. If the information and support needs of women are determined correctly with tools such as this adapted scale, trainings by midwives and nurses will positively affect the knowledge and beliefs about breast cancer and early diagnosis methods in women with risk [24].

The Cronbach's Alpha value of the Information and Support Requirements Scale of Women with First-Degree Relatives of Breast Cancer was 0.863 in the Information section and 0.925 in the Support section. This value was similarly developed by Chalmers et al. [14], on the original scale (0.92, 0.91, respectively); It was found to be "reliable" in the Turkish version (0.87, 0.91, respectively) and by the scale adapted by other researcher (respectively 0.81, 0.83). In the study, it was calculated that the factor information part loads of the items were between

0.533-0.926 and the factor support part loads of the items were between 0.425-0.929. The relationship between the items of the scale was found to be statistically significant ($p < 0.05$). Chalmers et al. in the original scale developed by [14], it was stated that the item total score coefficients of all n items were above 0.33, which is over 0.25. On the same scale adapted to Turkish version by this criterion was accepted above 0.20 [16].

From all the above subjects, conclusion can be drawn that ISNQ can be used as a valid and reliable scale consistent with cultural conditions in Iran to identify the information and support needs of women with first-degree relatives of breast cancer. One of the limitations in this study, the study population was limited to only one hospital in Iran. Therefore, it is recommended that similar studies should be conducted in other regions and hospitals to increase the study validity.

This scale, whose Persian validity and reliability study has been carried out, can be translated into other languages as well as Iranian women, and can be used to prepare questions about breast cancer, to make periodic health education and counseling. It is easy and fast to apply and evaluate the scale. Therefore, the use of the scale will facilitate the work of healthcare workers for trainings to be given to women with genetic risk in terms of breast cancer, and also reduce possible healthcare costs.

ETHICS APPROVAL

Ethics committee approval was received after this study from Noor-e Nejat Hospital Baghe Shomal, Tebriz.

INFORMED CONSENT

Written informed consent was obtained from womens who participated in this study. Peer-review: Externally peer-reviewed.

AUTHOR CONTRIBUTIONS

Concept – E.C.T., M.C.; Design – E.C.T., M.C.; ; Supervision – M.C., E.C.T.; Resources – M.C., E.C.T.; ; Materials – M.C., E.C.T.; ; Data Collection and/or Processing – M.C.; Analysis and/ or Interpretation – M.C., E.C.T.; Literature Search – M.C., E.C.T.; ; Writing Manuscript – E.C.T., M.C.; Critical Review – E.C.T., M.C.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

FINANCIAL DISCLOSURE

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