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An instrument to collect data on frequency and intensity of symptoms in older palliative cancer patients: A development and validation study

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ABSTRACT

Purpose: To develop and validate an instrument to collect data on symptoms (frequency/intensity) in older palliative cancer patients.
Methods: A four-phase instrument development and validation study was performed. A preliminary version of the instrument was developed through a literature review. Face- and content validity were assessed in a Delphi-procedure with eleven experts. Cognitive interviewing with 24 older cancer patients was performed to enhance content validity of the instrument. Test–retest was performed to assess the stability.
Results: An 40-item instrument was developed. The Assessment Symptoms Palliative Elderly (ASPE) collects data on frequency and intensity of 24 physical, 10 psychological, 3 functional, 1 spiritual and 2 social symptoms. Content validity was excellent (I-CVI 81.8%–100.0% and S-CVI 92.9%). Cognitive interviewing allowed to improve the content validity. Test–retest showed substantial to almost perfect agreement for 87.5% of the items. No item had poor or fair agreement.
Conclusion: This study resulted in the development of the ASPE which reflects good properties for face- and content validity and reliability. Cognitive interviewing has a valuable contribution in the validation process. The instrument can be used to gain insight in symptoms in older palliative cancer patients.

1. Background

In approximately 60% of the older patients with cancer, the focus on 'cure' will eventually shift to palliative 'care' (Ferlay et al., 2010). The World Health Organisation (2002) define palliative care as "*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*" This definition points out that symptom assessment in different domains and appropriate interventions to control these symptoms are essential parts of palliative care (World Health Organisation, 2002).

Literature revealed that adults in a palliative stage of cancer suffer from a variety of symptoms and that the prevalence of some symptoms is high (Gilbertson-White et al., 2011; Teunissen et al., 2007). Moreover, as the number of symptoms and their severity increases, the quality of life of patients decreases (Gilbertson-White et al., 2011; Teunissen et al., 2007). Research demonstrated that cancer patients experience different symptoms compared to non-cancer patients (Krouse et al., 2007). Literature also indicates that older patients experience different symptoms than younger patients (Teunissen et al., 2006; Cataldo et al., 2013; Walsh et al., 2000). This is mainly due to the complex interplay of symptoms

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related to the ageing process and the expression of health problems through specific symptoms such as incontinence, disorientation, and the presence of airway mucus (Depp and Jeste, 2006). The physiological changes related to the ageing process in older people make them more vulnerable for comorbidities, polypharmacy, psychosocial problems, and functional and cognitive decline (Depp and Jeste, 2006). As a result, holistic care which is not solely focused on the physical aspects of care is essential. Symptom assessment should be performed comprehensively and allow identification of symptoms on multiple domains (World Health Organisation, 2002). A valid and reliable instrument should be used for symptoms assessment (Strasser, 2006). The use of validated instruments in research is required to avoid measurement bias (Polit and Beck, 2008).

Over the past years, many instruments have been developed to assess symptoms in palliative, oncologic and older populations. Nevertheless, the current instruments merely cover a limited number of symptoms and domains (Katz et al., 1970; Nekolaichuk et al., 2008; Yesavage et al., 1982). In 2014, a systematic review was performed on the prevalence of symptoms in older palliative cancer patients (Van Lancker et al., 2014). The authors reported that the available data were merely based on small sample sizes, seldom being collected using validated instruments (Van Lancker et al., 2014). The findings indicate the need for a validated instrument to collect data on symptoms in older palliative cancer patient. The authors judge one comprehensive assessment which is population- and disease specific and includes symptoms on multiple domains as the most suitable in terms of feasibility (minimal burden for patients) and provision of valid and reliable results.

2. Aim

The aim of this study was to develop and validate (face- and content validity and test–retest reliability) an instrument to collect data on frequency and intensity of symptoms in the older palliative cancer patient.

3. Methods

3.1. Design

A five phase instrument development and validation study was performed:

(1) Instrument development
(2) Delphi-procedure to evaluate the face- and content validity of the instrument
(3) Cognitive interviewing to evaluate the content validity of the instrument
(4) Test–retest to evaluate the reliability of the instrument
(5) Evaluation of the applicability and acceptability of the instrument

3.2. Procedure

3.2.1. Phase I instrument development

The Assessment Symptom Palliative Elderly (ASPE) instrument was developed based on a review of the literature on available symptom assessment instruments in the target population. A literature search revealed that no validated instrument existed to assess and collect data on symptoms in the physical, psychological, functional, social and/or spiritual domains in older palliative cancer patients. Consequently, a broader systematic search was performed to identify instruments for the assessment of symptoms in the different domains, developed and validated in palliative and/or cancer patients of all ages. Following keywords were used: symptoms AND (instrument OR scale OR tool OR questionnaire) AND (cancer OR palliative). The literature search was performed in August 2011.

A matrix was developed to make an inventory of all the symptoms being reported in the available symptom assessment instrument.

3.2.2. Phase II Delphi-procedure

Face- and content validity of the initial instrument were assessed by a panel of experts. The experts were healthcare professionals with clinical and/or research expertise in oncology, palliative care, geriatric care and/or nursing. Thirteen experts were invited to participate in an anonymous Delphi procedure. The experts independently evaluated relevance and clarity of all items, domains, and the answer categories (Polit and Beck, 2008). A 4-point scale (1 = *not relevant*; 2 = *somewhat relevant*; 3 = *quite relevant*; 4 = *very relevant*) and a dichotomous scale (1 = *clear*; 2 = *not clear*) were used to assess relevance and clarity of the wording, respectively (Polit and Beck, 2006). Experts could write comments, such as additional items or suggestions in re-wording. The Item-Content Validity Index (I-CVI) was calculated to evaluate the extent of expert agreement on relevance of the items, domains and answer options (Polit and Beck, 2008). Lynn (1986) recommends an I-CVI $\geq$80.0% in a panel of 10 or more experts. Items with an I-CVI < 80.0% were eliminated. If an item obtained an I-CVI $\geq$80% but was evaluated as unclear, the item was revised per experts' comment. All modifications were presented to the expert panel in a second and third round. The content validity of the instrument was calculated after the third round by the Scale-Content Validity Index (S-CVI), which is defined as "the proportion of experts who score items as relevant" (Grant and Davis, 1997). In other words, the S-CVI provides information on the proportion of items scored as rather to highly relevant by all experts (Polit and Beck, 2006). The S-CVI was computed by averaging the I-CVIs. Polit and Beck (2008) recommended a S-CVI $\geq$90.0%.

Face-validity of the instrument was enhanced through preliminary feedback on the (1) clarity of wording, (2) ambiguity of items, and (3) layout of the instruments. This was obtained through a pilot evaluation in hospitalized older patients (Polit and Beck, 2008). Feedback provided by the patients was discussed within the research team to allow refinement of the instrument.

3.2.3. Phase III cognitive interviewing

The third phase included cognitive interviewing, which allowed a more in-depth. Cognitive interviewing is based on the theories of cognitive psychology and is useful for instrument development when there is a probability of response errors such as interpretation, language, and recall problems (Drennan, 2003; Willis et al., 1991). The aim of cognitive interviewing is to obtain a more in-depth understanding of how respondents perceive and interpret items, and to identify problems that may arise when completing the instrument (Drennan, 2003; Willis et al., 1991). In our study, verbal probing was used and consisted of asking the participants to define the meaning of the symptoms, and based on the answer further probes were used (Willis et al., 1991). First, participants were asked to complete the ASPE instrument. Second, the researcher conducted a face-to-face semi-structured interview with the participants. The researcher initiated the interview by asking which symptom bothered the patient most. Verbal probing was used to request more in-depth information about the interpretation of the items (Willis et al., 1991). Questions such as what does the symptom mean to you, can you tell me about a specific