



Measuring family needs of people living with cancer. Portuguese validation and descriptive studies of the Family Inventory of Needs



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ABSTRACT

Purpose: The aim of this study was to validate the Portuguese version of the Family Inventory of Needs (FIN). The FIN aims to measure important family needs and their fulfilment by a healthcare team.

Methods: This cross-sectional study involved a sample of 364 family members of cancer patients, recruited from three medical institutions and through online recruitment. Three instruments were used: a socio-demographic questionnaire, the FIN and the Brief Symptom Inventory – 18 (BSI-18). Construct validity and reliability were considered regarding the FIN's psychometric properties. The method used to determine construct validity was factor structure analysis (confirmatory factor analysis), inter-factor correlations (Spearman's rank correlation) and convergent validity (Spearman's rank correlation). To assess scale reliability, the FIN's internal consistency was evaluated (Cronbach's alpha coefficient). Descriptive and frequency statistics and tests to compare means were used to assess important needs and to what extent they were met.

Results: The four-factor structure of the FIN was confirmed. Thus, the FIN has four domains: Basic Information, Information on treatment and care, Support and Patient Comfort. Convergent validity with the BSI-18 was verified. Both subscales of the FIN and each domain exceeded the minimum reliability standard of 0.70. Family members also reported important needs that were not adequately met by healthcare professionals.

Conclusions: The Portuguese version of the FIN seems to be a reliable and valid tool for identifying cancer patients' important family needs and to what extent these are met.

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1. Introduction

It is widely recognised that a life-threatening and chronic illness such as cancer affects not only the patient but also the entire family unit (Rolland, 2005).

Cancer imposes multiple demands on families. The family of a person with cancer is expected to participate in treatment decision-making care for the patient by monitoring and managing complex symptoms, handling finances, and providing emotional support to the patient. The family is called upon to function at its best during a crisis, which may induce high levels of stress for the entire family and each of its members (Veach et al., 2002).

Although the impact of cancer on families and family members is recognised, limited information is available regarding the needs of patients' relatives and the extent to which those needs are met by healthcare professionals (Fridriksdottir et al., 2006).

The development of methods (such as measurement tools) to assess and identify unmet family needs is a priority for research in this area because these methods will enable healthcare professionals to better address family members' needs (Hudson et al., 2011).

Until now, there has been no validated assessment tool for family needs in Portugal. The Family Inventory of Needs (FIN) measures the needs of family members of people with cancer and assesses to what extent those needs are met (Kristjanson et al., 1995). The FIN can also help healthcare professionals to more accurately identify a wide range of needs and thus ensure more adequate family support (Buzgová and Kozaková, 2016).

Given the FIN's potential as a useful tool in the oncology context, the aim of this study was to evaluate the psychometric properties of

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the Portuguese version of the FIN – with particular attention to construct validity and reliability – and to ultimately provide a Portuguese measurement tool to assess the needs of families of people with cancer. As a second objective, this study aimed to explore important family needs and to determine to what extent they are met by healthcare professionals.

2. Methods

2.1. Study design and participants

A cross-sectional survey design was used. The study was conducted in a general hospital, an oncology hospital, two hospice palliative care units and through a web-based survey from January 2014 to March 2016. The sample consisted of 364 family members of people with cancer. The inclusion criteria required the participants to be (1) a relative of a cancer patient, (2) 18 years of age or older, (3) a native Portuguese language speaker, and (4) willing to provide consent to participate in the study.

2.2. Collection of data and measures

Three questionnaires were used for the data collection: a socio-demographic and complementary data questionnaire, the FIN and the Brief Symptom Inventory – 18 (BSI-18).

Socio-demographic and complementary data questionnaire.

The socio-demographic and complementary data questionnaire was used to collect general information and data related to (1) demographics, (2) family, (3) patient care, (4) social support, (5) psychological/spiritual support and (6) patient medical history.

FIN. The FIN, originally developed by Kristjanson et al. (1995), is a questionnaire designed to measure the importance of the care needs of families of people with advanced cancer and the extent to which these needs are met. It has 20 items rated according to two subscales: FIN-Importance, which measures the importance of each need, and FIN-Fulfilment, which measures the extent to which needs are met by healthcare professionals.

In the original version of the FIN (Kristjanson et al., 1995), FIN-Importance was rated from 0 (not important) to 10 (very important), and FIN-Fulfilment was rated using a dichotomous scale (0, not met; 1, met). During the scale-development study, a one-dimensional structure was ascertained, and a Cronbach's alpha of 0.83 was reported for FIN-Importance. Additionally, further refinements were suggested, such as restructuring the response options in both subscales and further testing of the FIN's structural validity using structural equation modelling (Kristjanson et al., 1995).

In the present study, we used the modified/Icelandic version of the FIN (Fridriksdottir et al., 2006), which was developed based on the refinements suggested in the first validation study (Kristjanson et al., 1995). This modified version maintained the original 20 items and the two subscales, but substantial changes were made to the response rate. The modified version of the FIN reported Cronbach's alphas of 0.92 and 0.96 for the FIN-Importance and FIN-Fulfilment subscales, respectively (Fridriksdottir et al., 2006).

Recently, a study conducted by Buzgová and Kozaková (2016) failed to confirm that the FIN-Importance had a one-dimensional structure. Instead, four domains were found: Basic Information (4 items), Information on Treatment and Care (7 items), Support (7 items) and Patient Comfort (2 items). However, to the best of our knowledge, no other studies have confirmed the FIN's four-factor structure.

The FIN was translated from English to Portuguese following the World Health Organization's recommendations for translation and adaptation of instruments (WHO, 2013), as detailed in the first FIN's

Portuguese exploratory psychometric studies (Areia et al., 2016). The final translation (back-translation) was sent to the author of the original scale, who approved it and endorsed its application with family members of cancer patients regardless of the phase of illness.

According to the modified/Icelandic version of the FIN (Fridriksdottir et al., 2006), the following rating scale was used: for FIN-Importance, respondents should indicate how important each need is on a scale that ranges from 1, "not important", to 5 "extremely important". If the respondent answers 2, "somewhat important", or above in FIN-Importance, then in FIN-Fulfilment, the respondent should indicate whether that need was met (1), partly met (2) or unmet (3). The FIN-Importance total score corresponds to the mean importance of the 20 needs. Similarly, the FIN-Fulfilment total score corresponds to the average score of the 20 items.

BSI-18. The BSI-18 is a short version of the Brief Symptom Inventory. This is a distress screening tool that includes 18 items across three dimensions – Somatization, Anxiety and Depression – and one Global Severity Index (GSI), which corresponds to an individual's global distress. Respondents indicate to what extent they are troubled by each complaint on a five-point Likert scale, in which 0 corresponds to "not at all" and 4 corresponds to "very much". Both the original (Derogatis, 2001) and the Portuguese version of the BSI-18 show good psychometric properties (Canavarro et al., 2017). Although Portuguese validation studies for the BSI-18 were conducted for community and clinical populations (Canavarro et al., 2017), to the best of our knowledge, no other studies have been conducted with this tool with family members of people with cancer in Portugal. For the present study, the following Cronbach's alphas were obtained: 'somatization', $\alpha = 0.81$; 'depression', $\alpha = 0.85$; 'anxiety', $\alpha = 0.86$; GSI, $\alpha = 0.92$.

2.3. Ethics

The study was approved by Fundação para a Ciência e Tecnologia (Foundation for Science and Technology). Additionally, ethical approval was obtained from the Ethics Committee of the involved medical institutions.

Family members of people with cancer were invited to participate in the study and were provided with additional information about the research. Participation was voluntary. Before completing the questionnaire, the participants gave their consent by signing a consent form (in person) or choosing the option related to participation acceptance (online). Data confidentiality was maintained during the research.

2.4. Statistical analysis

SPSS version 22 statistical software and AMOS version 22 were used to perform the data analyses.

Descriptive statistics were calculated to describe the sample.

To evaluate the FIN's evidence of construct validity, structural validity, inter-factor correlations and convergent validity were assessed (Ribeiro, 1999). To explore the evidence of structural validity, confirmatory factor analyses (CFA) were performed to analyse the model structure of the FIN through structural equation modelling. The original one-factor structure (Kristjanson et al., 1995) and four-factor structure (Buzgová and Kozaková, 2016) were compared to determine which showed better adjustment to the data. Critical assumptions for the CFA analysis were considered, specifically the presence of multivariate outliers and the multivariate normality of the data. To determine the model's fit, the Pearson chi-square (χ^2) statistic with degrees of freedom (df), the goodness-of-fit index (GFI), the comparative fit index (CFI), and the root mean

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