JAMDA xxx (2017) 1–6

JAMDA

journal homepage: www.jamda.com

Original Study

Development and Validation of the Symptom Assessment to Improve Symptom Control for Institutionalized Elderly Scale

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Keywords:
Symptom assessment
symptom assessment tool
frail older persons
nursing home
symptom control

A B S T R A C T

Objectives: To validate a newly developed multiple symptom self-assessment tool in nursing homes.
Design: Thirty prevalent symptoms identified in the literature were classified by a 2-round Delphi procedure to a top 10 of the most relevant, burdensome symptoms. Because no existing symptom scale fully covered this top 10, we developed a new scale, consisting of a horizontal numerical scale for the top 10 symptoms, with the possibility to add and rate 3 other symptoms. This scale was validated.
Setting and participants: Hundred seventy-four participants, mean age 85 (±5.94) years, were recruited from 7 nursing homes (86%) and 3 acute geriatric wards (14%).
Methods: To test the construct validity, participants with and without a palliative status were enrolled. Participants completed the Symptom Assessment to Improve Symptom Control for Institutionalized Elderly (SATISFIE) scale on day 0 and day 1 (intrarater reliability). Nurses completed the scale on day 0 (inter-rater reliability). Descriptive statistics described the characteristics of the study population and symptom scores. Differences in symptom scores between palliative and nonpalliative participants were analyzed with the Mann-Whitney U test. Intrarater and inter-rater reliability were calculated by means of an intraclass correlation coefficient. Factor analysis searched for possible symptom clusters. Feasibility was evaluated by measuring the assessment time and by providing a questionnaire for the nurses.
Results: In the nonpalliative group (n = 130), the highest self-rated median scores were pain on day 1 [median 3, interquartile range (IQR) 0–5] and pain on day 2. In the palliative group (n = 44), the highest median self-rated scores were fatigue on day 1 [median 5 (IQR 0–6)], lack of energy on day 1 and 2 [both median 5 (IQR 0–8)]; and depressed feeling on day 2 [median 3 (IQR 0–5)]. Nurse assessments median scores were the highest for depressed feeling [median 5 (IQR 1–7)], fatigue [median 4.5 (IQR 0–6.5)], and lack of energy, [median 3 (IQR 0–6)] in the palliative group. In the nonpalliative group, none of the median scores was 3 or more. Intraclass correlation coefficients for intrarater reliability varied between 0.65 and 0.89 and for inter-rater reliability (patients-nurses) between 0.18 and 0.63. Mean assessment time for nurses was 2.0 minutes [standard deviation (SD) = 1.01]. For participants, it decreased from 10.5 minutes (SD = 5.41) at the first assessment to 7.5 minutes (SD = 3.72) at the second assessment. Nurses determined the SATISFIE instrument to be useful, applicable in daily practice, and sufficiently comprehensible for the patients.
Conclusions: The SATISFIE scale is a valid and feasible instrument for regular, multiple symptom assessment in institutionalized older persons.

With the rising proportion of older people in our society,[1,2] more and more people die at an older age, after a period of chronic health problems. As a consequence, an increasing amount of people require care toward the end of life.[3] Palliative care aims to relieve pain and other distressing symptoms by the means of "early identification and impeccable assessment."[4] For adequate symptom assessment, valid and feasible instruments are needed. Traditionally, the development and validation of symptom scales for a palliative care population have predominantly taken place in cancer patients.[5,6] However, attention to

The PhD trajectory of Marc Tanghe is funded by the "PACE" project of the EU (Framework Program 7 Grant Agreement 603111).
The authors declare no conflicts of interest.
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http://dx.doi.org/10.1016/j.jamda.2017.08.013
1525-8610/

noncancer populations and the elderly population in particular is growing, especially in the domain of pain assessment.[3] Studies concerning pain assessment in dementia indicate that self-assessment is valid and even preferable for patients with moderate to severe dementia.[7–9]

Nonetheless, symptom assessment and control are broader than pain only. Currently, several symptom assessment scales are available. An overview is given in Appendix 1. To our knowledge, however, only 2 instruments have been specifically tested in and adapted for an older population: the Symptom Assessment Scale for Elders[10] and the Minimal Documentation System for palliative care tool,[11] a German version of the Edmonton System Assessment Scale.[12]

This study aims to present and validate an instrument for self-rated symptom assessment in an elderly palliative population. Furthermore, this study describes the prevalence of symptom distress in a population of older persons.

Methods

Development of a New Instrument

In the first step, a Medline-search, which searched for terms "symptom control, measuring symptoms, measuring tool, symptom scale," combined with "end-of-life, palliative patient, palliative care, palliative elderly or geriatric patient" withheld 100 symptoms, prevalent in an older population. After removing overlapping and nonrelevant symptoms, a list of 30 symptoms remained, which was presented in alphabetical order to an expert panel, consisting of 7 physicians and 6 nurses who work in geriatric and palliative care settings and are familiar with the use of assessment instruments. The experts scored these 30 symptoms for frequency (1 = rarely; 2 = sometimes; 3 = often; 4 = very often) and distress (1 = light; 2 = average; 3 = serious). The frequency and distress scores per symptom were multiplied, resulting in a total score, ranging from 1 to 12. Symptoms were ranked by median and in case of ex aequo, also by mean score from high to low. The top 30-symptom list is presented in Appendix 2. Above all, we did not want the assessment instrument to be too burdensome[8] for this frail population. Therefore we selected the top 10 of most relevant symptoms. Because, in the Dutch language, the terms "concentration problems" and "being confused" are often used concurrently, we combined them into the term "confusion," which we defined as problems with concentration or memory. As a consequence, fatigue, which was ranked as the eleventh symptom, was also included in the 10-item symptom list, resulting in the SATISFIE scale that scores breathlessness, depressed feeling, feeling nervous, pain, respiratory secretions, swallowing problems, lack of appetite, fatigue, confusion, and lack of energy.

The second step was to examine whether these 10 symptoms were part of existing symptom scales. After comparison of these 10 items with the assessment instruments found in the literature (Appendix 1), we concluded that none of the existing instruments contained all 10 items. Some instruments had less than 10 items, and other instruments were much longer and contained additional symptoms.

Therefore, it was decided to develop a new scale containing the top 10 symptoms. In addition, we offered the possibility to add 3 symptoms that patients might experience but are not included in our top 10.

A horizontal numerical scale was chosen, with 0 being "not at all" and 10 being "worst possible." This type of scale is widely used and proven to be a well-understood and easy to complete.[6,7,13,14] The final instrument is shown in Figure 1.

Validation Study Sample

Because a change of 1.0 in a symptom VAS score is considered clinically relevant, sample sizes of 96 and 48 achieve 80% power to detect a clinically relevant difference between the 2 groups with a significance level of 0.05, using a 2-sided 2sample *t* test. Participants were recruited from 7 residential long-term care facilities and 3 acute geriatric wards and were included if aged 70 years or older, able to sign an informed consent, and have a Mini-Mental State Examination score of 18/30 or more. For validation, we hypothesized that overall symptom burden in a palliative population would exceed the symptom burden of a nonpalliative population. Participants were classified as palliative when the medical record mentioned a palliative care-oriented nursing plan or a formal decision to forego life-sustaining treatments, reflecting dying is expected and care focuses rather on comfort than cure. Other participants were considered as a nonpalliative group. The ethical committee of Ghent University Hospital (Belgium) approved the study protocol. Informed consent was obtained from all participants.

Psychometric Properties and Statistics

In presence of the researchers, who briefly explained the use of the scale, participants performed symptom self-assessment with the SATISFIE-instrument on 2 consecutive days. After scoring of the 10 listed symptoms, participants were asked if they suffered from other symptoms, without limiting the number of additional symptoms, although the printed version only had room to add 3 additional symptom scores. These additional symptoms were also scored on a level from 0 to 10. Nurses only completed the assessment on day 1.

Descriptive statistics describe the characteristics of the study population and symptom scores. To evaluate the concurrent validity of the SATISFIE-instrument, we analyzed the symptom score differences between the palliative and nonpalliative group participants with the aid of the nonparametric Mann-Whitney U test. Test-retest or intrarater reliability was calculated by means of an intraclass correlation coefficient (variability between the participants' score on the first and the second day), as was the interrater reliability (difference between participants' and nurses' rating on the first day). To verify if reduction of the number of symptoms in the scale is needed, possible symptom clusters were detected by means of factor analysis. Feasibility was evaluated with the help of the assessment time and a providing a questionnaire for the nurses. All analyses were performed with IBM SPSS Statistics software v 20.0 (IBM Corporation; Armonk, NY). The significance level was set at 0.05.

Results

Characteristics of the Validation Sample

A total of 174 participants were included in this study. Mean age of the total group was 85 years (SD = 5.94 years). The majority of the participants were female (69%). One hundred fifty participants resided in a long-term care facility (86%), and 24 participants were recruited from an acute geriatric ward in a hospital (14%). Mean Mini-Mental State Examination (MMSE) score was 23.8/30 (SD = 3.21). MMSE scores were only obtained in 111 out of 174 participants as some care facilities only perform a MMSE test when cognitive problems are suspected.

A total of 130 participants were in the nonpalliative group, and 44 in the palliative group. Four participants did not consent to take part in the second assessment and dropped out.