



The Leuven Questionnaire on Patient Knowledge of Chemotherapy (L-PaKC): Instrument development and psychometric evaluation



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A B S T R A C T

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Purpose: Evidence suggests that patients who gain knowledge perform better self-care, cope better and are more satisfied. Today, up-to-date and valid instruments for evaluating patient knowledge on chemotherapy are unavailable. Hence, our aim was to develop a valid instrument to assess patients' knowledge on chemotherapy.

Method: We performed a literature review to develop a topic list for the construct. Using a triple Delphi procedure, an expert panel of nine oncologists and oncology nurses evaluated the face and content validity of the topic list and the generated items. A preliminary psychometric evaluation of 144 patients allowed to identify and remediate items having limited applicability and item validity. A convenience sample of 440 patients was used to evaluate item statistics (item difficulty), reliability (Cronbach alpha) and construct validity (exploratory factor analysis) of the final instrument.

Results: We developed a 20-item instrument reflecting 14 relevant themes of patient knowledge on chemotherapy in 13 questions. Twelve items cover general chemotherapy aspects, eight items cover treatment-specific knowledge. Three questions are facultative and address oral chemotherapy. Content validity was excellent (CVI = 0.78–1.00). Item difficulty ranged from 0.25 to 0.95. Internal consistency was acceptable (Cronbach's alpha = 0.67). Exploratory factor analysis defined four underlying factors: general aspects of chemotherapy treatment, negative treatment-related events, information resources and intake of oral chemotherapy.

Conclusions: The Leuven Questionnaire on Patient Knowledge of Chemotherapy (L-PaKC) demonstrated good content validity and psychometric properties, permitting application in both research and practice for evaluating patient knowledge on chemotherapy.

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Introduction

The start of chemotherapy treatment is a distressing event at which most cancer patients report high needs for information (Hack et al., 2005; Rutten et al., 2005). Health professionals provide information to prepare patients for their treatment, increase their adherence to therapy and abilities to cope with the illness, and promote recovery (van der Meulen et al., 2008). Accurate knowledge has indeed established a broad range of outcomes. Educational interventions for patients starting chemotherapy treatment

have shown to increase patient satisfaction and adherence to advice given by professionals, to enhance self-care and coping and to decrease treatment-related symptom burden (Chelf et al., 2001; Devine and Westlake, 1995; Devine, 2003; Hack et al., 2005). At the same time, achieving adequate patient knowledge seems critical. Jansen et al.'s research on recall of chemotherapy information pointed out that, within 10 days of their initial consultation with an oncologist, patients with cancer recalled only 50% of the information given (Jansen et al., 2008a). Immediately after their pre-chemotherapy consultation with a nurse, patients older than 65 recalled less than 25% of the information provided to them (Jansen et al., 2008b).

With the importance of patient knowledge as well as the challenges of patient education becoming clear, the need for

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instruments that accurately assess knowledge of patients receiving chemotherapy has become imperative. Unfortunately, up-to-date, valid and applicable instruments are lacking. The Chemotherapy Knowledge Questionnaire (Dodd and Mood, 1981; Dodd, 1982) is a 20-item questionnaire that was developed three decades ago. It covers the following themes: names of drugs, possible side effects of the drugs and the purpose for receiving chemotherapy. Benefits and risks are evaluated by rating the clarity with which – in the perception of the patient – these topics were explained instead of evaluating whether patients actually understand benefits and risks correctly. To the best of our knowledge, no update of this 30-year-old instrument exists, and no data on the psychometric quality of the original instrument are available. However, Dodd and Mood (1981) do report that 10 oncologists were involved in judging the content validity of the questionnaire. Recall, i.e. the remembering and reproducing of information, is another way to evaluate the performance of patient information and education. A systematic review of interventions aimed at improving recall of medical information in patients with cancer indicates that many different methods and instruments are used to measure recall (van der Meulen et al., 2008). Recall instruments in the included studies were often designed to evaluate the specific educational intervention applied in the study. Therefore, these instruments are based on the local approach and content of educational interventions (e.g., pre-chemotherapy consultation, written information) instead of a valid set of relevant topics regarding chemotherapy. This may hamper the use of the instruments in other settings or interventions. Also, measuring recall of information often consisted of comparing with the actual information given through use of audiotapes, videotapes, or observation of educational consultations. This approach weighs heavily on the analyses and the practicality of recall evaluations and may explain the rather small study samples (generally around 30 patients) of the 10 studies included in the review (van der Meulen et al., 2008).

Given the importance of patient knowledge in improving adherence, satisfaction and coping on the one hand and the lack of instruments to measure knowledge of patients treated with chemotherapy on the other hand, the aim of this study was to develop a valid and reliable instrument to assess patient knowledge on chemotherapy. The following research questions were addressed through this instrument development study:

- (1) What are the relevant themes and topics regarding patients' knowledge of chemotherapy?
- (2) What is the psychometric quality (e.g., face validity, content validity, construct validity, internal consistency) of the Leuven Questionnaire on Patients' Knowledge of Chemotherapy (L-PaKC)? What is the underlying structure of the L-PaKC?

Methods and results

The development of the instrument was conducted in three phases, as outlined by Mishel (1989):

1. Defining the constructs of the instrument
2. Instrument development
3. Psychometric evaluation

The original plan of the instrument development study consisted of a review of the literature, two Delphi rounds and an evaluation of psychometric properties. After completing this process, it was clear that the instrument needed further refinement. Hence, the study plan was extended to include a third Delphi round and a final psychometric evaluation.

Methods and results are integrated and reported per phase in order to provide clear and step-by-step overview of this instrument development and evaluation study. Fig. 1 summarizes the instrument development process.

Defining the construct of the instrument

Topic generation

The aim of this phase was to identify themes and topics that cover the most relevant themes of patient knowledge on chemotherapy. Because chemotherapy is heterogeneous, some themes may be relevant for some therapy protocols and not for others. However, for the instrument to be relevant, logically it should contain not only broad and generic aspects but also more specific therapy-related topics. Pubmed and Cinahl were searched for relevant publications published between 1990 and 2009 using combinations of the following keywords: chemotherapy, cancer treatment, oncology, adverse effects, information, patient education and information needs. Available information leaflets and information packages were screened for additional topics. Our review revealed 16 themes and 75 topics (see Fig. 1, left panel).

Content validity evaluation of the topics

Generated themes and topics were reviewed by an expert panel using a Delphi procedure in order to assess content validity (McKenna, 1994). Nine experts participated in this procedure. The panel consisted of medical doctors ($n = 3$) and expert nurses ($n = 6$) from Flanders ($n = 5$) and the Netherlands ($n = 4$). All the experts had training and clinical experience in oncology and chemotherapy. In the construction of the expert panel, we took into account the heterogeneity of chemotherapy by covering most branches of oncology (hemato-oncology, respiratory, gynecological, digestive, and general oncology).

The expert panel was asked to evaluate whether retrieved themes and topics were relevant for measuring patient knowledge of chemotherapy using a four-point Likert scale (1 = not relevant; 2 = a bit relevant; 3 = relevant; 4 = highly relevant). The item-level content-validity index (I-CVI) was used to evaluate the expert's agreement on the relevance of the themes and topics (Lynn, 1986). The I-CVI is the ratio of the number of experts agreeing on relevance of the theme (i.e. rating the theme as relevant or very relevant) to the total number of experts. A criterion proportion is required to establish acceptable content validity. If the proportion of experts in agreement was not met, the theme or topic was considered to be insufficiently relevant to the instrument's construct and was removed. With nine experts involved, an I-CVI of 0.78 was the cutoff for either removing or retaining a topic (Lynn, 1986). Two themes and 14 topics were removed due to too low I-CVI.

Besides evaluation of the topic list, the experts were given the opportunity to propose additional themes or topics. Evaluating the relevance of these topics was part of the second Delphi round. The experts identified 19 new topics, of which 6 (24%) were removed after the expert panel's evaluation.

Instrument development

Item generation

The development of the instrument involved the translation of the selected themes and topics into questions. How to formulate questions about certain topics was considered in light of both relevance of content and practical usability of the instrument. For

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