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Original article

Cultural adaptation and validation of the Portuguese End of Life Spiritual Comfort Questionnaire in Palliative Care patients

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ABSTRACT

Background: Holistic comfort is an important outcome in palliative care and an important goal for patients, relatives and healthcare workers. Holistic comfort considers one's acceptance of life circumstances, support from loved ones and health care professionals, and peaceful resolution of relationships during stressful situations. However, this type of comfort is still difficult to measure, particularly in palliative care patients, as there is a lack of instruments available, especially in the Portuguese language. This study aims to provide an accurate and sensitive instrument to assess the spiritual comfort of Portuguese palliative care patients.
Objective: To perform the cultural adaptation and validation of a Portuguese version of the End of Life Comfort Planning Questionnaire in Palliative Care patients.
Methods: Methodological research, with analytical approach. The translation, synthesis, back translation, review, pretest, semantic evaluation and analysis of the psychometric properties were performed. A total of 141 palliative care patients from acute medical-surgical settings at a central hospital in the north of Portugal were recruited. The Ethics Committee approved the research.
Results: The internal consistency analysis of the adapted instrument resulted in a global alpha value of 0.84 and the factor analysis presented a solution with five factors with rational meaning. The Portuguese version comprised 20 items.
Conclusions: The instrument has good psychometric properties. It was reliable, valid and sensitive to the existence of the spiritual comfort of palliative care patients, and appropriate for further research.

Introduction

Holistic comfort is important in all human life, from the beginning of life to death and grieving. Several authors have been researching the conceptual definition and implementation of comfort in recent years, particularly in the context of illness, crisis situations or life transitions.[1,2] The most widely known of the abovementioned work is Kolcaba's Comfort Theory, in which comfort is described as a holistic state resulting from satisfaction of the needs of relief, ease and transcendence in the physical, psychospiritual, sociocultural and environmental contexts.[1]

Recent studies have identified some inconsistencies and gaps in knowledge, particularly in terms of classifications and taxonomies of nursing knowledge, in which the concept is defined in a reductionist perspective as it is predominantly associated with the physical dimension.[2,3] These gaps and inconsistencies may be related to the difficulty of measuring the concept. Therefore, Pinto et al.[2–4] supported the idea of comfort as a complex experience, dependent on the behaviors of different actors and factors in every dimension of human life. Nevertheless, current scientific evidence demonstrates the existence of several deficits in the operational implementation and measurement of the concept with patients in palliative care. Problems with measurement in this population

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Table 1
The End of Life Comfort Planning Questionnaire-Patient.

	Strongly disagree					Strongly agree
1. There are those I can depend on when I need help.	1	2	3	4	5	6
2. I don't want to think about planning for end of life care*.	1	2	3	4	5	6
3. My condition gets me down*.	1	2	3	4	5	6
4. I feel confident.	1	2	3	4	5	6
5. I feel my life is worthwhile right now.	1	2	3	4	5	6
6. I am inspired by knowing that I am loved.	1	2	3	4	5	6
7. I trust my doctor to make the right decisions.	1	2	3	4	5	6
8. No one understands me*.	1	2	3	4	5	6
9. My anxiety is difficult to endure*.	1	2	3	4	5	6
10. I am scared when I am alone.	1	2	3	4	5	6
11. My body is relaxed right now.	1	2	3	4	5	6
12. I feel agitated right now.	1	2	3	4	5	6
13. I do not feel healthy right now*.	1	2	3	4	5	6
14. Advance directives makes me feel scared*.	1	2	3	4	5	6
15. I am afraid of what is next*.	1	2	3	4	5	6
16. I am very tired*.	1	2	3	4	5	6
17. I am content.	1	2	3	4	5	6
18. I feel dependent on others to make decisions for me*.	1	2	3	4	5	6
19. My faith helps me be strong.	1	2	3	4	5	6
20. I feel out of control*.	1	2	3	4	5	6
21. I have experienced changes that make me feel uneasy*.	1	2	3	4	5	6
22. My family is aware of my wishes regarding care at the end of my life.	1	2	3	4	5	6
23. I need to be better informed about my health*.	1	2	3	4	5	6
24. I don't have many choices about end of life care*.	1	2	3	4	5	6
25. It helps to get information about end of life care.	1	2	3	4	5	6
26. I feel peaceful.	1	2	3	4	5	6
27. I am depressed.	1	2	3	4	5	6
28. I have found meaning in my life.	1	2	3	4	5	6

In http://www.thecomfortline.com/resources/cq.html.[13]

represent a serious limitation to the study and testing of the efficacy and effectiveness of nursing interventions, particularly at end of life.[2,5]

Currently there are in Portugal some instruments to measure similar constructs in palliative care patients, such as quality of life or wellbeing.[6] However there are very few tools available worldwide to assess specifically patient comfort at the end of life, and in Portugal there is only one: Escala de Conforto Holístico HCQ – PT-DC©.[7] Although validated in a sample of palliative care patients, some inconsistencies were found in Querido's instrument which may jeopardize the global score and an accurate evaluation of the implemented interventions. One of these inconsistencies is related to item #13 ("I made the right choice in choosing this place"). Indeed, contrary to what happens in the United States (where the original version is from), the patient in Portugal is rarely able to choose the place to be treated or hospitalized, despite all the developments in palliative care in the country.[8]

Moreover, item #8 ("My pain is difficult to endure") may promote difficulties in the interpretation of the concept of pain, allowing the patient to understand the concept related to total pain exclusively in a physical perspective or, alternatively, from a more holistic point of view, so promoting bias. Furthermore, in the United States, patients rate their physical pain all the time from one to ten. It does not include existential pain. In Portugal, there is a growing effort to implement the pain as the fifth vital sign, but its evaluation is not yet a standardized practice.[9,10] Also in palliative care, we do not believe that addiction is an appropriate concept when pain is pervasive or severe. In palliative care, many patients may be under the influence of opioids or other analgesics, which may have influenced in their answers.[11,12]

Taking into account the importance of an accurate assessment (either in the clinical practice, whether for research purposes/evaluation of the effectiveness of nursing interventions), we consider it important to study another instrument. For this project, we adapted and translated the *End of Life Comfort Planning Questionnaire-Patient-Version* found on Kolcaba's website (www.thecomfortline.com).[13] This instrument closely approximated the holistic, spiritual qualities we were seeking to capture in palliative care patients in Portugal.

The End of Life Comfort Planning Questionnaire-Patient

The *End of Life Comfort Planning Questionnaire-Patient* (Table 1) was adapted and shortened from the original instrument of the Hospice Comfort Questionnaire-Patient.[14] The new instrument is composed of 28 items, using a Likert scale from 1 to 6 (1 means "Strongly Disagree" and 6 "Strongly Agree"). It assesses spiritual comfort and the final score ranges from 28 to 168. The final score is calculated by the sum of the scores obtained in each item. The lower the score, the lower the comfort of the patient. For the analysis of the results it is important to consider that items #2, 3,8, 9, 13, 14, 15, 16, 18, 20, 21 and 23 and 24 are reversed.[1,14] The original instrument had a Cronbach's Alpha of 0.98.[14] Our *End of Life Spiritual Comfort Questionnaire-Patient* excludes pain and other physical symptoms assessment; however, it is very comprehensive in the assessment of psycho-spiritual-social dimensions, which are frequently neglected in health contexts in Portugal.

The instrument has already been adapted to the Brazilian population with Cardiac Insufficiency[15] but there are few instruments concerning the assessment of non-physical comfort in palliative care. Non physical comfort refers to dimensions which do not "pertain to bodily sensations and homeostatic mechanisms",[1, p. 12] not only in Portugal but also around the world. Given the above, and with the objective of a holistic assessment of comfort, we propose that the Spiritual Comfort instrument supplements a physical comfort assessment. This supplemental assessment could be used in conjunction with a pain scale or in a more comprehensive approach, the assessment of the most prevalent physical symptoms in end of life stages, for example through the revised *Edmonton Symptom Assessment Scale*.[16]

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