

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

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ABSTRACT

Aims: Develop and psychometrically assess the Palliative Nursing Care Quality Scale (PNCQS, escala de Calidad del Cuidado Enfermero Paliativo, CCEP, in Spanish). An interview-based qualitative study was conducted to verify construct validity evidence, with psychometric properties of reliability and validity verified by two quantitative studies.

Design: Quantitative instrumental, correlational and transversal.

Methods: Study 1 was carried out with 10 key informants. For study 2, a sample of 103 nursing professionals was obtained, and 176 nurses from palliative care resources in Spain participated in study 3. Data were collected between May 2017 and May 2018.

Results: Evidence of adequate reliability (internal consistency) and validity was found. The confirmatory factor model yielded a single latent factor for the 20 items, with favorable goodness of fit indices. The convergent validity data showed that the highest correlations were with the Dedication subscale of the *Utrecht Work Engagement Scale* and the Personal Growth subscale of Psychological Well-being, with values of .35 ** and .34 ** respectively.

Conclussion: The scale shows very good psychometric properties, with high internal consistency and evidence of internal and convergent validity.

Impact: Proposing a valuable instrument which identifies good nursing in different areas of palliative care while also establishing quality indicators to guide nursing practice entails the recognition of autonomy in care. The resulting work tool can be used to systematize the assessment of nursing care in a process of open and continuous improvement.

Key words: "scale design" "quality palliative care" "end of life nursing care" "instrument development"

Caring is an intrinsic part of the nursing profession; in the field of palliative care, the nursing professional plays a fundamental role in improving the quality of life of patients with advanced and terminal illness.

Ensuring quality requires deep reflection on the part of professionals on the values, knowledge, attitudes and norms which guide them towards the conceptualization of the internal good and to continuous improvement. The nursing profession needs to construct specific indicators which are sensitive to nursing practice and which measure aspects of the experiences, behaviors or state of health of people affected by the quantity and quality of nursing care (Planas-Campmany & Icart-Isern, 2014).

Assessing the quality of palliative nursing care is usually done from the perspective of the patient's and/or the family's satisfaction with the care received from the team. However, questionnaires specifically assessing palliative nursing care are scarce, even more so in Spain, where no specific measuring instrument is available. The general objective of this study is, therefore, to design and validate a scale which assesses the quality of palliative nursing care as perceived by the nursing professionals themselves.

To this end, we describe firstly the available knowledge on the quality of nursing care, secondly the quality of palliative care in general, and, finally and more specifically the quality of palliative nursing care.

Background

Nursing care quality

The nature of care, the reason for providing it, the objectives and the physical, financial, technological and human resources are the components making up nursing care quality. The assessment of nursing care quality should be a continuous and flexible process, based on data regarding structure, process and outcome (Donabedian, 1988).

The development of taxonomies and classifications relating to nursing interventions and the classification of nursing outcomes, better known as *Nursing Outcomes Classification* (NOC), has served as a benchmark for measuring nursing practice. However, existing indicators which are applied in the measurement of the quality and performance of health organizations have been used for some time to assess nursing practice. In 2004, the American *National Quality Forum* (NQF) facilitated the approval of a set of nursing standards, the NQF-15, which allowed nursing performance measures to be identified in Anglo-Saxon countries. Once these indicators or standards of quality of care have been identified, reliable instruments need to be established to assess quality from a multidimensional perspective.

The measurement instruments found mainly assess nursing care quality as perceived from a patient satisfaction perspective. At the international level, we can highlight instruments such as the *Newcastle Satisfaction With Nursing Scale* (NSNS) of Thomas, McColl, Priest, Bond and Boys (1996), *Karen*, validated by Anderson and Lindgren in 2008, and the human care scales based on Watson's transpersonal theory: *Caring Efficacy Scale* (CES) and *Nyberg's Caring Assessment* (NCA), validated by Poblete-Troncoso, Valenzuela-Suazo and Merino (2012).

In Spain, the following have been used, among others: Nursing Care Quality Questionnaire (CUCADE in Spanish) by Alonso, Blanco-Ramos and Gayoso (2005), the *Caring Assessment Instrument* (CARE-Q) by Sepúlveda, Rojas, Cárdenas, Rojas, and Castro (2009), or the Perception of Humanized Nursing Care Behaviors Questionnaire (PCHE in Spanish) by Reina and Vargas (2008) (Borré, Lenis & González, 2014). All these questionnaires can be applied to the general hospital care setting but are not designed in particular to assess specific aspects of the quality of nursing care in palliative contexts.

Quality of care in palliative contexts

There is a broad consensus on the essential areas which constitute palliative care quality. The *National Consensus Project* (NCP) established eight domains which integrate the quality of palliative care. The NQF also identified 38 examples of good practice related to these eight domains (Ferrell et al., 2007), and Heyland et al. (2010) identified the areas of least satisfaction and those considered most important through the *Canadian Health Care Evaluation Project Questionnaire* (CANHELP). According to Murlaski et al. (2007), the nine domains for assessing the quality of palliative care are: symptom control, holistic consideration of the person and their quality of life, functional aspects, satisfaction, interpersonal relationships, decision making and care planning, continuity and communication, family burden and well-being, and finally the quality of death and end-of-life experience.

The European Association for Palliative Care (EAPC) has developed up to 12 recommendations for designing and using different quality measurement instruments in palliative care (Bausewein et al., 2016). Of these, we can highlight that assessment instruments should be multidimensional measures to capture the holistic nature of palliative care to assess not only the needs of the patient but also the family and caregivers, and that they should be appropriate to the clinical practice of the professionals who work in palliative care.

The *Palliative Care Outcome Scale* (POS) scale, validated by Serra-Prat, Nabal, Santacruz, Picaza, & Trelis (2004) is a fitting example. It consists of a version for

professionals and another for patients. It assesses different aspects of palliative care in patients with advanced neoplastic disease and consists of 10 items and an open question. While not providing a global score, the POS provides a useful profile in the evaluation of palliative care and is not focused on nursing work in particular.

Quality of palliative nursing care

The *Standards for hospice palliative care nursing*, quality standards developed by the *Canadian Palliative Care Association* (CPCA) in 2001, are based on the theoretical model of *Supportive Care* by Davies and Oberle (1990), which includes six interrelated dimensions (Canadian Hospice Palliative Care Association Nursing Standards Committee, 2002). More recently, Dobrina, Tenza and Pales (2014) reviewed three models of care, among which Reed's unitary model (2010) stood out. This model is based on the quality standards established by the EAPC in 2009 to improve the advanced practice of palliative nurses. In Spain, the Spanish Association of Palliative Nursing Care (AECPAL in Spanish) established the values and competencies of a good palliative care nurse.

With regard to specific assessment instruments for assessing the quality of palliative nursing care, Cameron and Johnston (2015) developed and validated the *Quality Measure for Palliative Nursing questionnaire*, organized across five topics: personal characteristics of nurses (strategies for coping with stress, emotional intelligence, empathy and authenticity), communication skills, knowledge of palliative care, professional relationship with the patient and care oriented towards well-being or comfort. Nakazawa et al. (2010) proposed the development of two measuring instruments, the *Palliative Care Self-Reported Practices Scale* (PCPS) scale and the *Palliative Care Difficulties Scale* (PDCS) scale, with the aim of assessing the

effectiveness of training programs in improving the skills of professional palliative care nurses. The questionnaires were validated in a sample of 797 nurses in Japan, and 18 items were subsequently selected for the PCPS, distributed across six domains: terminal care, patient and family-centered care, dealing with pain, dyspnea, delirium, and communication. For the PDCS, 15 items were selected, grouped into five domains which included: communication in the multidisciplinary team, communication with the patient and family, expert support, symptom relief and coordination with other services such as home care. The internal reliability of both scales was good, with Cronbach's α for the PCPS between .80 and .91, and between .85 and .93 for the PDCS (Nakazawa et al., 2010).

As we can see, instruments used to assess the quality of nursing care are not common and, in addition, measure quality from a patient satisfaction perspective, and only in hospital settings. The lack of studies assessing the quality of palliative nursing care from the perspective of the professionals leaves a field of research open to exploration.

THE STUDY

Aims

The purpose of the study was to develop and test the psychometric properties of the Palliative Nursing Care Quality Scale (PNCQS, CCEP in Spanish). For this purpose, three studies were carried out. Study 1 was qualitative, to demonstrate the validity of the construct; study 2 was a pilot study to analyze reliability in terms of the scale's internal consistency and structure through exploratory factor analysis; study 3 analyzed internal validity through confirmatory factor analysis and the convergent validity of the PNCQS.

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We hope the scale yields adequate internal consistency, a unifactorial structure and significant correlation with the variables of well-being, work engagement, and provisional meaning, since many of the theoretical principles which form the basis of good palliative nursing care, including finding meaning in one's work, taking care of oneself, promoting self-awareness and self-reflection, seem to be related to these variables.

Study 1

Methodology

The aim of this study was to configure the dimensions and elements of the scale. To this end, after defining the "quality of palliative nursing care" construct on the basis of a review of the literature, we considered the nine domains for assessing the quality of palliative care according to Murlaski et al. (2007), the nursing care plans prepared by the AECPAL working group, and two of the few instruments found in the literature, the PCPS and the PDCS, by Nakazawa et al. (2010), described above.

The scale was structured in five dimensions: Control and Relief of Symptoms, Family and/or Primary Caregiver, Therapeutic Relationship with the patient and family, Spiritual Support and Continuity of Care, including the most relevant topics, which will be described in the instrument section. To evaluate these, 19 items were drawn up in accordance with suggestions by Morales, Urosa and Blanco (2003), and Martín-Arribas (2004), with a proposed response format of a five-point Likert-type scale (1 = almost *never* and 5 = almost always).

Ten semi-structured interviews were subsequently conducted with a series of key informants: nine professionals in the field of palliative care and the primary caregiver of a person in an end-of-life situation. The first version of the scale consisted of 19 items; however, once the results of the semi-structured interviews were analyzed, the final version of the PNCOS with 20 items (Appendix 1) was prepared.

The resulting scale was reviewed by three skilled nurses in the field of palliative care, who confirmed that the scale represented the essential aspects of palliative nursing care and found that its items were easy to understand.

The data collection period was from May to September 2017.

Ethical considerations

The interview process guaranteed the ethical criteria of data confidentiality, informant anonymity, voluntariness of the interviewees and the right of the participants to abandon eli. the study.

Study 2

Study 2, which was quantitative in nature, was undertaken to analyze the psychometric properties of the scale, its reliability (internal consistency using Cronbach's Alpha) and evidence of its internal structure (exploratory factor analysis).

Sample/Participants

In study 2, a total of 103 nursing professionals took part, 3 of whom were eliminated due to a response error, thus leaving a final sample of N = 100. Those nursing professionals who worked in the various public, private and publicly subsidized palliative care resources of the Community of Madrid were selected through the information bank of the Madrid Association of Palliative Care and with the collaboration of AECPAL. The management and nursing supervisors of the acute and medium-stay palliative treatment units were contacted to help with the dissemination of the online scale. The print version of the scale was also presented in some of the palliative units, and its anonymous and

confidential nature was affirmed. Data were collected from October 2017 to January 2018.

Instrument

The Palliative Nursing Care Quality Scale (PNCQS) scale consists of 20 items which assess the five most representative dimensions related to palliative nursing care. It is a self-assessment scale to be answered by the nursing staff, with a Likert-type response format of 1 to 5 (1 = almost never and 5 = almost always). The first dimension of the scale, Control and Relief of Symptoms, includes aspects such as pain, dyspnea, constipation, anxiety and asthenia. It consists of three items, such as "evaluate the effectiveness of care by asking the patient and/or family about their well-being or comfort." The second dimension, Family and/or Primary Caregiver has five items such as, for example, "support family members and/or primary caregiver in their work of caring for and accompanying the patient". The third dimension, Therapeutic Relationship with the patient and family has five items, such as "help the patient and/or family to reflect on or clarify concerns about pending issues". An example of the five items comprising the fourth dimension, Spiritual Support, is "together with the patient, seek elements of satisfaction which have value for him/her". Finally, the fifth dimension, Continuity of Care, has two items, one of which is "ensure communication and coordination between all team members and the different levels of care". The total score ranges between 20 and 100 points, with higher scores indicating higher perceived quality of palliative nursing care.

Data collection took place from October 2017 to December 2017.

RESULTS

The distribution of the items was asymmetric, with excess kurtosis (values > 1). Using the FACTOR program (Lorenzo-Seva & Ferrando, 2006), an exploratory factor analysis of the PNCQS was performed with polychoric correlations, which are appropriate when there is an asymmetry or excess kurtosis in the variable distributions (Freiberg, Stover, Iglesia, & Fernández, 2013). Prior to the exploratory factor analysis, we calculated the Cronbach α reliability statistic and the KMO measure of sample adequacy, and applied the Bartlett test. Finally, the Robust Unweighted Least Squares (RULS) and Promin rotation for factor extraction were applied.

The PNCQS results yielded good internal reliability, with a Cronbach's α of .94. The data obtained to assess the fit and adequacy of the factor analysis were good, with a KMO of -.91 and a significant Bartlett sphericity test, p < .001.

Table 1 shows the descriptive statistics of each item on the scale.

Exploratory factor analysis indicated the clear existence of a single factor which explained 62.7% of the total variance. The factor weight values of the 20 items were very similar and all saturated to one factor, so there are no clear criteria for eliminating or modifying any of the items. Table 2 describes the relationship between the 20 items and the extracted factor.

Study 3

Study 3, also of a quantitative nature, was designed to assess the scale's internal validity through confirmatory factor analysis, and convergent validity through correlations with the constructs of psychological well-being, work engagement and sense of care.

Sample/Participants

Study 3 involved 176 nursing professionals who were not the same as those in study 2. Study 3 participants came from different palliative centers in Spain and a total population

of N = 1016 (Oriol, Gómez, Gándara & Herrera, 2014). Table 3 shows the distribution of the sociodemographic and employment variables of the sample. In order to contact the professionals, a meeting was held with the nursing supervisors and with the coordination of palliative care in the Health Service of the Community of Madrid. In the other Autonomous Communities, representatives of the board of directors of AECPAL were approached personally to explain the objective of the study and request their collaboration. The SECPAL directory of palliative resources (Doblado et al., 2016) was used to contact people in charge of the healthcare teams in the different palliative fields (hospital, social health and home) via email and telephone, and coordination structures and non-healthcare resources related to palliative care were also contacted. Finally, the scale was disseminated through the different academic social networks. Data collection was carried out from January to May 2018.

Instruments

The Palliative Nursing Care Quality Scale (PNCQS), already described in study 2.

The Sense of Care Scale (SCS), which assesses the sense of care in family caregivers of patients with dementia. The Spanish version of the *Finding Meaning Through Caregiving Scale*, translated and validated into Spanish by Fernández-Capo and Gual-García (2005), consisting of 43 items scored on a Likert-type scale (1 = strongly *disagree* and 5 = strongly agree), with a total score ranging from 43 to 215 points. These items are distributed across three subscales: Powerlessness/Loss (PL), Provisional Meaning (PM) and Ultimate Meaning (UM). In this investigation we used the Provisional Meaning scale (PM), adapted to nursing professionals in the palliative field. It consists of 12 items, such as: "Caring for my patients and/or relatives gives my life direction and meaning", with a scoring range from 12 to 60 on which higher scores reflect a greater sense of care. In our study this scale yielded a Cronbach's α coefficient of .91.

The Ryff Psychological Well-being scale (1989) was used in its abbreviated form adapted and validated in the Spanish population by Diaz et al. (2006). The new abbreviated version of 29 items presents an excellent level of fit to the theoretical model and good internal consistency. Its items, with a response range of 1 to 6 (1 = *strongly disagree*, 6 = *strongly agree*), are distributed across six subscales: Self-Acceptance (SA), Positive Relationships (PR), Environmental Mastery (EM), Personal Growth (PG), Purpose in Life (PL), and Autonomy (A). Oliver, Sansó, Galiana, Tomás, and Benito (2017) validated the Ryff Psychological Well-being scale with 123 nursing professionals in the field of palliative care, finding good mean fit and adequate reliability for all dimensions except Autonomy. In our study, the reliability of the total Psychological Wellbeing Scale was good, with a Cronbach's α of .89. The internal consistency values of the six subscales ranged from .47 for Autonomy to .83 for Personal Growth. Given the Autonomy subscale's low reliability, its results were discarded.

The Utrecht Work Engagement Scale (UWES) was used to assess how professionals felt about their work. Its Spanish adaptation was used with a sample of workers by Salanova, Shaufeli, Llorens, Peiro and Grau (2000). The UWES is composed of 17 items organized in three subscales, Vigor (Vi), Dedication (De) and Absorption (Ab), the responses to which are scored on a seven-point scale (0 = never, at no time, 6 =*always, every day*) and reflect the frequency of feelings experienced at work. The internal consistency values of Cronbach α of the UWES in our study were .80 for the total UWES and from .68 to .76 for the three subscales.

Ethical considerations

For both study 2 and 3, prior to the application of the scale and participation of the professionals, the attached approval of the Ethics Committee of the institution where the

research was conducted was presented, and the anonymous and confidential nature was of the scale was affirmed.

RESULTS

Confirmatory factor analysis was performed with Mplus, version 7.11 (Muthén & Muthén, 2012). Goodness of fit, mean and adjusted variance indices were estimated using the WLSMV (*Mean-and Variance-adjusted Weighted Least Square*) method for an adequate analysis of categorical data and to obtain robust indices, as well as appropriate estimates of the parameters and their margins of error (Rincón et al., 2014).

The scale factor model contains a single latent factor for the 20 items, the standardized factor loads of which are shown in Table 4.

The scale's 20 items presented standardized factorial loads, with high values above .56 indicating that they were largely conditioned by the latent factor value.

For the proposed factor model, the goodness of fit indices yielded the following values: χ^2 (170, N = 176) = 452.856, p < .001, CFI = 0.96, TLI = 0.95, RMSEA = 0.09 (CI 90% = .086, .01), which generally indicated a good fit of the model. The literature on structural equation modeling recommends RMSEA values equal to or lower than 0.08, CFI greater than 0.90 and TLI values of 0.90. Although some authors, such as Hu and Bentler (1999), argue for adherence to the strictest criteria, recent literature questions the use of rigorous goodness of fit limits and suggests that descriptive model of fit statistics should be used for the comparison or classification of models (Varas-Díaz, Neilands, Guilamo-Ramos, & Cintrón, 2010).

As can be seen, the model meets the goodness of fit criteria, with the exception of the RMSEA approximation error rate, > 0.08. This may be due to the moderate sample size; conclusions to be drawn from data with regard to the distribution of the fit indices

and the standard errors for the estimated parameters are more reliable as sample size increases (Herrero, 2010). It may also be because when the polychoric matrix is not defined as positive, the goodness of fit indicators derived from the chi-square test may be incorrect, so it is recommended that fit be assessed with indicators which do not depend directly on chi-square such as the GFI index and RMCR (Ferrando & Lorenzo-Seva, 2014).

Confirmatory factor analysis shows that the items which were most conditioned by the latent factor were item 7 (Support family members and/or primary caregiver in their work of caring for and accompanying the patient), item 12 (Help the patient and/or family to reflect on or clarify concerns about pending issues) and item 15 (Together with the patient, seek elements of satisfaction which have value for him/her).

After performing the confirmatory factor analysis of the scale, its convergent validity was measured. Significant correlations are shown in Table 5.

In line with expectations, all correlations were significant and positive. The highest correlations of the Palliative Nursing Care Quality Scale were with the Psychological Well-being Scale (r = .34), particularly with the Personal Growth subscale (r = .34) and with the Work Engagement Scale (UWES) (r = .33), in particular with its Vigor (r = .34) and Dedication (r = .35) subscales.

DISCUSSION

The Palliative Nursing Care Quality Scale (PNCQS) yielded adequate psychometric properties, both in terms of reliability and evidence of its construct validity, internal structural validity and convergent validity.

In addition to very high internal consistency, the evidence of the scale's internal structural validity points to the existence of a single factor. The 20 items of the scale are

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organized around a single dimension, which suggests that the quality of palliative nursing care is a more global and comprehensive concept than one differentiated by areas. The three items most conditioned by the latent factor of the scale are those related to the encouragement and support of family care work, dealing with pending issues of the patient and/or family and seeking to find elements of satisfaction for the patients which are meaningful to them. According to the qualitative analysis of the study, the most representative items of the PNCQS scale are those related to the dimensions of good nursing care which centers on the patient and/or family, respecting their final wishes and the things which have value or meaning for them, rather than for the professional.

The validity of the measurement model is supported by both confirmatory factor analysis, which shows the suitability of the model to the goodness of fit criteria, with the exception of the RMSEA approximation error rate, as well as the theoretical criteria based on a deep conceptual review, expert opinion and semi-structured interviews with professionals and relatives of palliative patients.

Finally, evidence of convergent validity is shown by the positive correlations, both significant and moderate, obtained by the Provisional Meaning, UWES and Psychological Well-being scales; the greatest effect is seen in the Personal Growth and Dedication subscales. It is significant that the concepts of personal growth and dedication are the ones most closely related to the quality of palliative nursing care. The Personal Growth subscale reflects the effort to develop one's own potential and achieve the greatest capacity, while the Dedication subscale is related to high work involvement and a feeling of significance, enthusiasm, inspiration, pride and challenge in the job. These results seem consistent with some of the values guiding nursing professionals to provide quality palliative care, including: meaningfulness, understood as a way of furthering patient well-being through nursing care (Reed, 2010), self-improvement, overcoming problems,

motivation, capacity for effort to improve, and maturity, which allows the personal growth of the nursing professional (Codorniu, Guanter, Molins, & Utor, 2013). It seems logical to expect that those professionals who strive to develop their full potential, continue to grow as a person, and experience enthusiasm, pride and challenge at work, will seek excellence or improvement in their care work.

Our qualitative study leads us to the conclusion that to provide good care, it is necessary to identify the needs and desires of the terminal patient, an aspect which requires the nursing professional to be self-aware, and secondly, to develop relationship skills and spiritual accompaniment. These results are in line with the study by Fillion et al. (2009), who found that nurses who are more aware of their own spirituality, values or meaning better identified the needs of the patient at the end of life.

Limitations

Among the limitations of the design and validation of the PNCQS are, first of all, that the quality of palliative nursing care is assessed by self-assessment of the professional's own perception. Although the nursing professional's vision regarding their own care is essential as the first link in an assessment of quality, it is suggested that future research develop an adapted version for family members and/or caregivers and patients in end-of-life situations.

Second, the moderate sample size N = 176 influences the confirmatory factor analysis result since fit indices and standard error improve when the sample size is larger. However, given that it is a very specific professional group, the population is not very wide; in fact, our sample represents more than 17% of the population, which constitutes a considerable sample.

CONCLUSION

In conclusion, the design and validation of the PNCQS offers very important contributions to the study of palliative nursing care quality. Carrying out a qualitative study based on interviews which support the concept of nursing care quality, together with two quantitative studies confirming internal and convergent validity, provides a contribution of notable value to the construct validity of the scale. Grounding the concept of "quality of palliative nursing care" in an exhaustive review of the literature, in expert opinion and the experiences of family and professionals in the field of palliative care reflects the sound and coherent approach to careful scale design. In short, the PNCQS allows criteria of proven efficacy to be established when applied in any area of palliative or end-of-life care.

The design of a specific scale which defines good nursing in the field of palliative care is an important milestone for the nursing profession, involving as it does a recognition of our autonomy in care and an attempt to establish indicators to guide our practice. Nurses need tools which facilitate awareness of the activities we carry out every day in search of excellence in the care of the patient and/or family in an end-of-life situation. The possibility of using the scale as a work tool to systematize the assessment of our care in a process of open and continuous improvement represents a contribution worthy of note.

Conflict of Interest statement

The authors declare no conflict of interest

References

- Alonso, R., Blanco Ramos, M. A., & Gayoso, P. (2005). Validación de un cuestionario de calidad de cuidados de enfermería [Validation of a nursing care quality questionnaire]. *Revista de Calidad Asistencial*, 20(5), 246-250.
- Andersson, I., & Lindgren, M. (2008). The karen instruments for measuring quality of nursing care. Item analysis. Nordic Journal of Nursing Research y Clinical Studies, 28(3), 14-18.
- Bausewein, C., Daveson, B. A., Currow, D. C., Downing, J., Deliens, L., Radbruch, L.,
 Higginson, I. J. (2016). EAPC white paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services recommendations from the European Association for Palliative Care (EAPC) task force on outcome measurement. *Palliative Medicine, 30*(1), 6-22. doi:10.1177/0269216315589898
- Borré, M., Lenis, C., & González, G. (2014). Utilidad del cuestionario SERVQHOS-E para medir calidad percibida de la atención de enfermería [Usefulness of the SERVQHOS-E questionnaire to measure perceived quality of nursing care]. *Revista CES Salud Pública, 5*(2), 127-136.
- Cameron, D., & Johnston, B. (2015). Development of a questionnaire to measure the key attributes of the community palliative care, specialist nurse role. *International Journal of Palliative Nursing*, *21*(2), 87-95. doi:10.12968/ijpn.2015.21.2.87
- CHPCA Nursing Standards Committee. (2002). Hospice palliative care nursing standards of practice. Retrieved from http://aecpal.secpal.com/archivos-on-line-2
- Codorniu, N., Guanter, L., Molins, A., & Utor, L. (2013). Competencias enfermeras en cuidados paliativos [Nursing competencies in palliative care]. Sociedad Española de Cuidados Paliativos. Retrieved from <u>http://aecpal.secpal.com/archivos-on-line-2</u>

- Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. In *Oncology nursing forum 17*(1), 87-94.
- Díaz, D., Rodríguez-Carvajal, R., Blanco, A., Moreno-Jiménez, B., Gallardo, I., Valle,
 C., & Van Dierendonck, D. (2006). Adaptación española de las escalas de bienestar psicológico de Ryff [Spanish adaptation of Ryff's psychological well-being scales]. *Psicothema, 18*(3), 572-577.
- Doblado Valderrama, R., Herrera Molina, E., Librada Flores, S., Lucas Díaz, M. A., Muños Mayorga, I., & Rodríguez Álvarez-Ossorio, Z. (2016). Directorio de Recursos de Cuidados Paliativos en España. *Madrid: SECPAL*.
- Dobrina, R., Tenze, M., & Palese, A. (2014). An overview of hospice and palliative care nursing models and theories. *International Journal of Palliative Nursing*, 20(2), 75-81. doi:10.12968/ijpn.2014.20.2.75
- Donabedian, A. (1988). The quality of care: How can it be assessed? *Jama, 260*(12), 1743-1748.
- Fernández-Capo, M., & Gual-García, P. (2005). Sentido del cuidado y sobrecarga [Finding meaning of caregiving and overload]. *Revista Española de Geriatría y Gerontología, 40*, 24-29. doi:10.1016/S0211-139X (05)75070-8
- Ferrando, & Lorenzo-Seva. (2014). El análisis factorial exploratorio de los ítems:
 Algunas consideraciones adicionales [The exploratory factor analysis of the items:
 Some additional considerations]. *Anales de Psicología, 30*(3), 1170-1175.
- Ferrell, B., Connor, S., Cordes, A., Dahlin, C., Fine, P., Hutton, N., Meier, D. (2007). The national agenda for quality palliative care: The national consensus project and the national quality forum. *Journal of Pain and Symptom Management*, 33(6), 737-744.

- Fillion, L., Duval, S., Dumont, S., Gagnon, P., Tremblay, I., Bairati, I., & Breitbart, W.
 S. (2009). Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care nurses. *Psycho-Oncology*, *18*(12), 1300-1310. doi:10.1002/pon.1513
- Freiberg, A., Stover, J., Iglesia, G., & Fernández, M. (2013). Correlaciones policóricas y tetracóricas en estudios factoriales exploratorios y confirmatorios [Polychoric and tetracholic correlations in exploratory and confirmatory factor studies]. *Ciencias Psicológicas*, 7(2), 151-164.
- Herrero, J. (2010). El análisis factorial confirmatorio en el estudio de la estructura y estabilidad de los instrumentos de evaluación: Un ejemplo con el cuestionario de autoestima CA-14 [The confirmatory factor analysis in the study of the structure and stability of the evaluation instruments: An example with the self-esteem questionnaire CA-14]. *Psychosocial Intervention, 19*(3), 289-300.
- Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik,
 & Cohen, S. R. (2010). Defining priorities for improving end-of-life care in Canada. *CMAJ: Canadian Medical Association Journal, 182*(16), E747. doi:10.1503/cmaj.l00131
- Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural equation modeling: a multidisciplinary journal*, 6(1), 1-55.
- Lorenzo-Seva, U., & Ferrando, P. J. (2006). FACTOR: A computer program to fit the exploratory factor analysis model. *Behavior Research Methods*, *38*(1), 88-91.
- Martín-Arribas, M.C. (2004). Diseño y validación de cuestionarios [Design and validation of questionnaires]. *Matronas Profesión, 5 (17)*, 23-29.

- Morales, P., Urosa, B., & Blanco, A. (2003). Construcción de escalas de actitudes tipo Likert: Una guía práctica [Construction of Likert-type attitude scales: A practical guide]. Madrid, España: La muralla.
- Mularski, A., Rosenfeld, K., Coons, S., Dueck, A., Cella, D., Feuer, D., & Sloan, J. (2007). Measuring outcomes in randomized prospective trials in palliative care. *Journal of Pain and Symptom Management*, *34*(1), 7-19.
- Muthén, L., & Muthén, B. (2012). *Mplus version 7 user's guide*. Los Ángeles, CA: Muthén y Muthén.
- Nakazawa, Y., Miyashita, M., Morita, T., Umeda, M., Oyagi, Y., & Ogasawara, T. (2010). The palliative care self-reported practices scale and the palliative care difficulties scale: Reliability and validity of two scales evaluating self-reported difficulties experienced in practices and palliative care by health professionals. Journal of Palliative Medicine, 13(4), 427-437. doi:10.1089/jpm.2009.0289
- Oliver, A., Sansó, N., Galiana, L., Tomás, J. M., & Benito, E. (2017). Evaluación psicométrica en profesionales de enfermería de cuidados paliativos [Psychometric evaluation in palliative care nursing professionals]. *Aquichan, 17*(2), 183-194
- Oriol, I., Gómez, M., Gándara, A., & Herrera, E. (2014). *Informe de la situación actual en cuidados paliativos* [Report on the current situation in palliative care]. Retrieved from <u>https://www.aecc.es/es/todo-sobre-cancer/observatorio/estudios-</u> realizados/situacion-actual-cuidados-paliativos
- Planas-Campmany, C., & Icart-Isern, M. T. (2014). Indicadores sensibles a la práctica enfermera: una oportunidad para medir la contribución de las enfermeras [Indicators sensitive to nurse practice: an opportunity to measure the contribution of nurses]. *Enfermería Clínica, 24*(2), 142-147. doi:10.1016/j.enfcli.2013.07.003

- Poblete-Troncoso, M.C, Valenzuela-Suazo, SV, & Merino, J.M. (2012). Validación de dos escalas utilizadas en la medición del cuidado humano transpersonal basadas en la Teoría de Jean Watson [Validation of two scales used in the measurement of transpersonal human care based on Jean Watson's Theory]. *Aquichan, 12*(1), 8-21.
- Reed, S. M. (2010). A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holistic Nursing Practice*, *24*(1), 23-34.
- Reina, C., & Vargas, E. (2008). Validez de contenido y validez facial del instrumento "Percepción de comportamientos de cuidado humanizado" [Content validity and facial validity of the instrument "Perception of humanized care behaviors"]. Avances en Enfermería, 26(2), 71-79.
- Rincón, P., Gysling, M., Jiménez, C., Lloyd, S., Navarro, M. F., Retamal, L., Haquin, C. (2014). Propiedades psicométricas de la escala de síntomas de TEPT para niños (CPSS) en población chilena afectada por el terremoto y tsunami del 27-F de 2010. *Terapia Psicológica*, 32(1), 57-64. 10.4067/S0718-48082014000100006
- Ryff, C. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069.
- Salanova, M., Schaufeli, W., Llorens, S., Peiro, J. M., & Grau, R. (2000). Desde el 'burnout' al engagement: Una nueva perspectiva [From burnout to engagement: A new perspective]. *Revista de Psicología del Trabajo y de las Organizaciones, 16*(2), 117-134.
- Sepúlveda, G.J, Rojas, A., Cárdenas, O. L., Rojas, E., & Castro, A. M. (2009). Estudio piloto de la validación del cuestionario 'CARE–Q' en versión al español en población colombiana [Pilot study of the validation of the 'CARE Q' questionnaire

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in Spanish version in Colombian population]. *Revista Colombiana de Enfermeria, 4*(4), 13-22.

- Serra-Prat, M., Nabal, M., Santacruz, V., Picaza, J. M., & Trelis, J. (2004). Traducción, adaptación y validación de la Palliative Care Outcome Scale al español [Translation, adaptation and validation of the Palliative Care Outcome Scale into Spanish]. *Medicina Clínica*, *123*(11), 406-412. doi:10.1016/S0025-7753(04)74535-2
- Thomas, L. H., McColl, E., Priest, J., Bond, S., & Boys, R. J. (1996). Newcastle satisfaction with nursing scales: An instrument for quality assessments of nursing care. *Quality and Safety in Health Care*, *5*(2), 67-72. doi:10.1136/qshc.5.2.67
- Varas-Díaz, N., Neilands, T., Guilamo-Ramos, V., & Cintrón, F. (2008). Desarrollo de la escala sobre el estigma relacionado con el VIH/SIDA para profesionales de la salud mediante el uso de métodos mixtos [Development of the stigma scale related to HIV/AIDS for health professionals through the use of mixed methods]. *Revista Puertorriqueña de Psicología, 19*, 183-215.

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Table 1

Item Descriptive Statistics

Item	M	SD	Variance	Asymmetry	Kurtosis
1	4.27	0.97	0.93	-1.50	2.12
2	4.49	0.71	0.51	-1.54	2.47
3	4.60	0.61	0.38	-1.29	0.56
4	4.33	0.82	0.68	-1.33	1.94
5	4.43	0.74	0.54	-1.18	0.88
6	4.18	0.88	0.76	-1.08	1.06
7	4.47	0.73	0.52	-1.15	0.41
8	4.42	0.69	0.48	-0.97	0.37
9	4.41	0.75	0.56	-1.12	0.66
10	4.56	0.64	0.40	-1.16	0.21
11	4.62	0.58	0.33	-1.26	0.58
12	4.38	0.73	0.53	-1.04	0.70
13	4.14	0.80	0.64	-0.61	-0.20
14	4.22	0.81	0.65	-0.65	-0.50
15	4.22	0.90	0.81	-1.36	2.04
16	4.09	0.98	0.96	-1.14	0.91
17	3.98	0.96	0.92	-0.78	0.03
18	3.98	1.02	1.04	-0.81	-0.18
19	4.35	0.85	0.72	-1.33	1.13
20	4.40	0.82	0.68	-1.51	2.38

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Table 2

Rotated Factor Matrix

ltem	Factor 1	Commonality
1	.77	.59
2	.79	.63
3	.78	.62
1	.77	.60
5	.73	.54
6	.71	.50
7	.71	.51
8	.73	.53
)	.74	.56
10	.70	.49
11	.75	.57
2	.76	.59
13	.72	.52
14	.75	.56
15	.80	.63
16	.79	.63
17	.75	.56
18	.76	.57
19	.69	.48
20	.76	.58

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Table 3

Distribution of Sociodemographic and Work Variables of the Sample

Variable	Mean	SD	Category	%
Sex			Female	85%
			Male	15%
Age	44.1	9.8		
Autonomous Community			Madrid	30%
			Cataluña	21%
			Andalucía	10%
			Navarra	9%
			Comunidad Valenciana	9%
			Other	21%
Educational level			Vocational Training	7%
			Degree/Diploma	57%
			Postgraduate	36%
Palliative care training			Sí	91%
			No	9%
Emotional training			Yes	74%
			No	26%
Employment estagery			Nurse	75%
Employment category				25%
			Nursing assistant	2370
Type of contract			Permanent	82%
			Temporary	18%
Shift			Morning	62%
			Afternoon	6%
			Night	5%
			Rotating	27%
Years of experience	9.7	7.06		
Palliative care field			Social health	21%
			Hospital	36%
			Hospital support	11%
			Home support	32%
Type of patient			Adult	75%
•			Pediatric	7%
			Both	18%

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Table 4

Factor structure of the PNCQS

tem	Standardized loading	gs Standard error
	.66**	.04
,	.74**	.04
}	.56**	.04
ļ	.72**	.03
5	.81**	.03
	.84**	.02
1	.86**	.02
	.82**	.03
	.85**	.02
0	.68**	.04
1	.80**	.03
2	.86**	.02
3	.73**	.03
4	.86**	.02
5	.87**	.02
6	.78**	.03
7	.71**	.03
8	.73**	.04
9	.71**	.04
0	.71**	.04

** *p* <.01.

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Table 5.

Correlations between the PNCQS, SP, PW, UWES, and their subscales.

	Palliative Nursing Care Quality Scale (PNCQS)
Psychological Wellbeing (PW)	.34**
Self-acceptance	.32**
Positive relationships	.23**
Environmental Mastery	.22**
Personal Growth	.34**
Purpose in Life	.28**
Provisional Meaning (PM)	.24**
UWES	.33**
Vigor	.34**
Dedication	.35**
Absorption	.19*

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Appendix 1.

FINAL VERSION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Below, you will find a series of statements about different actions in palliative care. Please read each statement carefully and indicate how often you carry out the following actions in your field of work.

1	2	3	4	5					
Almost never	Ocassionally	Sometimes	Often	Almos alway					
				1	2	3	4	5	
Perform a thorough assessment of pain, e.g. its location, frequency, intensity, and impact on the patient's quality of life.									
symptoms (an		or the managemen confusion, dyspnea ting).							
	ectiveness of car heir well-being	re by asking the par or comfort.	tient and/or						
	mmunication wi	th family members nd private place.	and/or						
Include family members and/or primary caregiver in planning and executing care, depending on their disposition.									
Assess family	and/or primary	caregiver overload							
Support family members and/or primary caregiver in their work of caring for and accompanying the patient.									
	ily and/or primation of the state of the sta	ary caregiver to ex	xpress their						
	nonverbal mess l as words they j	ages from the pat prefer to avoid.	tient and/or						
	of the feelings	silence for non- , thoughts and be							
		armth when the pa s fear, anger or sad							
1 1	nt and/or family at pending issues	to reflect on or cla	rify						
Stay with the p of greatest suf		mily, especially du	ring periods						

GOOD PALLIATIVE NURSING CARE: DESIGN AND VALIDATION OF THE PALLIATIVE NURSING CARE QUALITY SCALE (PNCQS)

Detect "warning signs" of the spiritual needs of the patient and/or family such as expressions of emotion, values or ethical conflicts.			
Together with the patient, seek elements of satisfaction which have value for him/her.			
Help the patient and/or family identify situations of realistic hope.			
Help the patient when reviewing the most significant events of his/her life.			
Ask open and specific questions to support the patient in his/her decision making or final wishes.			
Ensure communication and coordination between all team members and the different levels of care.			
Adequately inform the patient/family throughout the process of the illness of the resources available for the continuity of care.			

3.