

Citation for published version:

Maria Remedios Sánchez-García, Jose Antonio Gutiérrez-Romero, Manuel Fernández Alcántara, César Hueso-Montoro, Claire Goodman, and Rafael Montoya-Juárez, 'End of life care in nursing homes in Spain: Exploratory analysis and evidences of validity of a new scale', *Applied Nursing Research*, Vol. 37: 6-12, October 2017.

DOI:

<https://doi.org/10.1016/j.apnr.2017.07.001>

Document Version:

This is the Accepted Manuscript version.

The version in the University of Hertfordshire Research Archive may differ from the final published version.

Copyright and Reuse:

© 2017 Elsevier Inc. All rights reserved.

This manuscript version is made available under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License CC BY NC-ND 4.0

(<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Enquiries

If you believe this document infringes copyright, please contact the Research & Scholarly Communications Team at rsc@herts.ac.uk

Title:

End of life care in nursing homes in Spain: exploratory analysis and evidences of validity of a new scale.

Authors:

Sanchez-Garcia, Maria Remedios¹; Gutiérrez-Romero, Jose Antonio²; Fernández-Alcántara, Manuel³
Hueso-Montoro, Cesar⁴; Goodman, Claire⁵; & Montoya-Juarez, Rafael⁶.

- 1- RN. PhD Student. University of Granada. Andalusian Public Health System. Granada (Spain)
mrsanc@correo.ugr.es
- 2- RN. PhD Student. University of Granada. Nursing Home “Santa Ana”. Cordoba (Spain)
janguro@ugr.es
- 3- Assistant Lecturer. Department of Health Psychology. University of Alicante (Spain).
mfernandeza@ua.es
- 4- Assistant Lecturer. Department of Nursing. University of Granada (Spain) cesarhueso@ugr.es
- 5- Centre for Research in Primary and Community Care. University of Hertfordshire (United Kingdom). c.goodman@herts.ac.uk
- 6- Assistant Lecturer. Department of Nursing. University of Granada (Spain) rmontoya@ugr.es

Corresponding Address:

Fernández Alcántara, Manuel. mfernandeza@ua.es

Facultad de Ciencias de la Salud. Campus de Sant Vicent del Raspeig. Ap. Correos 99 E-03080 Alicante

Funding:

This research has been funded by the government of the Junta de Andalucía (Spain) (P1-0619/2011)

Abstract

Quality end-of-life care is a central issue in nursing homes, requiring the assessment of individual and family needs by health professionals. Although previous instruments have been developed, they usually rely on family reports and have been adapted from other clinical contexts (hospital or primary care). It is important to consider how health care professionals working in nursing homes perceive what is necessary to achieve quality end-of-life care.

In this study, the objective was to develop an instrument to assess quality of end-of-life care in the context of Spanish care homes. A 24 item scale Nursing Home End of Life Care Scale (NHEOLC) was developed through a systematic evaluation of existing tools combined with an iterative process of consultation with group experts in end of life care in long term care settings. A total of 307 health care professionals agreed to participate in the study and completed the scale. The scale was grouped in six dimensions: physical, psychological aspects and spiritual aspects of care, family care, bereavement, and patient/family preferences management. The results suggest an adequate factorial structure of the scale and good internal consistency for the total score and the subscales. In addition, the results showed significant differences depending on the size of the nursing home, the category of health professionals, and their own perceptions of his work regarding end-of-life care.

Keywords: quality of end-of life; nursing homes; instrument; palliative care; health professionals.

End of life care in nursing homes in Spain: exploratory analysis and evidences of validity of a new scale.

Across Europe and other developed countries their changing demography would indicate that new age sensitive models of service provision are required to support the increasing numbers of older people with complex needs (Comas-Herrera, Wittenberg, Pickard, & Knapp 2007; Hall, Petkova, Tsouros, Costantini, & Higginson, 2011). Many of the oldest people in Europe will spend their last years of life in long-term care. The average resident in long term care is over 85 years old, in the last year(s) of life, living with three or more clinical conditions including dementia and take seven or more medications (Gordon, Franklin, Bradshaw, Logan, Elliott, & Gladman, 2014). The European Association of Palliative Care (EAPC) Taskforce report “Palliative Care in Long-Term Care Settings for Older People” concludes that, in European countries, there are concerns about the consistency and quality of care provided in such facilities (Froggatt et al., 2013). One response is to develop recognised processes and systems of audit to manage and assess quality of end-of-life care (QELC) provision. This paper provides an account of the development of a quality assessment tool for end of life care for use in Spanish nursing homes.

Background

To achieve an adequate quality of end of life care (QELC) for older people living in long term care settings requires an ability to address the needs of the individual and their families, staff skilled in end of life care and access to specialist clinical support (van Soest-Poortvliet et al., 2011). Care workers in nursing homes face significant difficulties in their daily work that may affect how they provide QELC (Juthberg & Sundin, 2010). These include demanding workloads, financial pressures, lack of specificity in the role, feelings of uncertainty around how responsibilities are negotiated and who has the authority to make decisions about how and where care is provided (Froggatt et al., 2013, Goodman, Froggatt, Amador, Mathie, & Mayrhofer, 2015).

Initiatives that support palliative care in nursing homes measure their impact against usual care, rather than considering the relative effectiveness of different approaches providing QELC (van der Steen & Goodman, 2015). The development of specific instruments to assess QELC in nursing homes can support improvement in care, report fluctuations in QELC in the same institution and comparison between

different centres over time. It may also be useful to determine what is required for centres to demonstrate a minimum standard in QELC.

Several instruments to assess quality of care for those who are dying are potentially suitable for quality assessment and research in long-term care settings. However, the majority were initially developed in other contexts such as hospitals or primary care (van Soest-Poortvliet et al., 2012), compromising their validity. A recent study that compares the psychometric properties of a large number of measures of end-of life care and outcomes among residents of nursing homes concludes that few measures exhibit an acceptable factor structure (Zimmerman et al., 2015). In addition, some scales did not distinguish between QELC and quality of dying, or were directly focused on bereaved population (such as the Quality of Dying in Long-Term Care: Munn et al., 2007). Finally, using only family reports on end of life in nursing homes may have an inherent selection bias in how relatives are identified and what aspects of quality of care are reported (van der Steen, Deliens, Ribbe, & Onwuteaka-Philipsen, 2012).

An alternative approach involves directly asking the health professionals that provide end of life care in nursing homes about what needs to be in place to achieve quality care. Health professionals that work in nursing homes have direct experiential knowledge and daily-experience of providing QELC (Carlson, Rämgård, Bolmsjö, & Bengtsson, 2014; Hirakawa, Kuzuya, & Uemura, 2009). Phillips, Salamonson and Davidson (2011) established that the assessment of the levels of self-reported ability of professionals who implement end of life care is an acceptable way to evaluate the quality of services provided. Focusing on staff accounts of their confidence in providing QELC complements other clinically driven indicators of quality of care (van Soest-Poortvliet et al., 2011, van Soest-Poortvliet et al., 2012), and captures the contextual factors that shape how QELC is provided in nursing homes. Other published scales have assessed professionals' perception on QELC, but all of them have been focused on analysing retrospectively patients' deaths (van Soest-Poortvliet et al., 2012, Zimmerman et al., 2015). As far as we know, no previous study have analysed professionals' perception of overall QELC provided in nursing homes.

Spain had more than 371.000 beds for nursing and residential care facilities in 2013 (Wolff, & Piirto, 2016). Spain is divided in 17 autonomous states and each has their own regulatory framework

regarding care homes. In Andalucía (Southern Spain), for example, only nursing homes over 60 beds are required to offer 24 hours nursing services and its own medical care. Nursing homes under 60 beds could also offer these services, but it is not mandatory (Junta de Andalucía 2007). Most of the care homes are privately run (71-76%) and state funded according to eligibility criteria (Froggatt et al., 2013). Care homes for older people who do not require nursing care; residential care homes, are committed to provide 24 h personal care, social support and leisure activities, and some also provide physiotherapy, occupational therapy and psychological care. Nursing homes, in addition to this provide nursing and medical care 7 days a week (Froggatt et al., 2013).

Little is known about QELC in nursing homes in Spain. Data suggest that in these centres, there is a poor control of pain, depression (López-López, 2014), nutritional status (Serrano-Urrea & García-Meseguer, 2014) and limited cognitive and affective assessment of residents (Maseda, Balo, Lorenzo-López, Lodeiro-Fernández, Rodríguez-Villamil, & Millán-Calenti, 2014). Previous literature shows that there are high levels of frailty (de la Rica-Escuín et al., 2014) and poor quality of life in dementia patients (Marventano et al., 2015), which could be related to a poor QELC, to date, no specific assessment of QELC in these facilities has been published.

The aim of this study was to develop an instrument, reporting its reliability and validity evidences, to assess quality of end of life care in Spanish care homes from the perspective of the professionals who work in them.

Methods

Instrument development

A group of 9 experts from different disciplines who were members of a specialist research group (3 nurses, 2 physicians, 2 anthropologists, 1 social worker and 1 psychologist) took part in the development of the QELC tool. After a systematic review of existing QELC tools, this group developed in a first meeting, a 33 items first version of the scale. Items were grouped in six dimensions of end-of-life care: physical, psychological and spiritual aspects of care, family care, bereavement, and patient/family preferences management. The physical, psychological, spiritual and social (family) aspects of care are

identified in similar scales (Zimmerman et al., 2015). Experts decided to include a specific dimension of bereavement (distinct to the dimension of psychological aspects of care). This was in response to a belief that providing ongoing support to grieving relatives is a particular challenge for auditing end of life care in nursing homes (Levy, Kinley & Conway, 2016). Finally, a patient/family preferences management dimension was included. The items regarding end-of-life decisions in this domain are particularly relevant for the health care professionals working at nursing homes (Sánchez-García, Moreno-Rodríguez, Hueso-Montoro, Campos-Calderón, Varella-Safont, & Montoya-Juárez, 2016). In a second meeting, each item was qualitatively assessed through an iterative process of consultation, considering its importance, relevance, clarity of language for health-care professionals working in Spain and redundancy of each item. A total of nine items were removed after the consensus of all experts in the group. The final version of the Nursing Home End of Life Care Scale (NHEOLC) was composed by 24 items (see Supplementary Material).

Items were presented as affirmative sentences, in relation to interventions that could be provided at end of life in nursing homes. Professionals were asked to rate on a Likert scale with five response options (values from 1 to 5) from "strongly disagree" to "strongly agree", their strength of agreement that the activities described occurred in their care home.

Sampling procedures

To pilot the tool a sampling frame was developed from the register of the Junta de Andalucía, which included a total of 68 nursing homes of the neighbouring provinces of Granada and Cordoba. Directors were telephoned by a researcher, which explained the objectives of the study and invited them to participate in the study. Researchers appointed a meeting with the staff in 46 of the 68 nursing homes that finally decided to collaborate. Inclusion criteria were: (a) being a health professional in a nursing home, providing direct care to residents (care assistants, nurses, physicians, physiotherapists, psychologists, occupational therapists and social workers) and (b) a minimum of 6 months experience of working in the nursing home. Data were collected from January of 2013 to June of 2014. The researchers administered the instrument individually in a single session to study participants. The study was approved

by the Ethical Research Committee of the Junta de Andalucía (Reference number: PI 619). This study followed the ethical principles of the Declaration of Helsinki and the Guidelines for Good Clinical Practice of the European Union. Informed consent forms were signed by each participant.

Data Analysis

A series of analysis were performed to explore the internal structure of the NHEOLC and to test its reliability and validity. Firstly, an item analysis of the scale was carried out and descriptive statistics (including mean, standard deviation, skewness and kurtosis) were provided. Secondly, the internal structure of the scale was obtained through exploratory factor analysis (EFA). The adequacy of sample size was assessed using the Kaiser-Meyer-Olkin and the Bartlett test of sphericity. Thirdly, reliability of the scale and sub-scales were calculated using Cronbach's alpha. Fourthly, validity was tested through univariate ANOVAs having as independent variables: (a) the religious affiliation (religious vs non-religious), (b) the size of the nursing home (Small= ≤ 30 ; Medium=30-59, Large=60-120, and extra-Large= ≥ 120), (c) the funding (Private vs Public) and (d) the profession of participants (care assistants, nurses and physicians, physiotherapists and occupational therapists, and psychologists and social workers). Finally, ANOVAs were used to check the validity of the scale using as an independent variable the perception that participants have relating end of life care (poor opinion vs good opinion). To assess this independent variable, participants completed in a 5-point Likert scale (a) the degree to which they perceived that their institution had an adequate practice regarding end-of-life care, (b) the degree to which they perceived that their colleagues had an adequate practice regarding end-of-life care and (c) the degree to which they perceived that themselves had an adequate practice regarding end-of-life care (see Supplementary Material). Those participants with scores between 1 and 3 were grouped into the inappropriate practice group and those whose scores were 4 or 5 were included in the appropriate practice group. SPSS statistical software (22 version) was used for all analysis.

Results

Forty-six nursing homes of Granada (N=29, 63.0%) and Cordoba (N =17, 37.0%), participated in the study. Most of them had a nonreligious approach (N = 31, 67.4%), and were publicly funded (N = 36, 78.3%). Capacity of nursing homes ranged from 20 to 218 patients (M=72.3, SD=47.6).

307 healthcare professionals from Granada (N=163, 53.1%) and Cordoba (N=144, 46.9%) participated in the study. The majority were women (N=276, 90.2%) with a mean age of 34.09 years (SD=9.88) and an average of 5.56 years working in their current position (SD=5.30). Regarding their professional role, 45.6% were care assistants, 21.2% nurses, 9.7% psychologists, 7.2% physiotherapists, 3.6% physicians, 6.8% occupational therapists and 5.9% social workers. Taking into account the whole population of direct care staff who were invited to participate (1230 professionals) the response rate was 25%.

Item analysis

Descriptive data of each of the 24 items are shown in Table 1. All items showed adequate variability and mean values ranged from 2.76 to 4.55.

-----Insert table 1 around here-----

Factorial structure

An EFA was performed using Varimax rotation. The sample size was adequate at the discretion of Kaiser-Meyer-Olkin value (KMO = 0.858) and the Bartlett sphericity test ($\chi^2(276) = 2943.39, p < .001$). A total of 6 components, which explained a 61.65% of the variance, were identified: physical aspects, psychological aspects, spiritual aspects, patient-family preferences management, family care and bereavement. Table 2 shows the factor loadings for each item. Items with similar factor loadings were grouped due to theoretical criteria.

Reliability

The scale, including all items, showed appropriate values of reliability, assessed through Cronbach's alpha ($\alpha = .89$). No items were found whose elimination improved reliability, so no changes were made. Regarding the different subscales, reliability values were acceptable (see Table 2), being

superior to .70 in family care ($\alpha=.792$), bereavement ($\alpha=.790$), physical aspects ($\alpha=.756$) and spiritual dimensions ($\alpha=.755$). Alfa values were lower for patient/family preferences management ($\alpha =.671$) and psychological aspects ($\alpha=.628$).

-----Insert table 2 around here-----

Validity evidences

Validity was tested by univariate ANOVAs, comparing the overall score of the NHEOLC and its distinct subscales with a set of characteristics of the nursing homes and participants: religious affiliation, size of the nursing home, funding and profession.

Firstly, no statistical significant differences were found in the total value scale depending on whether the nursing home has a religious (N= 92, Mean= 25.19, SD= 4.53) or a secular basis (N= 215, Mean= 23.82, SD= 5.07) to its organisation (F (1,305) = .289, $p = .591$). However, higher values on the NHEOLC were found in religious nursing homes for the Family Care subscale (Mean Religious=25.19, SD= 4.53), in comparison with secular (Mean= 23.82, SD=5.07) nursing homes (F (1,305) = 5.02, $p = .026$). Nevertheless, religious nursing homes reported lower score (Mean =15.27, SD=3.61) than secular homes (Mean 16.22, SD=3.04) for the Patient/Family Preferences Management subscale (F (1,305) = 5.61, $p = .018$).

Secondly, the size of the nursing home was assessed considering the number of beds and four groups were created: small, medium, large and extra-large (see Table 3). Statistically significant differences were found regarding the size of the nursing home in the total score (F (3,303) = 4.32, $p=.005$). Post-hoc analysis indicates that professionals of small nursing homes (<30 patients) showed lower scores than the rest ($p=.051$ compared to Medium NH, $p =.004$ compared to Large NH, and $p =.012$ for Extra Large NH). Specifically, differences were found in Family care (F (3,303)=3.83, $p=.010$), Bereavement (F(3,303)=5.68, $p = .001$) and Psychological subscales (F (3,303)=7.97, $p <.001$) (see Table 3).

-----Insert table 3 around here-----

Thirdly, different across the different health professional were analysed regarding the total score and the subscales (see Table 4). Differences were found between the four groups ($F(3,303)=5.18, p=.002, \eta^2_p=.05$) in the overall score of the NHEOLC. Post-hoc analysis indicates that the group of psychologist and social workers had higher scores, in comparison with the rest of the groups. Specifically, differences were found in Family care ($F(3,303)=8.67, p<.001$), Bereavement ($F(3,303)=4.58, p=.004$) and Psychological aspects ($F(3,303)=4.10, p=.007$).

-----Insert table 4 around here-----

The NHEOLC overall score, and all the subscales, were lower when participants perceived more negatively their own end-of-life care, the practice of their colleagues and the nursing home performance ($p < 0.01$ in all cases) (Table 5).

-----Insert table 5 around here-----

Discussion

The present study, as far as we know, is one of the first to address the QELC for people dying in nursing home settings, in the Spanish context, providing a culturally and context specific assessment instrument useful for these institutions.

According to the initial results, the NHEOLC scale shows good internal reliability in the overall scores and in all dimensions, in line with other instruments that assess the QELC (Zimmerman et al., 2015). The exploratory analysis supports the different dimensions, although further studies are needed to confirm its structure. Regarding internal validity the scale seems to distinguish between professionals' perception about their colleagues, nursing home and their own practice regarding end of life care.

Results regarding religious affiliation were unexpected. It could be expected that religious nursing homes should have higher scores in the Spiritual Aspects subscale. This could suggest that participants differentiated between religious beliefs and spirituality as aspects of end of life care. Van Soest-Poortvliet et al. (2014) state that patients with dementia with religious affiliation admitted to nursing homes were more likely to have a comfort care goal, but faith based nursing homes of our study rated lower than non-

faith nursing homes in preferences management. This could be explained according to cultural characteristics in Spain, where strong family ties and Catholic tradition are linked to negative attitudes towards discussing end-of-life preferences with patients (Meñaca et al., 2012).

Another interesting finding was that the size of the care home affected perceptions of QELC. There is a more negative perception of QELC in Small NH (<30 patients) than in Medium or Large NH. One hypothesis to explain this finding is that in Southern Spain, NH with less than 30 patients, do not receive public funding (Junta de Andalucía 2007), so the staff are more likely to recognise that there are limits to what they can and cannot achieve for residents who are dying. Public funding also entails more quality control (audit) on staff recruitment, facilities and processes.

Lack of funding also has an impact on the number of health professionals that are employed in the nursing home. Although studies have highlighted the difficulties of establishing a causal relationship between nurse staffing and quality of care (Spilsbury, Hewitt, Stirk, & Bowman, 2011), it seems to be a crucial variable for a good provision of QELC. For example, a recent systematic review of nurse staffing impact in nursing homes showed that there was a positive relationship between staffing and quality of care in general (Backhaus, Verbeek, van Rossum, Capezuti, & Hamers, 2014). In addition, the results of a multivariate analysis performed on home-care and residential care agencies in Japan showed that a large number of staff were positively associated with the provision of QELC (Igarashi et al., 2015).

Psychologists and social workers rated higher in “Family Care”, “Psychological aspects” and “Bereavement” dimensions than their nursing and care worker colleagues. One explanation for these findings is that these dimensions are core to their work, and they therefore feel confident about their skills in these areas. Discussion of these results is particularly difficult because few studies have been reported differences between professionals regarding QELC, although they have different professional roles (Iasevoli et al., 2012) and specific end-of-life education/training (Forte, Vincent, Velasco, & Park, 2012).

Our results are in line however, with previous research that involved both social workers and psychologist from nursing homes. Unroe et al (2014) conducted a survey of staff from several nursing homes in EEUU about attitudes of nursing home staff towards hospice, and found that more social

workers responded favourably to hospice involvement in nursing homes compared to nursing assistants. On the other hand, Kobayashi & McAllister (2014) found by interviewing different professionals in palliative care teams in the EEUU, that social workers reported feeling less connected with other members of the interdisciplinary hospice team. Regarding psychologists, Iasevoli et al (2012) found that Italian physicians are more communicative with relatives than with patients whereas psychologists tend to discuss these problems more with patients. More research, that can address differences within the multidisciplinary team using larger samples of these professionals is needed to explain the different perspective of QELC among health care professionals.

Study Limitations

These results have some limitations. First of all, the data have been collected from an intentional sample. This could affect the representativeness of the whole nursing home staff population in this region, where there is a considerable heterogeneity of centres. Despite this, previous studies have reported similar sample characteristics of nursing home professionals: mostly female, relatively young and inexperienced (Fariña-López, Estévez-Guerra, Gandoy-Crego, Polo-Luque, Gómez-Cantorna, & Capezuti, 2014). Response rate is lower than previous studies regarding end-of-life care conducted in long-term care settings in other countries (Albers, van den Block, & van der Stichele, 2014; Rys, Mortier, Deliens, & Bilsen, 2014), but not in Spain.

Secondly, this research used exploratory analysis, so the instrument will need further refinement and testing. We did not include cognitive interviews to pilot the interpretability and understanding of the items in the study population. Future studies using qualitative methodology may be useful to improve and refine the NHEOLC and to avoid redundancy or ambiguity. In addition, there are some items, for example those linked to emotions or spiritual support, which seems to be very culturally sensitive, so it could be necessary to check patterns of responses in other cultural contexts.

Finally, high scores of the scale may indicate a high recognition of the importance of end of life care in nursing homes, but these data need to be compared with other clinical settings in order to establish

if the perception of end-of-life care is reflected in how care is provided and if this is consistent for other professionals.

Conclusion

The NHEOLC scale has showed an adequate factor structure and good internal consistency, both for the total score and for each of the sub-scales. The development and feasibility testing of this instrument found that nursing home staff could recognise and assess different aspects and dimensions of end of life care in long-term settings. The NHEOLC scale has potential as a proxy measure for highlighting areas of practice that require additional support and investment.

References

- Albers, G., Van den Block, L., & Van der Stichele, R. (2014). The burden of caring for people with dementia at the end of life in nursing homes: a postdeath study among nursing staff. *International Journal of Older People Nursing*, 9(2), 106-117.
- Backhaus, R., Verbeek, H., van Rossum, E., Capezuti, E., & Hamers, J. P. (2014). Nurse staffing impact on quality of care in nursing homes: a systematic review of longitudinal studies. *Journal of the American Medical Directors Association*, 15(6), 383-393.
- Carlson, E., Rämgård, M., Bolmsjö, I., & Bengtsson, M. (2014). Registered nurses' perceptions of their professional work in nursing homes and home-based care: A focus group study. *International Journal of Nursing Studies*, 51(5), 761-767.
- Comas-Herrera, A., Wittenberg, R., Pickard, L., & Knapp, M. (2007). Cognitive impairment in older people: future demand for long-term care services and the associated costs. *International Journal of Geriatric Psychiatry*, 22(10), 1037-1045.
- de la Rica-Escuín, M., González-Vaca, J., Varela-Pérez, R., Arjonilla-García, M. D., Silva-Iglesias, M., Oliver-Carbonell, J. L., & Abizanda, P. (2014). Frailty and mortality or incident disability in institutionalized older adults: The FINAL Study. *Maturitas*, 78(4), 329-334.

- Fariña-López, E., Estévez-Guerra, G. J., Gandoy-Crego, M., Polo-Luque, L. M., Gómez-Cantorna, C., & Capezuti, E. A. (2014). Perception of Spanish nursing staff on the use of Physical restraints. *Journal of Nursing Scholarship*, *46*(5), 322-330.
- Forte, D. N., Vincent, J. L., Velasco, I. T., & Park, M. (2012). Association between education in EOL care and variability in EOL practice: a survey of ICU physicians. *Intensive Care Medicine*, *38*(3), 404-412.
- Froggatt, K., Reitinger, E., Heimerl, K., Hockley, J., Brazil, K., Kunz, R., & Morbey, H. (2013). *Palliative care in long-term care settings for older people: EAPC taskforce 2010-2012 report*. Milan: EAPC.
- Goodman, C., Froggatt, K., Amador, S., Mathie, E., & Mayrhofer, A. (2015). End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliative Care*, *14*, 42.
- Gordon, A. L., Franklin, M., Bradshaw, L., Logan, P., Elliott, R., & Gladman, J. R. (2013). Health status of UK care home residents: a cohort study. *Age and Ageing*, *43*(1), 97-103
- Hall, S., Petkova, H., Tsouros, A.D., Costantini, M., & Higginson, I.J. (2011). *Palliative Care for Older People: better practices*. Copenhagen: WHO.
- Hirakawa, Y., Kuzuya, M., & Uemura, K. (2009). Opinion survey of nursing or caring staff at long-term care facilities about end-of-life care provision and staff education. *Archives of Gerontology and Geriatrics*, *49*(1), 43-48.
- Iasevoli, M., Giantin, V., Voci, A., Valentini, E., Zurlo, A., Maggi, S., ... & Manzato, E. (2012). Discussing end-of-life care issues with terminally ill patients and their relatives: comparisons among physicians, nurses and psychologists. *Aging Clinical and Experimental Research*, *24*(3 Suppl), 35-42.

- Igarashi, A., Kurinobu, T., Ko, A., Okamoto, Y., Matsuura, S., Feng, M., & Yamamoto-Mitani, N. (2015). Factors related to the provision of home-based end-of-life care among home-care nursing, home help, and care management agencies in Japan. *BMC Research Notes*, 8(1), 434.
- Junta de Andalucía (2007). *Normativa sobre centros residenciales de personas mayores* [Regulation on residential centers for the elderly]. Sevilla: Escadon.
- Juthberg, C., & Sundin, K. (2010). Registered nurses' and nurse assistants' lived experience of troubled conscience in their work in elderly care--a phenomenological hermeneutic study. *International Journal of Nursing Studies*, 47(1), 20-29.
- Kobayashi, R., & McAllister, C. A. (2014). Similarities and differences in perspectives on interdisciplinary collaboration among hospice team members. *American Journal of Hospice and Palliative Medicine*, 31(8), 825-832.
- López López, C. (2014). *Estudio de la construcción de la calidad de vida percibida por los/as ancianos/as institucionalizados/as en una residencia asistida* [Study of the construction of the perceived quality of life for the elderly institutionalized as in a nursing home]. Master Thesis: Universidade da Coruña. Facultade de Enfermaría e Podoloxía.
- Levy, J, Kinley, J & Conway, F. (2016). *The challenges of implementing a multi-centre audit of end-of-life care in care homes*. *International Journal of Palliative Nursing*. DOI: <http://dx.doi.org/10.12968/ijpn.2016.22.11.534>
- Marventano, S., Prieto-Flores, M. E., Sanz-Barbero, B., Martín-García, S., Fernandez-Mayoralas, G., Rojo-Perez, F., ... & Forjaz, M. J. (2015). Quality of life in older people with dementia: A multilevel study of individual attributes and residential care center characteristics. *Geriatrics & Gerontology International*, 15(1), 104-110.
- Maseda, A., Balo, A., Lorenzo-López, L., Lodeiro-Fernández, L., Rodríguez-Villamil, J. L., & Millán-Calenti, J. C. (2014). Cognitive and affective assessment in day care versus institutionalized elderly patients: a 1-year longitudinal study. *Clinical Interventions in Aging*, 9, 887.

- Meñaca, A., Evans, N., Andrew, E. V., Toscani, F., Finetti, S., Gómez-Batiste, X., ... & Gysels, M. (2012). End-of-life care across Southern Europe: a critical review of cultural similarities and differences between Italy, Spain and Portugal. *Critical Reviews in Oncology/Hematology*, 82(3), 387-401.
- Munn, J. C., Zimmerman, S., Hanson, L. C., Williams, C. S., Sloane, P. D., Clipp, E. C., ... & Steinhauser, K. E. (2007). Measuring the quality of dying in long-term care. *Journal of the American Geriatrics Society*, 55(9), 1371-1379.
- Phillips, J., Salamonson, Y., & Davidson, P.M. (2011). An instrument to assess nurses' and care assistants' self-efficacy to provide a palliative approach to older people in residential aged care: a validation study. *International Journal of Nursing Studies*, 48(9),1096-1100.
- Rys, S., Mortier, F., Deliens, L., & Bilsen, J. (2014). The practice of continuous sedation until death in nursing homes in Flanders, Belgium: A nationwide study. *Journal of the American Geriatrics Society*, 62(10), 1869-1876.
- Sánchez-García, M. R., Moreno-Rodríguez, M., Hueso-Montoro, C., Campos-Calderón, C., Varella-Safont, A., & Montoya-Juárez, R. (2016). Dificultades y factores favorables para la atención al final de la vida en residencias de ancianos: un estudio con grupos focales [Facilitators and barriers regarding end of life care at nursing homes: A focus group study]. *Atención Primaria*. doi: 10.1016/j.aprim.2016.09.004
- Serrano-Urrea, R., & García-Meseguer, M. J. (2014). Relationships between nutritional screening and functional impairment in institutionalized Spanish older people. *Maturitas*, 78(4), 323-328.
- Spilsbury, K., Hewitt, C., Stirk, L., & Bowman, C. (2011). The relationship between nurse staffing and quality of care in nursing homes: a systematic review. *International Journal of Nursing Studies*, 48(6), 732-750.

- Unroe, K. T., Cagle, J. G., Dennis, M. E., Lane, K. A., Callahan, C. M., & Miller, S. C. (2014). Hospice in the nursing home: perspectives of front line nursing home staff. *Journal of the American Medical Directors Association, 15*(12), 881-884.
- van der Steen, J. T., Deliëns, L., Ribbe, M. W., & Onwuteaka-Philipsen, B. D. (2012). Selection bias in family reports on end of life with dementia in nursing homes. *Journal of Palliative Medicine, 15*(12), 1292-1296.
- van der Steen, J.T., & Goodman, C. (2015). What research we no longer need in neurodegenerative disease at the end of life: The case of research in dementia. *Palliative Medicine, 29*(3), 189-192.
- van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C., Hertogh, C. M., Onwuteaka-Philipsen, B. D., & Deliëns, L. H. (2014). Factors related to establishing a comfort care goal in nursing home patients with dementia: a cohort study among family and professional caregivers. *Journal of Palliative Medicine, 17*(12), 1317-1327.
- van Soest-Poortvliet, M. C., Van Der Steen, J. T., Zimmerman, S., Cohen, L. W., Klapwijk, M. S., Bezemer, M., ... & De Vet, H. C. (2012). Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Quality of Life Research, 21*(4), 671-684.
- van Soest-Poortvliet, M. C., Van Der Steen, J. T., Zimmerman, S., Cohen, L. W., Munn, J., Achterberg, W. P., ... & De Vet, H. C. (2011). Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *Journal of Pain And Symptom Management, 42*(6), 852-863.
- Wolff, P., & Piirto, J. (2016) *Europe in figures - Eurostat yearbook*. UE: Eurostat.
- Zimmerman, S., Cohen, L., Van Der Steen, J. T., Reed, D., van Soest-Poortvliet, M. C., Hanson, L. C., & Sloane, P. D. (2015). Measuring end-of-life care and outcomes in residential care/assisted living and nursing homes. *Journal of Pain and Symptom Management, 49*(4), 666-679.

Table 1. Item analysis of NHEOLC scale.

Items	Mean	SD	Skewness	Kurtosis
Physical Aspects				
1. Consultation to control pain and other symptoms is available and effective.	4.09	1.01	-1.12	.597
2. Pain is assessed and treated effectively.	4.30	.93	-1.55	2.17
3. Other symptoms (breathlessness, agitation, nausea) are assessed and treated effectively.	4.55	.70	-1.98	4.97
4. Staff has the knowledge and skills needed to care patients at the end-of-life and their families.	4.38	.81	-1.51	2.49
5. There is an effective continuity of care at the end-of-life (hospital wards, ICU, palliative care services, primary care).	4.10	1.09	-1.27	.96
Psychological Aspects				
6. Consultation to psychologist is available and accessibly.	3.82	1.45	-.872	-.771
7. Consultation to psychiatric is available and accessibly.	2.85	1.42	.141	-1.32
Spiritual Aspects				
8. Staff is informed and sensible regarding religious diversity and spiritual needs.	4.11	1.08	-1.26	.91
9. Spiritual assessment is used to identify preferences, beliefs and concerns of the patients regarding end-of-life.	3.74	1.23	-.73	-.49
10. Consultation to a spiritual guide, according to patient's beliefs, is available and accessibly.	3.93	1.20	-.97	-.05
11. Staff provides emotional and spiritual support to patients and families, during the end-of-life process.	4.13	1.08	-1.33	1.12
Patient/family preferences management				
12. Patients are asked about their wishes regarding end-of-life.	3.41	1.30	-.466	-.89
13. Options regarding place of death are offered to patients and families when it is possible.	4.11	1.14	-1.25	.69
14. Cultural aspects are taken in account in end-of-life care (diet, rituals, etc.).	3.96	1.21	-1.05	-.02
15. Communication with patients and families is respectful with cultural diversity.	4.46	.89	-2.05	4.25
Family care				
16. Staff held meetings with families to disclose information, help them in decision-making, determinate patient's wishes and improve communication with patients.	3.87	1.24	-.94	-.18
17. Care plan shows relevant information regarding family relationships.	3.81	1.18	-.73	-.45
18. Once different options are stated, care plan is implemented regarding patients and families preferences.	4.12	1.09	-1.34	1.06
19. Consultation to social worker is available and accessibly.	4.22	1.22	-1.52	1.12
20. Staff supports families during the advanced chronic illness and at the moment of death.	4.09	1.16	-1.28	.68
21. Consultation to Nurse Case Manager is available and accessibly.	4.12	1.16	-1.28	.70
Bereavement				
22. There is a bereavement programme.	2.80	1.39	.139	-1.30
23. There is an assessment to identify families with complicated grief risk.	2.76	1.35	.139	-1.35
24. Bereavement services are offered to families after patient's death.	2.79	1.43	.139	-1.35

Note. SD= Standard deviation.

Table 2. Factor loadings in exploratory factor analysis (only loadings > .30 are shown), mean, standard deviation and reliability values of each sub-scale.

Items	Physical aspects	Psychological aspects	Spiritual aspects	Patient/family preferences management	Family care	Bereavement
1. Consultation to control pain and other symptoms is available and effective	<u>.707</u>			.386		
2. Pain is assessed and treated effectively	<u>.825</u>					
3. Other symptoms (breathlessness, agitation, nausea) are assessed and treated effectively	<u>.787</u>					
4. Staff has the knowledge and skills needed to care patients at the end-of-life and their families.	<u>.400</u>			.485		
5. There is an effective continuity of care at the end-of-life (hospital wards, ICU, palliative care services, primary care)	<u>.424</u>	.375			.358	
6. Consultation to psychologist is available and accessibly.		<u>.779</u>				
7. Consultation to psychiatric is available and accessibly.		<u>.620</u>				.464
8. Staff is informed and sensible regarding religious diversity and spiritual needs.			<u>.787</u>			
9. Spiritual assessment is used to identify preferences, beliefs and concerns of the patients regarding end-of-life.			<u>.807</u>			
10. Consultation to a spiritual guide, according to patient's beliefs, is available and accessibly.			<u>.650</u>			
11. Staff provides emotional and spiritual support to patients and families, during the end-of-life process.			<u>.427</u>	.447		
12. Patients are asked about their wishes regarding end-of-life.			.389	<u>.668</u>		
13. Options regarding place of death are offered to patients and families when it is possible.	.400			<u>.485</u>		
14. Cultural aspects are taken in account in end-of-life care (diet, rituals, etc.)				<u>.479</u>		.303
15. Communication with patients and families is respectful with cultural diversity.			.502	<u>.365</u>		
16. Staff held meetings with families to disclose information, help them in decision-making, determinate patient's wishes and improve communication with patients.	.314				<u>.564</u>	
17. Care plan shows relevant information	.313	.496			<u>.487</u>	

regarding family relationships.

18. Once different options are stated, care plan is implemented regarding patients and families preferences.					<u>.597</u>	
19. Consultation to social worker is available and accessibly.					<u>.712</u>	
20. Staff supports families during the advanced chronic illness and at the moment of death.					<u>.672</u>	
21. Consultation to Nurse Case Manager is available and accessibly.				.351	<u>.644</u>	
22. There is a bereavement programme.						<u>.746</u>
23. There is an assessment to identify families with complicated grief risk.		.337				<u>.804</u>
24. Bereavement services are offered to families after patient's death.						<u>.708</u>
Eigenvalues	1.33	1.05	2.21	1.18	7.25	1.77
% of variance	10.53%	7.61%	10.93%	9.81%	12.12%	10.66%
Mean score (SD)	21.42 (3.27)	6.67 (2.45)	15.92 (3.50)	15.94 (3.25)	24.23 (4.95)	8.34 (3.50)
Cronbach's α	.756	.628	.755	.671	.792	.790

Table 3. Mean, standard deviation and post-hoc analysis results of NHEOLC regarding the nursing home size.

Size	N	Total Score		Psychological aspects		Family care		Bereavement	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
Small (<30 beds)	25	83.20 a	18.55	4.48 a	2.71	21.52 a	6.23	6.32 a	3.79
Medium (30-59 beds)	125	91.86 b	14.66	6.91 b	2.33	23.92 a, b	5.29	7.90 a, b	3.40
Large (60-120 beds)	106	94.55 b	13.71	6.72 b	2.40	25.03 b	4.25	9.10 b	3.47
Extra Large (>121 beds)	51	94.53 b	15.88	7.04 b	2.45	24.69 b	4.95	8.90 b	3.21

Note. Groups with different subscripts are significantly different at $p < .05$, using Bonferroni test, SD= Standard deviation.

Table 4. Mean, standard deviation and post-hoc analysis results of NHEOLC regarding profession.

Size	Total Score			Psychological aspects		Family care		Bereavement	
	N	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Care assistants	76	90.59 a	14.53	6.58 a	2.44	23.04 a	5.10	8.27 a, b	3.38
Nurses & Physicians	47	91.74 a	16.44	6.21 a	2.71	24.50 a	5.01	7.41 a	3.43
Physiotherapist & Occupational therapists	43	91.81 a	14.54	6.58 a, b	2.24	24.56 a, b	4.16	8.72 a, b	3.70
Psychologists & social workers	141	100.28 b	13.21	7.74 b	1.92	27.08 b	3.73	9.72 b	3.40

Note. Groups with different subscripts are significantly different at $p < .05$, using Bonferroni test, SD= Standard deviation.

Table 5. Means, standard deviation and ANOVA results depending on the subjective perception of the institution, colleagues and own end-of-life care.

	Appropriate (4-5)			Inappropriate (1-3)			<i>F</i>	<i>p</i>
	N	Mean	SD	N	Mean	SD		
Institution	258	94.83	12.92	46	79.59	19.89	45.14	<.001
Colleagues	249	94.16	13.84	55	84.81	18.38	18.04	<.001
Own care	235	94.22	14.55	70	86.70	15.82	13.81	<.001

Note. SD= Standard deviation.