

RESEARCH ARTICLE

Level of Knowledge and Attitudes Towards Palliative Care for People with Advanced Dementia in Spain: Role of Professional and Academic Factors

Pilar Pérez-Ros^{1,2}, Omar Cauli^{1,2,*}, Iván Julián-Rochina^{1,2}, Carol O. Long³ and Elena Chover-Sierra^{1,4,5}

¹Nursing Department, Facultat d'Infermeria i Podologia, University of Valencia, Valencia 46010, Spain; ²Frailty Research Organized Group (FROG), University of Valencia, Valencia 46010, Spain; ³Palliative Care Essentials, Fredericksburg, Virginia, USA; ⁴Nursing Care and Education Research Group (GRIECE), University of Valencia, Valencia 46010, Spain; ⁵Internal Medicine, Consorcio Hospital General Universitario de Valencia, Valencia 46014, Spain

Abstract: Background: Providing quality end-of-life care to individuals with advanced dementia is crucial. To date, little attention has been paid to palliative care knowledge and attitudes toward palliative care for people with advanced dementia in Spain

Objectives: To investigate the knowledge of and attitudes toward palliative care for advanced dementia among registered nurses and physicians in Spain.

Methods: A descriptive, cross-sectional survey design was used. This study included a convenience sample of 402 nurses (n = 290) and physicians (n = 112). Two instruments were administered: demographic characteristics and Spanish version of the Questionnaire of Palliative Care for Advanced Dementia (qPAD-SV). Descriptive statistics and multiple regression were used for data analysis.

Results: Overall, the nurses and physicians had moderate mean scores for both knowledge of and attitudes regarding palliative care for advanced dementia. Physicians had a higher level of knowledge ($p < 0.05$) compared to nurses. Additionally, physicians and nursing staff who had professional experience/education in geriatrics and those who had received palliative care and hospice training had greater ($p < 0.01$) knowledge of palliative care. In addition, healthcare professionals who had received dementia care training and who had worked in nursing homes had higher levels ($p < 0.05$) of knowledge and attitudes toward palliative care.

Conclusion: This study indicates the need to provide nurses and physicians with more education for select groups of professionals who have had limited education and experience in caring for older adults with advanced dementia.

Keywords: Palliative care, specialist nurse, training, attitudes, education, advanced dementia.

1. INTRODUCTION

Alzheimer's disease and other dementias are major public health problems; they are a lethal growing cause of death internationally [1, 2]. The prevalence of Alzheimer's disease in Europe was estimated at 5.05% (in men 3.31% and in women, 7.13%), and increased with age [3]. The number of deaths attributed to dementia increased by 526% in the last 20 years [4], representing the sixth leading cause of death in Spain and similar to other countries [5]. Caring for people with dementia raise ethical issues in the course of the disease, such as the determination of their levels of autonomy, decision-making health care decisions, the announcement, diagnosis, treatment associated with psychosocial education of the family, end-of-life care [6, 7].

Palliative care has historically developed with a focus on cancer. However, rapid global aging has brought renewed attention to palliative care for chronic non-cancer diseases such as dementia in the older (1-4). The boundaries between geriatrics and palliative care are therefore blurred [8-10], and overlap has been identified in terms of what geriatricians and palliative care specialists do or could do (5, 6). In Spain, palliative medicine and geriatrics share care levels in hospitals, residences and homes. They do it from a medical perspective and also from a nursing [8-13]. Expert opinion on palliative care in Europe has emphasized that dementia patients face unmet needs in the final stages of the disease and are frequently subjected to futile interventions. They experience unnecessary recurrent hospitalizations, inadequate pain management, use of antibiotics to treat pneumonia to prolong life, artificial hydration and nutrition to treat dehydration and nutritional problems, often due to inadequate knowledge and understanding of palliative care and minimal staff education [14, 15]. As a result, people with advanced dementia are less likely to be referred to palliative care or

*Address correspondence to this author at the Nursing Department, Facultat d'Infermeria i Podologia, University of Valencia, Valencia 46010, Spain and Frailty Research Organized Group (FROG), University of Valencia, Valencia 46010, Spain; E-mail: Omar.Cauli@uv.es

prescribed fewer palliative care medications for pain and symptom management compared to people without dementia [16].

Nursing and medical staff in institutional and community-based long-term settings (LTC) often lack palliative care education about people with advanced dementia, and this can lead to suboptimal care, compromised physical status, re-hospitalization of people with dementia, and increased healthcare costs [17, 18]. Previous studies have reported that nursing home residents with advanced dementia were more likely to experience burdensome interventions if their caregivers had a poor understanding of dementia progression and prognosis, which in turn influenced attitudes toward palliative care provided to terminally ill residents [6]. Jones and co-workers [19] also investigated the knowledge and understanding of dementia of staff working in dementia care units and found that most had low levels of understanding about late-stage dementia; furthermore, some believed that dementia education and training should only be provided to new employees. In addition, Chang *et al.* [20] reported that healthcare professionals lacked advanced dementia assessment and management skills, particularly pain assessment and management. A pioneering study in this field showed that level of knowledge about dementia contributed to attitudes toward care in dementia [21]; that is, healthcare providers who lacked knowledge about palliative care were less confident in providing high-quality care to terminally ill residents. The researchers asserted that, in addition to providing education about advanced dementia, it is critical to introduce palliative care concepts to healthcare facility staff, which in turn can improve residents' quality of life. Nurses and physicians are the main providers of palliative care and important medical decisions in the advanced stage of the disease.

To improve the knowledge, skills, and attitudes about palliative care for advanced dementia of nursing staff in health care facilities, it is vital to provide educational programs on palliative care [22, 23]. In order to develop comprehensive and specific educational programs for palliative care for advanced dementia, it is necessary to explore the knowledge and attitudes of healthcare staff towards palliative care for people with advanced dementia. Therefore, this study aimed to investigate the professional and academic factors that contribute to the knowledge and attitudes of registered nurses and physicians in Spain. This study will serve as a basis for developing educational intervention programs for healthcare professional who care for or will care for individuals with dementia.

2. MATERIALS AND METHODS

2.1. Design

A descriptive cross-sectional study was developed between June and December 2021 in Spain.

2.2. Population and Sample

Health professionals (medical doctors and nurses who gave informed consent) throughout Spain participated in an online survey. A non-probabilistic purposive sampling using social internet networks (Facebook, Twitter, and Instagram) helped the recruitment. Finally, 402 professionals from both categories participated in the survey.

2.3. Data Collection Instrument

A 2-part online form was created using the Google forms platform. In the first part, data was collected to characterize the sample and establish differences between groups. In addition to the age and gender of the participants, we collected the following variables related to academic and professional training and work experiences: (i) professional category (physician or nurse), (ii) highest educational level, (iii) years of professional experience in healthcare, (iv) having a specialty in their profession and which specialty they have, (v) actual work setting, (vi) having previous or actual experience in caring of people with advanced dementia, (vii) setting where they worked with people with advanced dementia, (viii) years of experience working with older people with advanced dementia, (ix) having (or not) education in the field of palliative care, (x) type of education in palliative care received.

The second part included the Spanish version of the qPAD questionnaire (qPAD-SV)[24]. This instrument developed initially by Long *et al.* [25], consisted of two different subscales, one of them with 23 questions (correct, incorrect, don't know) used to assess the level of knowledge about palliative care in people with advanced dementia, and the second one, with 12 assessment evaluated with a 5 point Likert-type scale (1-Strongly disagree; 2-Disagree; 3-Neutral; 4-Agree; 5-Strongly agree) analyzes attitudes towards palliative care in advanced dementia.

The knowledge part of the questionnaire consisted of three subscales: 1-Anticipating Needs (items 1, 7, 9, 11, 14, 18, 21, and 23), 2-Preventing Negative Outcomes (items 2, 3, 4, 5, 6, 10, 13, 15, 17, 19 and 20) and 3-Insight and Intuition (items 8, 12, 16 and 22); also the attitudes subscale had three dimensions: 1-Job Satisfaction Needs (items 6 to 12), 2- Perceptions and Beliefs (items 1 to 3), and 3-Work Setting Support of Families (items 4 and 5). A previous study validated this instrument in the Spanish language showed adequate indexes regarding its validity (CVI = 0.9; correlation with external criteria 0.86 and 0.92) and reliability (Cronbach's alpha = 0.78 for global questionnaire, 0.63 for knowledge subscale and 0.95 for attitudes subscale) [24]. The online questionnaire was distributed among health professionals using the social networks Facebook and Twitter with a message inviting them to participate in the study.

2.4. Ethical Aspects

Each questionnaire was accompanied by invitation to participate letter regarding the study, which also served as the informed consent, which had to be completed as a response to a final question. All personally identifiable information, or PII, was protected. The study was approved by the Ethics Committee of the University of Valencia (Valencia, Spain) (protocol number 158186, date 4th march 2021).

2.5. Statistical Analysis

Descriptive statistics were computed to characterize the sample and data distribution and check assumptions. The variables were reported as proportions and/or means and standard deviations (SD). The Kolmogorov-Smirnov test was used to assess normality. Parametric (t-test) and non-

parametric testing (U Mann Whitney test) were used to compare quantitative variables, while (chi-squared test) were used for categorical variables. The Spearman correlation coefficient was used for the analysis between quantitative variables. Two-factor model between subjects as performed to analyze qPAD-SV knowledge and attitude scores by discipline (nurses and physicians) according to specialty, current work setting and type of palliative care education. Effect sizes (η^2p) for analysis of variance (ANOVA) were also calculated, with values of 0.01 to 0.057 considered to represent a small effect; 0.058 to 0.137 a moderate effect; and 0.138 or more a large effect [26].

In order to adjust the p-value for multiple comparisons, Bonferroni corrections were calculated with a significance level of $p < 0.05$. In order to find out which factors influence higher qPAD-SV scores, we first categorized the qPAD-SV knowledge scores as follows. The qPAD-SV knowledge score ranges from 0 to 23, so the higher scores of the variable qPAD knowledge were categorized according to the highest quartile score, exactly between 17 and 23 points. The qPAD-SV attitude score ranges from 12 to 60, so the variable qPAD-SV attitudes higher scores were created with the highest quartile scores between 48 and 60. Once these new variables were obtained, two binary logistic regression models, one for qPAD-SV knowledge with higher scores and another for qPAD-SV attitudes with higher scores, were run to determine which factors were most strongly related to higher scores. The variables age, gender, professional category, type of training in palliative care, type of specialty, and previous experience in cancer care were included. Study data were entered in MS Excel spreadsheets, and statistical analysis was performed using the SPSS statistical package (version 23.0, IBM Corp., Armonk, NY, USA, 2013).

3. RESULTS

3.1. Sample Description

A total of 402 questionnaires were completed by Spanish nurses and physicians. Most of the participants were nurses (71.9%), most identified as women, and most were younger than the physician group (Table 1). No missing data were found. Of the participants with a specialty, the majority worked in Family or Primary Care settings (see Table 1 for details). A high percentage (81.35%) of the participants currently work with patients with advanced dementia, mainly in primary care. The mean number of years working with this type of patient was higher in physicians than in nurses (16.02 vs. 7.91 years). A high percentage of participants reported having received training in palliative care (89.55%). Most of the training chosen was postgraduate and/or continuing education in nursing and medicine disciplines (Table 1)

3.2. Knowledge and Attitudes Scores

The mean knowledge of care for people with advanced dementia assessed through the qPAD-SV was 16.54 (2.78) points, finding significant differences according to discipline with higher scores in the physicians 16.99 vs. 16.37, MD= 0.63, 95CI: 0.06-1.12; $p = 0.029$). Similarly, differences were found in the subscale "needs" 5.67 vs. 5.06, MD= 0.61, 95CI: 0.29-0.93; $p < 0.001$). No differences were found in the subscale "prevent" (8.49 vs. 8.60) and "insight" (2.83 vs.

2.7). The total qPAD-SV attitude score was 43.33 (8.54) with no differences by discipline but higher scores for physicians (44.38 vs. 42.93). There were differences in the "perception" subscales (12.42 vs. 11.48), MD= 0.94, 95CI: 0.52-1.36; $p < 0.001$] and "support" (7.13 vs. 6.7, MD= 0.42, 95CI: 0.03-0.82; $p = 0.036$). There were no differences in the "job satisfaction" subscale (24.8 vs. 24.75).

To determine the reliability of the values in the population analyzed, Cronbach's Alpha was calculated and was determined to be an acceptable value ($\alpha = 0.728$). The itemized responses of the total sample from the qPAD-SV knowledge and qPAD-SV attitudes (Supplementary File 1)

A negative correlation was observed in physicians between qPAD-SV knowledge total score and years of professional experience ($\rho = -0.251$; $p = 0.008$), whereas in nursing professionals, this correlation was positive ($\rho = 0.115$; $p = 0.049$) as well as in those working in advance dementia ($\rho = 0.116$; $p = 0.006$). There was also a positive correlation in nurses between qPAD-SV attitude and hours of AD training ($\rho = 0.219$ $p = 0.003$) and time spent in the work experience in AD ($\rho = 0.330$; $p < 0.001$).

3.3. Analysis of Knowledge Scores According to Discipline

We proceeded to analyze the differences in scores obtained according to discipline in knowledge and attitudes towards the care of people with advanced dementia according to their specialty, current place of employment in caring for patients with advanced dementia and the type of palliative care education. A statistically significant model was found for qPAD-SV knowledge scores according to discipline and specialty with a moderate effect size ($\eta^2p = 0.090$) (Table 2).

Physicians scored higher than nurses on most of the variables analyzed (Fig. 1, and Table 2). Nurses with other specialties had lower scores than the rest. These differences were not observed in the physician group. A similar pattern was also found in terms of the type of palliative care education received ($\eta^2p = 0.084$). The higher the academic degree, the higher the scores. There was greater knowledge among physicians and nurses who had studied for a Master's degree being higher than the physicians' scores (MD=-2; 95CI: -3.88, 0.12; $p < 0.001$) (Table 2, Fig. 1).

3.4. Analysis of Attitudes According to Discipline

With regard to qPAD-SV attitude scores, a statistically significant model was also found according to discipline and specialty with a moderate effect size ($\eta^2p = 0.078$), advanced dementia current work setting with a moderate effect size ($\eta^2p = 0.101$) and the type of education with a moderate effect size ($\eta^2p = 0.091$) (Table 3). Physicians scored higher than nurses on most of the variables analyzed, with those with a specialty in geriatrics and the remaining group of other specialties standing out (Fig. 1 and Table 3). Professionals who do not currently work with patients with advanced dementia have the lowest scores in this category. With regard to the type of training, higher scores were observed for higher academic training, with higher scores again being found for Master's degree training for physicians than for nurses being higher the physicians scores (MD=-5.75; 95CI: -11, 0.18; $p < 0.05$).

Table 1. Characteristics of the sample.

-	Total Number of Participants (n = 402) % (n)	Nurses (n = 290) % (n) Over Total Number of Participants	Physicians (n = 112) % (n) Over Total Number of Participants	p Value
Age (years) Mean $\pm$ SD	44.63 $\pm$ 10.75	42.87 $\pm$ 10.56	49.18 $\pm$ 9.93	<0.001 ^u
Gender	-	-	-	-
Male	23.63 (95)	50.5 (48)	49.5 (47)	<0.001 ^{x2}
Female	76.37 (307)	78.8 (242)	21.2 (65)	-
Highest Educational Level	-	-	-	-
Graduate	62.93 (253)	75.9 (192)	24.1 (61)	<0.001 ^{x2}
Master's degree	28.11 (113)	75.2 (85)	24.8 (28)	-
Doctorate	8.96 (36)	36.1 (13)	63.9 (23)	-
Years of Healthcare Professional Experience, Mean $\pm$ SD	19.28 $\pm$ 11.03	18.1 $\pm$ 11.11	22.36 $\pm$ 10.23	<0.001 ^u
Type of Specialty (Physicians and Nurses)	49.25 (198)	45.2 (90)	54.8 (108)	<0.001 ^{x2}
Family (Primary care)	50.51 (100)	23 (23)	77 (77)	-
Geriatrics	19.70 (39)	82.1 (32)	17.9 (7)	-
Other	29.79 (59)	59.3 (35)	21.4 (24)	-
Current Country of Employment	401	-	-	0.904 ^{x2}
Spain	92.77 (372)	72.6 (270)	27.4 (102)	-
Latin America	4.99 (20)	70 (14)	30 (6)	-
Other (EU)	2.24 (9)	66.6 (6)	3.33 (3)	-
Work Setting	402	-	-	-
Primary Health Care	35.57 (143)	57.3 (82)	42.7 (61)	<0.001 ^{x2}
Hospital	30.60 (123)	78 (96)	22 (27)	-
Long Term Care	23.13 (93)	87.1 (81)	12.9 (12)	-
Other	10.70 (43)	72.1 (31)	27.9 (12)	-
Previous Experience with Patients with Advanced Dementia	16.67 (67)	94.3 (63)	6 (4)	0.13 ^{x2}
Actual Experience with Patients with Advanced Dementia, yes	69.15 (278)	61.4 (178)	89.3 (100)	<0.001 ^{x2}
Advance Dementia Work Setting	341	-	-	<0.001 ^{x2}
No currently work in AD	4.11 (14)	6.74 (12)	2 (2)	-
Primary Health Care	45.45 (155)	55.5 (97)	58 (58)	-
Hospital	25.22 (86)	10.67 (19)	67 (67)	-
Long Term Care	25.22 (86)	41.57 (74)	12 (12)	-
Years of Experience Working with Older People with Advanced Dementia. Mean $\pm$ SD	10.18 $\pm$ 10.15	7.91 $\pm$ 8.92	16.04 $\pm$ 10.81	<0.001 ^u

(Table 1) contd.....

-	Total Number of Participants (n = 402) % (n)	Nurses (n = 290) % (n) Over Total Number of Participants	Physicians (n = 112) % (n) Over Total Number of Participants	p Value
Self-reported Education in Palliative Care, yes	89.55 (360)	89.65 (260)	89.3 (100)	0.105 ^{z2}
Type of Education in Palliative Care	-	-	-	<0.001 ^{z2}
No education	10.45 (42)	10.34 (30)	10.71 (12)	-
Undergraduate	14.92 (60)	17.93 (52)	7.16 (8)	-
Continuing or postgraduate	66.67 (268)	66.2 (192)	67.85 (76)	-
Master's degree	7.96 (32)	5.5 (16)	14.28 (16)	-
Previous Work Experience with Oncologic Patients	54.98 (221)	64.3 (142)	35.7 (79)	0.001 ^{z2}

Note: ^{z2} Chi square test

^u U mann Whitney test

Table 2. Two-factor factor model between subjects between qPAD-SV knowledge score by discipline (nurses and physicians) according to other study variables.

-	Total qPAD-SV Knowledge Score	Total qPAD-SV Knowledge Score by Discipline		Mean Difference (95% CI)	F	p	Partial η²
		Nurse	Physician				
Specialty							
No Specialty	15.19 (0.68)	16.13 (2.74)	14.25 (2.07)	1.87 (0.74, 4.51)	5.28	<0.001	0.09
Other	16.06 (0.36)	15.29 (0.45)	16.83 (0.55)	-1.55 (-2.94,0.15)*			
Family	17.41 (0.31)	17.83 (0.54) ^b	17 (0.29)	0.83 (-0.38,2.03)			
Geriatrics	18.5 (0.54) ^a	18 (0.45) ^c	19 (0.97)	-1 (-3.11,1.11)			
Currently Advance Dementia Work Setting							
Not Currently Employed	14.85 (1.1)	14.25 (0.82)	15.5 (1.99)	-1.25 (-5.49, 2.99)	1.75	0.097	0.035
Primary Health Care	16.69 (0.23)	16.27 (0.29)	17.1 (0.37)	-0.84 (-1.76,0.09)			
Hospital	16.65 (0.37)	16.24 (0.35)	17.05 (0.65)	-0.81 (-2.26, 0.63)			
Long Term Care [†]	16.53 (0.44)	16.49 (0.33)	16.58 (0.82)	-0.11 (-1.83,1.63)			
Type of Palliative Care Education							
No Education	16.33 (0.47)	16.37 (1.40)	16.25 (3.11)	0.12 (-1.74, 1.97)	1.81	0.031	0.084
Undergraduate	15.82 (0.62)	15.69 (0.38)	16.63 (0.96)	-0.93 (-2.95,1.1)			
Postgraduate or Workplace Training	16.65 (0.2)	16.56 (0.21)	16.98 (0.35)	-0.32 (-1.06, 0.41)			
Master’s Degree	17.25 (0.48)	16.25 (0.68)	18.25 (0.68)	-2 (-3.88, 0.12) **			

Note: [†] Nursing homes, hospice, care day centers

^a Significant between Geriatrics and Other**; Geriatrics and No specialty**

^b Significant between Family and Other **

^c Significant between Geriatrics and No specialty**; Geriatrics and other**

* Significant at $p < 0.005$

** Significant at $p < 0.012$ Bonferroni correction, significant p -value <0.012

As (Fig. 1) shows, qPAD-SV attitudes scores behave similarly to qPAD-SV knowledge scores (Fig. 1). Attitudes were similar between disciplines in the family specialty and behaved differently in knowledge (Figs. 1A and 1B). The

long-term care workplace unified knowledge between disciplines and promotes a better attitude for nursing professionals (Fig. 1C and 1D).

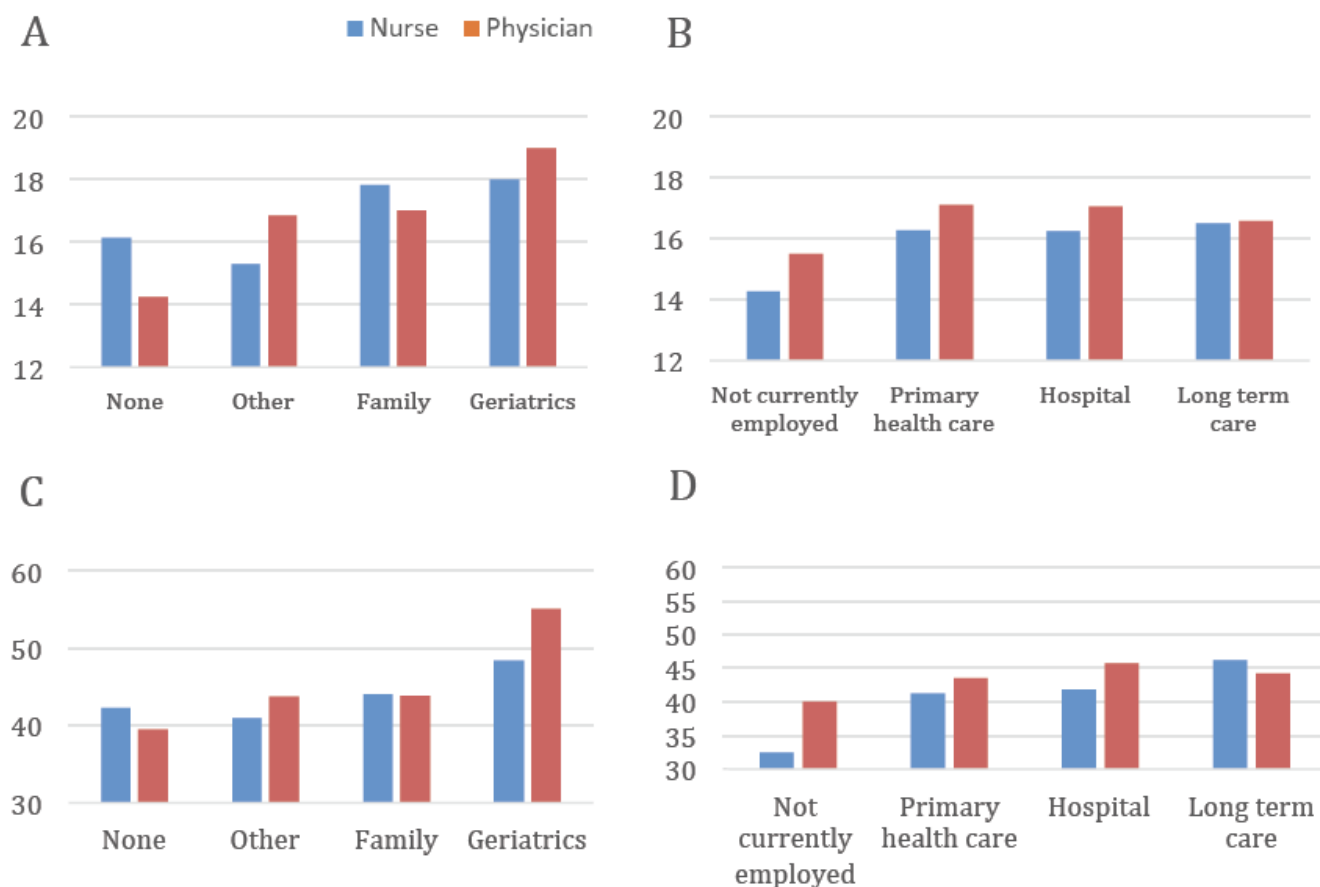


Fig. (1). qPAD-SV Knowledge means score discipline according to the type of (A) specialty, (C) advanced dementia work setting and qPAD-SV attitudes means score discipline according to the type of (B) specialty, (D). (A higher resolution / colour version of this figure is available in the electronic copy of the article).

Note: Legend: * significant at $p < 0.05$

3.5. Analysis of Professional and Academic Factors Associated with the Highest Level of Knowledge and Attitudes

Finally, to determine which factors have the greatest influence on the highest qPAD-SV scores, two binary logistic regressions were performed, one for qPAD-SV knowledge and one for qPAD-SV attitudes. The percentage of participants with highest scores was 40.5% in qPAD-SV knowledge (36.6% nurses vs. 50.9% physicians) and 28.6 in qPAD-SV attitudes (27.9% nurses and 30.4% physicians).

The knowledge model was statistically significant for the highest qPAD-SV knowledge scores, with an R^2 of 0.118. The family specialty (OR = 2.89; 95CI: 1.64-5.11; $p < 0.001$) and geriatrics (OR = 3.67; 95CI: 1.68-7.99; $p = 0.001$) have the greatest influence independent from the professional category. Those completing a master's degree (OR = 5.17; 95CI: 0.93-28.66; $p = 0.060$) are likely to acquire more knowledge. The model is statistically significant, with an R^2 of 0.04 for the highest scores in qPAD-SV attitudes. Only the specialty of geriatrics yielded the highest scores (OR = 3.02; 95CI: 1.42-6.44; $p = 0.004$).

4. DISCUSSION

Our aim was to explore the knowledge and attitudes of healthcare staff towards palliative care for people with advanced dementia and to know what factors contribute to the knowledge and attitudes. From this, we can develop comprehensive and specific educational programs for palliative care for advanced dementia.

Our sample presents similar socio-demographic characteristics to other studies in Spain and abroad [27]. The levels of knowledge and attitudes was higher in the group of healthcare professionals specializing in geriatrics with a moderate size effect. Specialisation allows both physicians and nurses to increase their knowledge. The type of training received and the place of work were not related to the level of knowledge and professional category, but it was found that physician training increased more than that of nurses. The need to include more training in undergraduate studies in the professions responsible for the care of these people is a fact, as this population is found in hospitals, emergency rooms, hospital admissions and not only in the socio-sanitary

Table 3. Two-factor factor model between subjects between qPAD-SV attitude score by discipline (nurses and physicians) according to other study variables.

-	Total qPAD-SV Attitude Score	Total qPAD-SV Attitude Score by Discipline		Mean Difference (95% CI)	F	p	Partial η ²
		Nurse	Physician				
Specialty							
No specialty	40.88 (2.09)	42.26 (0.58)	39.5 (4.11)	2.76 (-5.4, 10.92)	4.78	<0.001	0.078
Other	42.37 (1.09)	41 (1.39)	43.75 (1.69)	-2.75 (-7.03, 1.56)			
Family	43.97 (0.95)	44.09 (1.67)	43.86 (0.91)	0.23 (1.9, 0.9)			
Geriatrics	51.7 (1.67) ^a	48.41 (1.41)	55 (3.02)	-6.59 (-13.34, 0.15)			
Advance Dementia Work Setting Currently							
No work currently	36.25 (3.19)	32.5 (2.41) ^b	40 (5.90)	-7.5 (-20, 5.04)	5.34	<0.001	0.101
Primary health care	42.41 (0.69)	41.29 (0.85)	43.53 (1.1)	-2.45 (-4.97, 0.48)			
Hospital	43.78 (1.09)	41.88 (1.02)	45.68 (1.91)	-3.8 (-8.07, 0.46)			
Long term care ^f	45.19 (1.3)	46.13 (0.97)	44.25 (2.41)	1.88 (-3.22, 6.99)			
Type of Palliative Care Education							
No training	37.71 (1.38) ^c	37 (1.48) ^d	39.5 (2.34)	-2.5 (-7.94, 2.94),	5.65	<0.001	0.091
Undergraduate	40.87 (1.52)	40.9 (1.11)	40.63 (2.83)	0.28 (-5.7, 6.26)			
Postgraduate or workplace training	44.35 (0.6)	44.32 (0.59)	44.42 (0.94)	0.09 (-2.28, 2.09)			
Master	46.81 (1.42)	43.94 (2.01)	49.69 (2.01) ^e	-5.75 (-11, -0.18)*			

Note: ^a Significant between Geriatrics and Family **; Geriatrics and Other**; Geriatrics and No specialty**

^b Significant between No current work and Primary health care**, Hospital** and Long term care**

^c Significant between No PC training and Postgraduate**; No PC training and Master's degree**

^d Significant between No PC training and Continuing or Postgraduate**

^e Significant between No PC training and Master's degree**

* Significant at $p < 0.05$; **significant at $p < 0.001$

environment [28]. There is a lack of dementia education in undergraduate curricula in health and social care, considering the increase in the population with these needs in the coming years. Few countries offer postgraduate dementia curricula and there is much variability in the provision of dementia education at undergraduate, postgraduate and doctoral levels [29]. Professionals working in long-term care settings displayed higher levels of knowledge as in our country almost 50% percent of individuals living in nursing homes had advanced dementia [30]. These results fit with those observed in a recent study performed by nurses and nursing assistants in Taiwan [9]. These results may differ in other populations as the provision of specific palliative care services varies greatly between European countries. From specific palliative care units to find a person with advanced dementia admitted to any health care setting [31-34].

As previously highlighted, it should keep in mind that besides professional staff working in long-term care settings such as nursing homes and hospices in our context, the need for any health professional to acquire foundational education in palliative care has been postulated by different scientific societies [8, 10]. The implementation of specific palliative care training programs could improve the level as demonstrated in a study performed on eighty-five nursing home

staff working in three large nursing homes in New York City [35].

Our study reveals a significantly higher level of knowledge in the group of physicians in both the knowledge and attitude subscales, except for family and community specialist nurses, who achieve better results than other registered nurses. Other studies performed by healthcare professional in Spain that evaluate the level of training in palliative care not specific to advanced dementia have also found better results among medical doctors than in nurses [36]. These results can be explained in part by the longer duration of physicians' training, in fact, most medical doctors had a medical specialization (4-5 years duration, depending on the specialty). It is important to note that both professional experience and training are two variables that have been shown to be related to a higher level of knowledge in palliative care in various studies of nurses [37].

When analyzing the results for each of the two scales composing the qPAD-SV, we observed significant differences between physicians and nurses in the "anticipating needs" subscale of the knowledge, while in the attitudes subscale, the scores in "perceptions" and "support of families" subscales were again significantly higher in physicians com-

pared to registered nurses. These items assess the perception of professionals in their contact with the families of people with AD who require palliative care. From these results, nurses need to reinforce these aspects of communication/relationship with families [38, 39]. However, when comparing the results in knowledge and in attitudes scores, nurses without a specialty had a higher score than medical doctors without a specialty, suggesting better palliative care education during the bachelor's degree in Nursing compared to a Medicine bachelor. However, different studies carried out among physicians and registered nurses in other countries already show knowledge deficits in the management of people who require palliative care [39-41] but also their desire to improve that level of knowledge to improve their profession for now and the future [42, 43]. Education in palliative care and specifically about caring for people with advanced dementia, requires a substantive overhaul in both undergraduate medicine and nursing programs. This is necessary to ensure that people with advanced dementia receive interventions aligned with their wishes and supported by scientific evidence (or evidence-based) [11, 41]. A palliative care culture is necessary for caring for people with advanced dementia, necessitating that professionals acquire the requisite education and skills that meet the needs of this most vulnerable population [44]

This study has limitations, the first of which is the study design due to self-selection bias. In this type of study, participants who respond to announcements about a survey on palliative care for people with dementia may differ systematically from those who are not included in the survey. For example, these respondents may already be more knowledgeable about the survey topic because of their professional experience or personal interest. Even though the final number of these can be considered high, it cannot be maintained that they are a representative sample of Spanish physicians and nurses since no random sampling was done. The characteristics of the participants are indeed quite heterogeneous, and physicians and nurses from different areas of our country collaborated, so we cannot generalize the results. Also, this type of study does not allow us to know how many respondents who volunteered for the survey completed all the questionnaires

CONCLUSION

Studying the geriatrics specialty increases the knowledge and attitudes of nurses and physicians about advanced dementia to a greater extent than previous experience or type of training. This study indicates the need to provide nurses and physicians with more education for select professionals with limited education and experience in caring for older adults with advanced dementia.

AUTHORS' CONTRIBUTIONS

Pilar Pérez-Ros, Elena Chover-Sierra, Iván Julián-Rochina and Omar Cauli contributed to conceptualization, methodology, data curation, formal analysis, writing - original draft. Carol O. Long contributed to formal analysis, Writing - original draft and Writing - review & editing.

LIST OF ABBREVIATIONS

LTC = Community-based Long-term Settings
qPAD-SV = Questionnaire of Palliative Care for Advanced Dementia

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Informed written consent was obtained from all participants by the Declaration of Helsinki guidelines. This study has been approved by the Ethics Committee of the University of Valencia (Valencia, Spain) (protocol code 1581865 and date of approval 4 March 2021).

HUMAN AND ANIMAL RIGHTS

No animals/humans were used for studies that are the basis of this research.

CONSENT FOR PUBLICATION

Informed consent has obtained from all the participants involved.

STANDARDS OF REPORTING

STROBE guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

Not applicable.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

The authors would like to thank the nurses and physicians for their involvement in the study.

SUPPLEMENTARY MATERIAL

Supplementary material is available on the publisher's website along with the published article.

REFERENCES

- [1] Moga DC, Roberts M, Jicha G. Dementia for the primary care provider. *Prim Care* 2017; 44(3): 439-56. <http://dx.doi.org/10.1016/j.pop.2017.04.005> PMID: 28797371
- [2] Sidani MA, Reed BC, Steinbauer J. Geriatric care issues. *Prim Care* 2017; 44(1): e15-36. <http://dx.doi.org/10.1016/j.pop.2016.09.018> PMID: 28164825
- [3] Niu H, Álvarez-Álvarez I, Guillén-Grima F, Aguinaga-Ontoso I. Prevalence and incidence of Alzheimer's disease in Europe: A meta-analysis. *Neurologia* 2017; 32(8): 523-32. <http://dx.doi.org/10.1016/j.nrl.2016.02.016> PMID: 27130306
- [4] Lozano R, Naghavi M, Foreman K, *et al.* Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 2012; 380(9859): 2095-128.

- [http://dx.doi.org/10.1016/S0140-6736\(12\)61728-0](http://dx.doi.org/10.1016/S0140-6736(12)61728-0) PMID: 23245604
- [5] Gaugler J, James B, Johnson T, Scholz K, Weuve J. 2016 Alzheimer's disease facts and figures. *Alzheimers Dement* 2016; 12(4): 459-509.
<http://dx.doi.org/10.1016/j.jalz.2016.03.001> PMID: 27570871
 - [6] Sampson EL. Palliative care for people with dementia. *Br Med Bull* 2010; 96(1): 159-74.
<http://dx.doi.org/10.1093/bmb/ldq024> PMID: 20675657
 - [7] Caron CD, Griffith J, Arcand M. End-of-life decision making in dementia: The perspective of family caregivers. 2016; 4: 113-36.
<http://dx.doi.org/10.1177/1471301205049193>
 - [8] Oishi A, Murtagh FEM. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals. *Palliat Med* 2014; 28(9): 1081-98.
<http://dx.doi.org/10.1177/0269216314531999> PMID: 24821710
 - [9] Chen IH, Lin KY, Hu SH, *et al.* Palliative care for advanced dementia: Knowledge and attitudes of long-term care staff. 2018; 27: 848-58.
 - [10] Albers G, Froggatt K, Van den Block L, *et al.* A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective. *BMC Palliat Care* 2016; 15(1): 47.
<http://dx.doi.org/10.1186/s12904-016-0118-3> PMID: 27169558
 - [11] Pautex S, Roller-Wirnsberger R, Singler K, Van den Noortgate N. Palliative care competencies for geriatricians across Europe: a Delphi consensus study. *Eur Geriatr Med* 2021; 12(4): 817-24.
<http://dx.doi.org/10.1007/s41999-020-00445-5> PMID: 33523375
 - [12] Visser R, Borgstrom E, Holti R. The overlap between geriatric medicine and palliative care: a scoping literature review. *J Appl Gerontol* 2021; 40(4): 355-64.
<http://dx.doi.org/10.1177/0733464820902303> PMID: 32008412
 - [13] Goldsmith J, Wittenberg-Lyles E, Rodriguez D, Sanchez-Reilly S. Interdisciplinary geriatric and palliative care team narratives: collaboration practices and barriers. *Qual Health Res* 2010; 20(1): 93-104.
<http://dx.doi.org/10.1177/1049732309355287> PMID: 20019350
 - [14] Quinn KL, Stukel T, Stall NM, *et al.* Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study. *BMJ* 2020; 370: m2257.
<http://dx.doi.org/10.1136/bmj.m2257> PMID: 32631907
 - [15] Houttekier D, Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Hospitalizations of nursing home residents with dementia in the last month of life: Results from a nationwide survey. *Palliat Med* 2014; 28(9): 1110-7.
<http://dx.doi.org/10.1177/0269216314535962> PMID: 24866759
 - [16] Bayer A. Death with dementia—the need for better care. *Age Ageing* 2006; 35(2): 101-2.
<http://dx.doi.org/10.1093/ageing/afj033> PMID: 16414963
 - [17] Harasym P, Brisbin S, Afzaal M, *et al.* Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. *BMJ Open* 2020; 10(8): e037466.
<http://dx.doi.org/10.1136/bmjopen-2020-037466> PMID: 32759247
 - [18] Ersek M, Carpenter JG. Geriatric palliative care in long-term care settings with a focus on nursing homes. *J Palliat Med* 2013; 16(10): 1180-7.
<http://dx.doi.org/10.1089/jpm.2013.9474> PMID: 23984636
 - [19] Jones C, Moyle W, Stockwell-Smith G. Caring for older people with dementia: An exploratory study of staff knowledge and perception of training in three Australian dementia care facilities. *Australas J Ageing* 2013; 32(1): 52-5.
<http://dx.doi.org/10.1111/j.1741-6612.2012.00640.x> PMID: 23521737
 - [20] Chang E, Daly J, Johnson A, *et al.* Challenges for professional care of advanced dementia. 2009; 15: 41-7.
<http://dx.doi.org/10.1111/j.1440-172X.2008.01723.x>
 - [21] Kada S, Nygaard HA, Mukesh BN, Geitung JT. Staff attitudes towards institutionalised dementia residents. *J Clin Nurs* 2009; 18(16): 2383-92.
<http://dx.doi.org/10.1111/j.1365-2702.2009.02791.x> PMID: 19583668
 - [22] Powers BA, Watson NM. Meaning and practice of palliative care for nursing home residents with dementia at end of life. *Am J Alzheimers Dis Other Dement* 2008; 23(4): 319-25.
<http://dx.doi.org/10.1177/1533317508316682> PMID: 18453644
 - [23] Stevenson DG, Bramson JS. Hospice care in the nursing home setting: a review of the literature. *J Pain Symptom Manage* 2009; 38(3): 440-51.
<http://dx.doi.org/10.1016/j.jpainsymman.2009.05.006> PMID: 19735904
 - [24] Chover-Sierra E, Pérez-Ros P, Julián-Rochina I, Long CO, Cauli O. Knowledge and attitudes towards palliative care: validation of the spanish version of questionnaire on palliative care for advanced dementia. *Healthc* 2022; 10: 656.
<http://dx.doi.org/10.3390/healthcare10040656>
 - [25] Long CO, Sowell EJ, Hess RK, Alonzo TR. Development of the questionnaire on palliative care for advanced dementia (qPAD). *Am J Alzheimers Dis Other Dement* 2012; 27(7): 537-43.
<http://dx.doi.org/10.1177/1533317512459793> PMID: 23002199
 - [26] Cohen J. Statistical power analysis for the behavioral sciences. *Stat Power Anal Behav Sci* 2013.
<http://dx.doi.org/10.4324/9780203771587>
 - [27] Lasmarias C, Subirana-Casacuberta M, Mancho N, Aradilla-Herrero A. Spanish cross-cultural adaptation and psychometric properties of the advance care planning self-efficacy: a cross-sectional study. *J Palliat Med* 2021; 24(12): 1807-15.
<http://dx.doi.org/10.1089/jpm.2020.0653> PMID: 34143670
 - [28] Jones A, MacLagan LC, Watt JA, *et al.* Reasons for repeated emergency department visits among community-dwelling older adults with dementia in Ontario, Canada. *J Am Geriatr Soc* 2022; 70(6): 1745-53.
<http://dx.doi.org/10.1111/jgs.17726> PMID: 35238398
 - [29] Hvalič-Touzery S, Skela-Savič B, Macrae R, *et al.* The provision of accredited higher education on dementia in six European countries: An exploratory study. *Nurse Educ Today* 2018; 60: 161-9.
<http://dx.doi.org/10.1016/j.nedt.2017.10.010> PMID: 29132018
 - [30] Damián J, Valderrama-Gama E, Rodríguez-Artalejo F, Martín-Moreno JM. Health and functional status among elderly individuals living in nursing homes in Madrid. *Gac Sanit* 2004; 18(4): 268-74.
[http://dx.doi.org/10.1016/S0213-9111\(04\)72013-0](http://dx.doi.org/10.1016/S0213-9111(04)72013-0) PMID: 15324637
 - [31] Illiffe S, Davies N, Manthorpe J, *et al.* Improving palliative care in selected settings in England using quality indicators: a realist evaluation. *BMC Palliat Care* 2016; 15(1): 69.
<http://dx.doi.org/10.1186/s12904-016-0144-1> PMID: 27484414
 - [32] Mitchell SL, Black BS, Ersek M, *et al.* Advanced dementia: state of the art and priorities for the next decade. *Ann Intern Med* 2012; 156(1_Part_1): 45-51.
<http://dx.doi.org/10.7326/0003-4819-156-1-201201030-00008> PMID: 22213494
 - [33] Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med* 2004; 19(10): 1057-63.
<http://dx.doi.org/10.1111/j.1525-1497.2004.30329.x> PMID: 15482560
 - [34] Bausewein C, Daveson BA, Currow DC, *et al.* 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. *Palliat Med* 2016; 30(1): 6-22.
<http://dx.doi.org/10.1177/0269216315589898> PMID: 26068193
 - [35] Long C. Palliative care for advanced dementia: nursing home staff knowledge and attitudes (S714). *J Pain Symptom Manage* 2017; 53(2): 417.
<http://dx.doi.org/10.1016/j.jpainsymman.2016.12.224>
 - [36] Martín-Martín J, López-García M, Medina-Abellán MD, *et al.* Physicians' and nurses' knowledge in palliative care: Multidimensional regression models. *Int J Environ Res Public Health* 2021; 18(9): 5031.
<http://dx.doi.org/10.3390/ijerph18095031> PMID: 34068622

- [37] Leber W, McMullen H, Anderson J, *et al.* Promotion of rapid testing for HIV in primary care (RHIVA2): a cluster-randomised controlled trial. *Lancet HIV* 2015; 2(6): e229-35.
[http://dx.doi.org/10.1016/S2352-3018\(15\)00059-4](http://dx.doi.org/10.1016/S2352-3018(15)00059-4) PMID: 26423195
- [38] Hagan TL, Xu J, Lopez RP, Bressler T. Nursing's role in leading palliative care: A call to action. *Nurse Educ Today* 2018; 61: 216-9.
<http://dx.doi.org/10.1016/j.nedt.2017.11.037> PMID: 29245101
- [39] Sekse RJT, Hunsbæk I, Ellingsen S. The nurse's role in palliative care: A qualitative meta-synthesis. *J Clin Nurs* 2018; 27(1-2): e21-38.
<http://dx.doi.org/10.1111/jocn.13912> PMID: 28695651
- [40] Suikkala A, Tohmola A, Rahko EK, Hökkä M. Future palliative competence needs - a qualitative study of physicians' and registered nurses' views. *BMC Med Educ* 2021; 21(1): 585.
<http://dx.doi.org/10.1186/s12909-021-02949-5> PMID: 34789216
- [41] Martínez-Sabater A, Chover-Sierra P, Chover-Sierra E. Spanish nurses' knowledge about palliative care: a national online survey. *Int J Environ Res Public Health* 2021; 18(21): 11227.
<http://dx.doi.org/10.3390/ijerph182111227> PMID: 34769747
- [42] Bolt SR, Meijers JMM, Steen JT, Schols JMGA, Zwaakhalen SMG. Nursing staff needs in providing palliative care for persons with dementia at home or in nursing homes: a survey. *J Nurs Scholarsh* 2020; 52(2): 164-73.
<http://dx.doi.org/10.1111/jnu.12542> PMID: 32039556
- [43] Kim S, Lee K, Kim S. Knowledge, attitude, confidence, and educational needs of palliative care in nurses caring for non-cancer patients: a cross-sectional, descriptive study. *BMC Palliat Care* 2020; 19(1): 105.
<http://dx.doi.org/10.1186/s12904-020-00581-6> PMID: 32652984
- [44] Hodiamont F, Hock H, Ellis-Smith C, *et al.* Culture in the spotlight—cultural adaptation and content validity of the integrated palliative care outcome scale for dementia: A cognitive interview study. *Palliat Med* 2021; 35(5): 962-71.
<http://dx.doi.org/10.1177/02692163211004403> PMID: 33863246

DISCLAIMER: The above article has been published, as is, ahead-of-print, to provide early visibility but is not the final version. Major publication processes like copyediting, proofing, typesetting and further review are still to be done and may lead to changes in the final published version, if it is eventually published. All legal disclaimers that apply to the final published article also apply to this ahead-of-print version.