European Journal of Oncology Nursing 20 (2016) 49–57

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Information needs of cancer patients: Validation of the Greek Cassileth's Information Styles Questionnaire

G. Despoina Alamanou [a, *], A. Sotirios Balokas [a], V. Nikolaos Fotos [b], Elisabeth Patiraki [b], Hero Brokalaki [b]

[a] *2nd Internal Medicine Department, V.A. Hospital of Athens, Greece*
[b] *School of Health Sciences, National and Kapodistrian University of Athens, Greece*

ARTICLE INFO

Article history:
Received 26 August 2015
Received in revised form
7 November 2015
Accepted 13 November 2015

Keywords:
Cancer
Information needs
Oncology
Patient preferences
Questionnaire
Validation

ABSTRACT

Purpose: The aim of this study was to validate the translated in Greek Cassileth's Information Styles Questionnaire (ISQ).
Methods: It was a cross-sectional study. The sample consisted of one hundred and nine adult patients diagnosed with cancer, attending the oncology outpatient department (outpatients) or being hospitalized (inpatients), from January 2013 to September 2013, in one general hospital in Athens. Two instruments were used: The Control Preference Scale (CPS), an assessment tool to measure decision-making preferences of cancer patients and ISQ to assess the information needs of patients. Exploratory factor analysis (EFA) was carried out to evaluate construct validity of the ISQ. The internal consistency of subscales was analyzed with Cronbach's alpha and the association of demographics and clinical variables with the ISQ was explored using linear regression analysis.
Results: Sixty one (56%) patients were males. The mean age was 65.5 (SD = 11.9) years. Two dimensions of the ISQ were revealed. Cronbach's alpha was 0.92 for “Disease and treatment” dimension (12 of 17 items of the questionnaire) and 0.89 for “Psychological” dimension (5 of 17 items of the questionnaire). Statistical analysis showed that the patients' preferred decision making roles were associated with the ISQ dimensions. Also, age, sex, diagnosis, educational level and the existence of metastasis were associated with the score of “Disease and treatment” dimension. All the scales of ISQ, exceeded the minimum reliability standard of 0.70.
Conclusions: The results showed that the Greek ISQ is a reliable and valid tool for identifying the information needs of cancer patients.

1. Introduction

Announcing the diagnosis of cancer and discussing prognosis and treatment has become a very difficult common practice for health care professionals. The information patients receive about cancer and various aspects of their illness can be beneficial to them and create a positive impact on attitudes and feelings (Sainio and Eriksson, 2003). It can also reduce anxiety and mood disturbances and allow them to prepare for their future (Epstein, 2007; Iconomou et al., 2002).

Although cancer patients wish to be correctly informed of their condition and the choices regarding therapy, there are considerably significant differences on the amount and type of information they individually need. Cancer patients complain that clinicians do not always provide them with adequate information (Neumann et al., 2011), while other state that they do not fully understand the information provided (Arora, 2003). Also, there have been indications that the amount of information cancer patients need is influenced by the stage of their illness (Rutten et al., 2005), as well as socio-demographic factors such as gender (Manning and Quigley, 2002), education status and ethnicity (Im et al., 2008). For this reason, the assessment of cancer patients' information needs has become an important issue in clinical research and a variety of tools measuring the information needs have been developed.

Literature however usually focuses on subgroups of cancer patients (e.g. breast and prostate), during treatment (Rutten et al., 2005), often excluding certain patients such as those with less frequent types of cancer or those who have completed treatment (Mistry et al., 2010).

The Information Styles Questionnaire (ISQ) is a specific

---

* Corresponding author. 21 Magnisias Str., Nea Smirni, P.O. 17122, Athens, Greece.
E-mail address: despina_alamanou@hotmail.com (G.D. Alamanou).

http://dx.doi.org/10.1016/j.ejon.2015.11.002
1462-3889/

instrument designed for measuring information needs of cancer patients in general. It was early developed by Cassileth et al. (1980) and has demonstrated appropriate validity and reliability during the testing process (Ankem, 2006). Yet, the ISQ has not been validated in different populations in recently published studies. The ISQ was translated in Greek by Greek researchers (Almyroudi et al., 2011), however it has not been validated in Greek population.

Consequently, the aim of this study was to evaluate the construct validity and reliability of the Greek translation of ISQ in assessing the information needs of Greek cancer patients and to explore the association of their information needs with their decision-making preferences.

2. Methods

2.1. Study design and participants

It was a cross-sectional study, conducted in a large general public hospital of Athens. The sample consisted of 113 randomly selected patients diagnosed with cancer, attending the oncology outpatient department (outpatients) or being hospitalized (inpatients), from January 2013 to September 2013. Because of the variety of cancer diagnosis and the number of patients, five subgroups were created according to the type of cancer they were diagnosed with (gastrointestinal, breast, lung, hematologic and solid organs cancer). The gastrointestinal subgroup included patients diagnosed with gastric, colon and rectum cancer. Solid organ subgroup included patients diagnosed with prostate, ovarian, uterus, pancreas, liver bladder and gallbladder cancer.

The inclusion criteria used were (1) histologically documented diagnosis of cancer, (2) 18 or more years of age, (3) verbal communication ability and fluency in spoken and written Greek language and (4) consent to participate in the study. The exclusion criteria used were (1) alcohol and/or drug abuse, (2) dementia, (3) brain metastasis, (4) history of psychotic illness, (5) existence of other life threatening disease and (6) ignorance of diagnosis. The first five exclusion criteria were used because their existence could affect patients' consciousness and perception during the interview but also their answers regarding their real information needs and preferences on their role in treatment decisions.

Out of 113 patients, 109 agreed to participate in the study (response rate = 96.4%).

2.2. Collection of data and measures

Demographic data, diagnosis and clinical characteristics were obtained by patients' medical records. The ISQ and the Control Preference Scale (CPS) instrument were used in this study for the assessment of patients' information needs and consequently their decision-making preferences.

The ISQ, developed by Cassileth et al. (1980), is a questionnaire for the assessment of general and specific cancer patients' needs of information regarding their disease. It includes twenty-nine questions and consists of three parts. The first part includes two questions regarding diagnosis and the duration of the disease and one question measuring on a five-point Likert scale the amount of information details that patients desire regarding their disease. The second part includes twenty-five questions and measures, on a three-point Likert scale, the desire for specific types of information, concerning the disease, treatment choices but also psychological needs. The last part includes a statement (one question) that best describes patients' general attitude towards information regarding their illness. The ISQ has been used in published UK and European studies (Jenkins et al., 2001; Meredith et al., 1996). It was translated in Greek by Greek researchers, using the back-translation method, for the aims of a study on Greek breast cancer patients, published in 2011 (Almyroudi et al., 2011). However, the ISQ has not been validated in the Greek population.

The CPS, created by Degner et al. (1997), is an assessment tool which measures the decision-making preferences of cancer patients (Singh et al., 2010). It is a clinically relevant, easy-to-administer, reliable and valid measure of roles (preferred and actual) in decision making on health care issues among cancer patients (Tariman et al., 2010). It consists of five cards (A to E), each one describing a potential role of the patient in relation to the physician whenever a decision about treatment is made. Every card has a statement that describes the role and is illustrated by a cartoon in order to assist patients of lower literacy level to understand the meaning. The roles range from (A) the patient being the primary decision maker, (C) shared decision making, to (E) patient being completely passive to physician's decisions. In this study, the cards were presented to each patient who was asked to choose the one that was closer to his/her preferences in a hypothetical scenario of a consultation with their oncologist, when a decision about treatment must be made. In this way, patients felt free to choose the role they really prefer to play in decision making, without worrying about their physician's opinion. The CPS was translated from English to Greek by Almyroudi et al. (2011).

In order to test the discriminant ability of the ISQ dimensions, we tested possible differences according to CPS results. Participants were interviewed by the same interviewer.

2.3. Ethics

Ethical approval was obtained from the research team that conducted the Greek translations for the use of the above mentioned questionnaires (Almyroudi et al., 2011). A written authorization was obtained from the Ethics Committee and the Scientific Council of the hospital that was chosen for the study. Patients were invited to participate in the study and were then provided with additional information about the research. Prior to the interview, patients who were recruited read and signed an informed consent form. The research was conducted with respect to the patients and the confidentiality of the collected data in accordance with the Helsinki Declaration of 1975, as revised in 2000.

2.4. Statistical analysis

Continuous variables are presented with mean and standard deviation (SD) or with median and interquartile range (IQR). Qualitative variables are presented with absolute and relative frequencies. Exploratory factor analysis (EFA) was carried out to evaluate construct validity, disclose underlying structures and reduce the number of variables of the ISQ's questionnaire. Principal component analysis (PCA) was chosen as extraction method using Oblimin rotation. The cut-off point for factor loadings was 0.40 and for eigenvalues 1.00. The internal consistency of subscales was analyzed with Cronbach's α. Subscales with reliabilities equal to or greater than 0.70 were considering acceptable. Analysis of variance (ANOVA) was computed for the comparison of mean values. Bonferroni correction was used in order to control for type I error. In order to explore the association of demographics and clinical variables with the scores in the dimensions of ISQ's questionnaire, as resulted from factor analysis, univariate and multiple linear regression analysis in a stepwise method (p for removal was set at 0.1 and p for entry was set at 0.05) was used. The regression equation included terms for patients' demographics and clinical characteristics. Regression coefficients (β) with standard errors (SE) were computed from the results of the linear regression analyses.