The Leuven questionnaire for Patient Self-care during Chemotherapy (L-PaSC): Instrument development and psychometric evaluation

Annemarie Coolbrandt [a,*], Koen Van den Heede [b], Kathleen Clemens [c], Koen Milisen [c], Annouschka Laenen [d], Hans Wildiers [a], Chris Verslype [e]

[a] Department of Oncology, University Hospitals Leuven, Herestraat 49, 3000 Leuven, Belgium
[b] Nursing Competence Center, University Hospitals Leuven, Herestraat 49, 3000 Leuven, Belgium
[c] Center for Health Services and Nursing Research, Katholieke Universiteit Leuven, Kapucijnenvoer 35/4, 3000 Leuven, Belgium
[d] Interuniversity Centre for Biostatistics and Statistical Bioinformatics, Katholieke universiteit Leuven, Kapucijnenvoer 35/2, Bus 700, 3000 Leuven, Belgium
[e] Department of Hepatology, University Hospitals Leuven, Herestraat 49, 3000 Leuven, Belgium

A B S T R A C T

Purpose: Since chemotherapy has largely become an outpatient treatment, adequate self-management is of great importance. Available instruments focus exclusively on dealing with side effects. However, self-care during chemotherapy not only concerns symptom self-management. The aim of this study was to develop a valid instrument to assess patient self-care during chemotherapy.

Method: First, we developed a topic list for our construct by performing a theory and literature review. Second, an expert panel of nine oncologists and oncology nurses evaluated content validity of the developing construct and its items using a triple Delphi procedure. A preliminary psychometric evaluation in 144 patients allowed identification and correction of items with poor psychometric properties. A convenience sample of 448 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 22-item instrument with 7 themes expressing the most relevant aspects of patient self-care during chemotherapy. Seven items cover symptom self-management, while 15 items reflect other aspects of self-care during chemotherapy. Content validity was excellent (CVI = 0.78–1.00). Item difficulty index of the questions ranged from 0.17 to 0.89. Internal consistency is acceptable (Cronbach alpha = 0.76). Exploratory factor analysis defines two underlying factors: adhering to treatment recommendations and managing treatment-related negative events on the one hand, and relieving symptoms on the other hand.

Conclusions: The L-PaSC demonstrated good content validity and psychometric properties. The L-PaSC can be applied in research and clinical practice for evaluating patient self-care during chemotherapy.

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Introduction

Since the vast majority of chemotherapy patients are treated as outpatients or during short hospital stays, adequate self-management is critical. Chemotherapy patients need to be able to act adequately upon health issues (adverse events, complications arising from treatment effects, induction of co morbidity, etc) without professional supervision. At the same time, they must cope with their cancer diagnosis. Because of the outpatient organization of chemotherapy care, healthcare professionals have only limited time and opportunities to enhance patients' self-management through education.

In 1983, Dodd noted that chemotherapy patients perform very few self-care actions despite the many chemotherapy-related symptoms they experience (Dodd, 1983). She also found that patients wait to initiate self-care behaviors until symptoms become severe or persistent. Persistence and interference were recently confirmed to be predictors of enactment of symptom management strategies. Also, patients with more symptoms seem to enact fewer symptom management strategies (Given et al., 2010). Suggested reasons for poor self-care behavior are: patients' belief that side effects just have to be endured, patients' reluctance to complain, professionals' reluctance to tell patients what actions could alleviate side effects, and patients' poor recall of self-care information provided to them (Dodd, 1983). Research on pain and fatigue management in cancer patients has found that patients' reluctance to report symptoms and patients' misconceptions about their

symptoms and their treatment continue to be important barriers in adequate symptom management (Passik et al., 2002; Sun et al., 2008).

Promising in Dodd's early work was the finding that self-care instruction can improve patients' self-care behaviors. This empirical finding supports Orem's theory that self-care behaviors can be learned (Orem, 1991), and has encouraged the development of many educational interventions or programs aimed at improving self-management in chemotherapy patients and ultimately at improving quality of life during chemotherapy (Aranda et al., 2012; Craddock et al., 1999; Dodd and Miaskowski, 2000; Godino et al., 2006; Yates et al., 2005). At the same time, only few descriptive or experimental studies evaluating the performance of these interventions measure self-care as an endpoint. This may prevent us from gaining a good understanding of why certain interventions (or some parts of them) are effective in relieving symptom burden, while others are not, and may hamper practice improvement.

Searching the literature revealed several, and in many ways similar, instruments that evaluate self-management in chemotherapy patients: for example, the Self-Care Behavior Questionnaire (Dodd, 1982); the Self-Care Diary (Nail et al., 1991); the Dutch Self-Care Diary (Verstraete-Van den Bruaene, 1998); and the Dutch Self-Care Questionnaire for Chemotherapy Burden (Tanghe et al., 1998). The Self-Care Behavior Questionnaire allows patients to report on various aspects of 44 different side effects: (1) if and how severe each of these side effects were experienced, (2) what actions they took to deal with the side effects, (3) how effective each self-care action was in relieving symptom burden, and (4) the source of information for each self-care behavior tried (Dodd, 1982, 1983). Feedback from two groups of experts, including oncologists and oncology nurses, contributed to the content validity of the instrument. A scoring system allowed researchers to compute a self-care value or score for each subject, rewarding patients who performed and continued actions that were perceived effective or those who discontinued ineffective actions but initiated another self-care behavior (Dodd, 1982). Reliability of the Self-Care Behavior Questionnaire was established as a test-retest reliability in a small control group of 12 patients. The low test-retest reliability of $r = 0.21$ was said to reflect, in part, a slight increase in self-care behaviors over time (Dodd, 1983).

The Self-Care Diary (SCD) has much in common with Dodd's questionnaire but is limited to 17 side effects and does not ask information about patients' information sources (Nail et al., 1991). Although a sample of 49 patients established an acceptable test-retest reliability ($r = 0.80$), it was apparently measured from only side-effect severity data. Literature concerning patients' experiences with chemotherapy inspired the content of the diary. Moreover, two chemotherapy patients and three oncology clinical nurse specialists assessed SCD content and content validity (Nail et al., 1991).

The first Dutch Self-Care Diary was based on the Self-Care Behavior Questionnaire and the SCD. It uses a very open approach, querying patients about the five-most severe symptoms experienced (Verstraete-Van den Bruaene, 1998). Next, patients are asked to report self-care activities that they had performed in the past. Again, patients are asked to rate the perceived effectiveness of these activities. Content validity was established by an expert panel of two cancer nursing researchers, two cancer nurses, and one oncologist, who assessed the diary. Data on reliability and validity are not available. However, critical evaluation of patients' diary usage revealed that patients were reluctant to fill in the diary, as it involved too much writing. Also, they had difficulties reporting performed activities. Thus, the authors designed a diary with closed-ended questions. This resulted in the Dutch Self-care

Questionnaire for Chemotherapy Burden (Tanghe et al., 1998). In this questionnaire, patients are asked to rate which of 31 symptoms they experienced. As in the earlier version, for each experienced symptom, patients are asked to select the self-care activities they performed to relieve that symptom. As in the self-care diaries of Dodd and Nail (Dodd, 1982, 1983; Nail et al., 1991), the authors provide a list of defined self-care activities relevant to each symptom. Again, perceived effectiveness of these behaviors is rated on a five-point Likert scale. Content validity of this structured questionnaire was established by 16 oncology nurses from the Flemish and Dutch Oncology Nursing Societies. Evaluation among patients showed that the instrument was sufficiently usable. Construct validity was supported by a positive relationship between symptom burden and the number of performed self-care activities (Tanghe et al., 1998).

These instruments are not only outdated, but all of them attend exclusively to self-care related to chemotherapy-related side effects. However, self-care during chemotherapy is not limited to dealing with side effects alone. Therefore, the aim of this study was to develop a valid and reliable instrument for assessing self-management during chemotherapy. The following research questions were addressed during this instrument development study:

(1) What are the relevant themes and topics regarding self-management of chemotherapy patients?
(2) What is the psychometric quality (face validity, content validity, construct validity, internal consistency) of the Leuven Questionnaire for Patients' Self-care during Chemotherapy (L-PaSC)? What is the underlying structure of the L-PaSC?

Methods and results

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

1. Definition of 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. Thus, 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 and validate themes and topics that cover the most relevant aspects of self-care during chemotherapy. Pubmed and Cinahl were searched for relevant articles published between 1990 and 2009. We used the following combinations of keywords: chemotherapy, cancer treatment, oncology, adverse effects, information, patient education, self-care, and behavior. The literature review was completed with a study of relevant nursing theories, mainly Orem's self-care theory (Orem, 1991), and by screening available information leaflets and information packages. Our review of the literature and theory revealed 8 major themes (see Fig. 1, left panel), 41 topics, and 32 subtopics.

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