Nursing staff needs in providing palliative care for persons with dementia at home or in nursing homes: a survey

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Nursing Staff Needs in Providing Palliative Care for Persons With Dementia at Home or in Nursing Homes: A Survey

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Abstract

Purpose: This study aimed to evaluate what types and forms of support nursing staff need in providing palliative care for persons with dementia. Another aim was to compare the needs of nursing staff with different educational levels and working in home care or in nursing homes.
Design: A cross-sectional, descriptive survey design was used.
Methods: A questionnaire was administered to a convenience sample of Dutch nursing staff working in the home care or nursing home setting. Data were collected from July through October 2018. Quantitative survey data were analyzed using descriptive statistics. Data from two open-ended survey questions were investigated using content analysis.
Findings: The sample comprised 416 respondents. Nursing staff with different educational levels and working in different settings indicated largely similar needs. The highest-ranking needs for support were in dealing with family disagreement in end-of-life decision making (58%), dealing with challenging behaviors (41%), and recognizing and managing pain (38%). The highest-ranking form of support was peer-to-peer learning (51%). If respondents would have more time to do their work, devoting personal attention would be a priority.
Conclusions: Nursing staff with different educational levels and working in home care or in nursing homes endorsed similar needs in providing palliative care for persons with dementia and their loved ones.
Clinical Relevance: It is critical to understand the specific needs of nursing staff in order to develop tailored strategies. Interventions aimed at increasing the competence of nursing staff in providing palliative care for persons with dementia may target similar areas to support a heterogeneous group of nurses and nurse assistants, working in home care or in a nursing home.

Home care and nursing home staff have an important role in providing palliative care for persons with dementia and their loved ones (Smythe, Jenkins, Galant-Miecznikowska, Bentham, & Oyebode, 2017). Palliative care is aimed at optimizing the quality of life of persons facing a life-threatening illness and their families (World Health Organization, n.d.). Dementia is an incurable, neurodegenerative disease and a palliative approach to care is recommended for persons with dementia (van der Steen et al., 2014). In the Netherlands, direct nursing staff includes registered nurses, certified nurse assistants (i.e., licenced nurses), and nurse assistants

(Backhaus, 2017). Nursing staff have a prominent role in daily caregiving, and they are generally more accessible than physicians (Albers, Francke, de Veer, Bilsen, & Onwuteaka-Philipsen, 2014; Toles, Song, Lin, & Hanson, 2018). Thereby, they are conveniently positioned to discuss care wishes, to identify burdensome symptoms, and to increase quality of life (van der Steen et al., 2014). However, nursing staff may not feel competent to provide adequate palliative care for persons with dementia; they report difficulties in recognizing and addressing physical, psychosocial, and spiritual care needs, dealing with challenging behaviors, and communicating with persons with dementia (Bolt, van der Steen, Schols, Zwakhalen, Pieters, & Meijers, 2019).

Palliative care for persons with dementia is often complex, and heterogeneous care needs may arise (Perrar, Schmidt, Eisenmann, Cremer, & Voltz, 2015), especially in the advanced stages (Hendriks, Smalbrugge, Galindo-Garre, Hertogh, & van der Steen, 2015; Mitchell et al., 2009). Lacking skills and knowledge among nursing staff may adversely affect the quality of palliative care (Erel, Marcus, & Dekeyser-Ganz, 2017; Mitchell et al., 2009; Robinson et al., 2014). In the Netherlands, only persons needing 24-hr care qualify for nursing home care, which implies that persons with dementia in nursing homes are highly reliant on nursing staff (Maarse & Jeurissen, 2016). The majority of persons with dementia live in the community, and they require appropriate services to support living at home (Saks et al., 2015). Nursing staff working in home care or in nursing homes should be competent to safeguard the quality of (palliative) care. Today, there is limited knowledge about the specific competency needs that may help to close the knowledge and skills gap in the dementia workforce (Surr et al., 2017).

Interventions aimed at increasing the competence of nursing staff should be tailored to their needs and preferences (Smythe et al., 2017; Whittaker, George Kernohan, Hasson, Howard, & McLaughlin, 2006). The needs of nursing staff in providing palliative care for persons with dementia, particularly in the home care setting, have not been assessed in depth (D'Astous, Abrams, Vandrevala, Samsi, & Manthorpe, 2019). Moreover, research investigating and comparing the needs of nursing staff with different educational backgrounds and from different settings in providing palliative care for persons with dementia is scarce. Therefore, the purpose of this study was to evaluate the needs of nursing staff in providing palliative care for persons with dementia. The study aimed to compare nursing staff with different educational levels and

nursing staff working in home care or in nursing homes. Moreover, the study aimed to investigate what forms of support (e.g., digital, educational, emotional) nursing staff prefer.
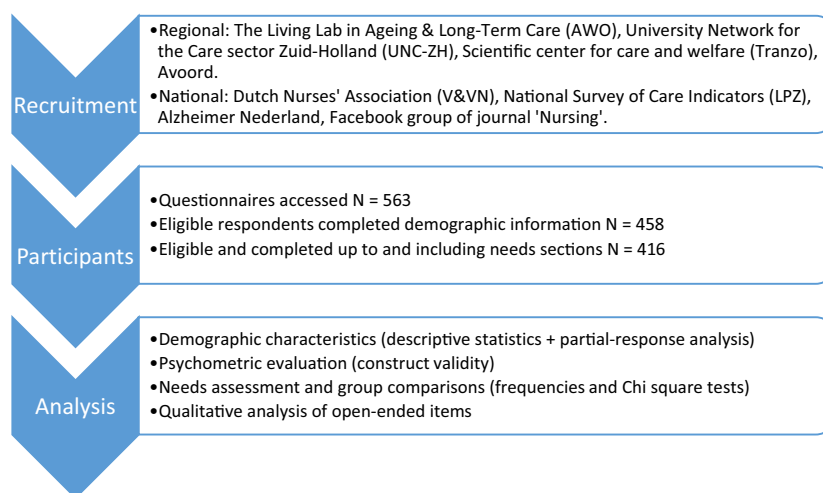
Methods

This cross-sectional, descriptive study is part of the Desired Dementia Care Towards End of Life (DEDICATED) project carried out in The Living Lab in Ageing & Long-Term Care in South Limburg (Verbeek, Zwakhalen, Schols, & Hamers, 2013). DEDICATED aims to develop a tailored intervention to empower nursing staff in providing palliative care for persons with dementia. A web-based questionnaire was administered to explore the needs of nursing staff in several aspects of palliative care in dementia. Data were collected in the Netherlands from July through October 2018, using Qualtrics (Provo, Utah, USA) online survey software. The Medical Ethics Committee approved the study (Zuyderland, METCZ20180079).

Sample, Recruitment, and Procedure

A convenience sample was recruited, and respondents from different sociodemographic areas and organizations were approached to increase representativeness. Eligible participants were: (a) nursing staff members; (b) who had been employed for at least 6 months; (c) currently working in home care or in a nursing home; (d) providing care for older persons (≥65 years of age) with dementia. The investigators shared a hyperlink granting access to the Qualtrics questionnaire with the main contact persons within the collaborating organizations. The contact persons then distributed the invitation with an information letter and a hyperlink to the consent form. Figure 1 provides an overview of the regional and national organizations that distributed the questionnaire. Participation was voluntary. Participants provided written informed consent for anonymous processing of data before they could access the questionnaire by checking a box stating "agreed" and submitting the answer. At the beginning of the questionnaire, participants confirmed they met the inclusion criteria and they were asked to indicate via which route the questionnaire had reached them.

Questionnaire Design

Because no instrument that matched this study's specific aims existed, a questionnaire was designed to explore the needs of nursing staff in providing palliative care for persons with dementia. The questionnaire

Recruitment
- Regional: The Living Lab in Ageing & Long-Term Care (AWO), University Network for the Care sector Zuid-Holland (UNC-ZH), Scientific center for care and welfare (Tranzo), Avoord.
- National: Dutch Nurses' Association (V&VN), National Survey of Care Indicators (LPZ), Alzheimer Nederland, Facebook group of journal 'Nursing'.

Participants
- Questionnaires accessed N = 563
- Eligible respondents completed demographic information N = 458
- Eligible and completed up to and including needs sections N = 416

Analysis
- Demographic characteristics (descriptive statistics + partial-response analysis)
- Psychometric evaluation (construct validity)
- Needs assessment and group comparisons (frequencies and Chi square tests)
- Qualitative analysis of open-ended items

Figure 1. Flowchart of the study process. [Colour figure can be viewed at wileyonlinelibrary.com]

included items covering the main focus areas of the DEDICATED project: palliative caregiving and end-of-life communication, and interprofessional collaboration and transitions of care. The full questionnaire is provided as supplementary material (Table S1). This article focuses on the sections regarding palliative caregiving and end-of-life communication.

Initial item development was informed by results of earlier work to investigate needs in palliative caregiving for persons with dementia (Bolt, van der Steen, Schols, Zwakhalen, Pieters, & Meijers, 2019; Bolt, van der Steen, Schols, Zwakhalen, & Meijers, 2019; Bolt, Verbeek, Meijers, & van der Steen, 2019). Moreover, the main literature sources used throughout the DEDICATED project involve a white paper established by the European Association for Palliative Care, with recommendations for palliative care for persons with dementia (van der Steen et al., 2014) and a systematic review of the palliative care needs of persons with dementia (Perrar et al., 2015). Lastly, the End-of-life Professional Caregiver Survey (Lazenby, Ercolano, Schulman-Green, & McCorkle, 2012) informed item development. Three investigators (J.M., S.P., and S.B.) developed items and discussed them with all members of the research team to reach consensus. To establish further face and content validity, the investigators invited a group of key informants (i.e., healthcare professionals, nurse education specialists, and patient representatives) to carefully review the questionnaire and to provide recommendations for improvement. From three local collaborating care organizations, separate test panels of nursing staff (two registered nurses, two certified nurse assistants, and two uncertified nurse assistants per organization) piloted the questionnaire for feasibility and provided feedback for final

improvement. Improvements were mainly in language usage.

The questionnaire asked about the demographic and work-related characteristics: age, sex, location of work (province), current work setting, current job title, years of experience in dementia care, additional training in dementia or palliative care, and self-perceived competence (on a scale from 0 to 10) in providing palliative care for persons with dementia. Thereafter, needs in palliative caregiving and in end-of-life communication were examined, presenting item lists of potential needs (Table S1). The last section showed items on preferred forms of support (Table S1). Respondents could select multiple items. The questionnaire finished with two optional open-ended items: "Are there any other aspects of palliative care for persons with dementia in which you need support?" and "If you had more time to do your work, what would you use it for?"

Analysis

Quantitative analyses were performed using IBM SPSS version 25 (IBM Corp., Armonk, NY, USA). Responses were included if completed at least up to and including the section asking about needs for support in palliative caregiving and end-of-life communication. A partial-response analysis was performed, comparing available characteristics of eligible participants that did and did not complete the questionnaire to this point. Chi-square tests and independent t-tests were used. Descriptive statistics were used to present demographic and work-related characteristics, which were compared using chi-square tests. Respondents' self-perceived competence in providing palliative dementia care was

Table 1. Summary of Respondents' Characteristics

Respondent characteristics ($N = 416$)	n	%
Gender		
Female	401	96
Male	15	4
Nursing degree/educational level		
Registered nurse[a]	164	40
Certified nurse assistant	218	52
Uncertified nurse assistant	34	8
Primary work setting[b]		
Nursing home	224	54
Home care	192	46
Additional training[c] in dementia care[d]		
Yes	201	48
No	215	52
Additional training[c] in palliative care[e]		
Yes	186	44
No	230	56
Providing palliative care is…[f]		
…a standard task for all nursing and care staff with a basic education	308	74
…a task for nursing and care staff specialized in palliative care	108	26

[a]Registered nurses included vocationally trained and baccalaureate-educated nurses, and nurse practitioners.
[b]Significant differences between educational levels (chi-square = 32.35, $p < .001$)
[c]Additional training was defined as an educational effort of at least 2 hr outside of one's basic nursing curriculum.
[d]Significant differences between work settings (more often in nursing homes; chi-square = 17.60, $p < .001$) but not educational levels.
[e]Significant differences between educational levels(chi-square = 7.39, $p < .05$) but not work setting.
[f]No differences found between educational levels or work setting.

compared between the different educational levels and the different settings using analysis of variance and an independent t test, respectively; p values of less than .05 were considered to be statistically significant. Pearson's correlations between the respondents' self-perceived competence and summed needs in palliative caregiving (16 items) and end-of-life communication (8 items) were calculated to explore the questionnaire's construct validity. Cronbach's alpha for internal consistency was not calculated, as the items were designed to explore a variety of needs rather than a single construct.

For each item concerning support needs and preferred forms of support, frequencies of the item being endorsed were counted. Chi-square tests were used to explore differences in item endorsement by educational level and work setting. Holm's sequential Bonferroni procedure was applied to adjust for multiple testing (Abdi, 2010). Therein, the smallest p value of a series of tests is significant at $p < .05$ per number

of test items. The second smallest p value is significant at $p < .05$ per number of test items - 1, the third at $p < .05$ per number of test items - 2, and so forth. Assumptions underlying the statistical analyses were tested using Levene's test and Q-Q plots.

Content analysis was used to explore answers to both open-ended questions (Bengtsson, 2016) using NVivo 11 software (QSR International Pty Ltd, headquarters in Doncaster, Victoria, Australia). Initial coding and clustering codes into categories was performed by one researcher (S.B.). Recurring categories were discussed with the research team to allow cross-validation. After fine tuning with the team, a final list of main categories was used to analyze the data a second time to ensure these covered all answers. Frequencies of answers reflecting the established main categories were counted.

Results

The sample included in the analyses comprised 416 respondents, of whom 192 (46%) worked in a home setting and 224 (54%) in a nursing home setting (Table 1). Their mean age was 45.5 (SD 12.1, range 18.0–65.0) years, and they had a mean of 15.6 (SD 10.9, range 0.8–43.0) years of experience in dementia care. Respondents rated their own competence in providing palliative care for persons with dementia with an average score of 7.5 (SD 1.3, range 0–10), indicating an overall good score (Nuffic, 2019). Nursing home staff scored higher (mean 7.9, SD 1.2) than home care staff did (mean 7.2, SD 1.4); t (414) = -4.8, $p < .001$. No differences were found between educational levels (registered nurses, certified nurse assistants, and uncertified nurse assistants).

Considering construct validity, there was a negative correlation between respondents' self-perceived competence and summed needs in caregiving (r = -.30, $p < .001$) and end-of-life communication (r = -.14, $p = .003$). Thus, respondents who feel less competent report more support needs. Respondents' needs were rank ordered by frequencies (Table 2). Most needs did not differ between educational levels and settings (Table S2).

Needs for Support in Palliative Caregiving and End-of-Life Communication

The highest-ranking needs for support in caregiving were recognizing and dealing with challenging behaviors (41%), pain (38%), and emotions (34%); providing guidance in the dying phase (34%); and communicating with persons with severe dementia (33%). The

Table 2. Frequencies for Each Item Regarding Needs in Palliative Caregiving and End-of-Life Communication, in Descending Order (N = 416)

	n (%)
Needs in palliative caregiving	
Recognizing and dealing with certain behavior, such as agitation or aggression	169 (41)
Recognizing discomfort and dealing with pain	156 (38)
Guiding persons with dementia and their loved ones in the dying phase	143 (34)
Recognizing and dealing with emotions, such as sadness, anxiety, or anger	141 (34)
Communicating with persons with severe dementia	139 (33)[a]
Recognizing (the start of) the dying phase	129 (31)
Using (validated) instruments, e.g., for measuring symptoms	113 (27)
Opportunities to get to know the person with dementia and their loves ones well	109 (26)
My personal contribution to meaningful activities for persons with dementia	107 (26)
Involving loved ones in the entire care process	103 (25)
Recognizing and optimizing physical comfort	89 (21)
Dealing with religious and existential questions	84 (20)
Supporting loved ones after bereavement	75 (18)
Feeling more comfortable interacting with loved ones	41 (10)
Feeling more comfortable when caring for persons with dementia	36 (9)[a]
Providing daily care/assisting self-care (ADL and IADL)	29 (7)[b]
Needs in end-of-life communication	
Dealing with disagreement between loved ones about end-of-life care	240 (58)
Involving people with dementia in end-of-life decision making	171 (41)[b]
Guiding people with dementia and their loved ones to document end-of-life wishes	165 (40)
Having a conversation about the end of life	136 (33)
Involving loved ones in end-of-life decision making	130 (31)
Being able to retrieve documented end-of-life wishes	118 (28)
Deciding on the right time to initiate end-of-life communication	116 (28)
Feeling comfortable talking about the end of life with people with dementia and their loved ones	101 (24)

[a]Significant differences between settings.Details are shown in Table S2.
[b]Significant differences between educational levels. Details are shown in Table S2.

highest-ranking needs for support in end-of-life communication were dealing with family disagreement (58%) and involving persons with dementia in end-of-life decision making (41%). There were significant differences between settings in support needs in "communicating with persons with severe dementia," which was endorsed by 42% of the home care respondents and 23% of nursing home respondents (chi-square = 15.95, $p <$ .001). Needs in "feeling comfortable when caring for persons with dementia" was endorsed by 13% of the

home care respondents and 3% of nursing home respondents (chi-square = 13.78, $p <$ .001). Nursing staff with different educational levels differed in support needs in "providing daily care/assisting self-care (ADL and IADL)," which was endorsed by 2% of the registered nurses, 9% of the certified nurse assistants, and 21% of the uncertified nurse assistants (chi-square = 17.43, $p <$ .001). Moreover, "involving persons with dementia in end-of-life decision making" was endorsed by 48% of the registered nurses, 40% of the certified nurse assistants, and 15% of the uncertified nurse assistants (chi-square = 13.30, $p =$ .001).

Preferred Forms of Support

Nursing staff chiefly preferred support in the form of peer-to-peer learning (51%, Table 3). Also frequently endorsed were joint case discussions (48%) and classical education (45%). The fourth-ranking form involved organizational support (43%). Frequencies were mostly similar across settings and educational levels (Table S3). Jointly discussing cases differed between registered nurses (54%), certified nurse assistants (49%), and uncertified nurse assistants (13%, chi-square = 17.62, $p <$ .001).

Open-Ended Questions

Additional issues that were raised beyond the survey items included wishes for specific knowledge and skills in palliative dementia care (e.g., caring for specific groups, such as people with aphasia or with another ethnical background, applying complementary therapies), general awareness about palliative care, family involvement and support, and dealing with ethical matters. If respondents had more time to do their work, the main priority would be to devote more personal attention by making a connection, being present and "in the moment," investing in a close care relationship, and learning about the individual person (Table 4). Moreover, extra time would be invested in supporting families, safeguarding quality of care, deepening one's knowledge, and exchanging and reflecting on experiences with colleagues.

Discussion

This study explored and compared the needs of nursing staff with different educational backgrounds and from different settings and highlighted that dealing with challenging behaviors and managing pain were the most frequently reported needs in palliative caregiving for persons with dementia. Dealing with family disagreement in end-of-life decision making was the

Table 3. Frequencies of Reported Forms of Support in Descending Order (N = 366[a])

Preferred forms of support	n (%)
Exchanging experiences with colleagues (peer-to-peer learning)	185 (51)
Jointly discussing cases	176 (48)[b]
Classical education (e.g., clinical lessons)	164 (45)
General organizational support (e.g., sufficient time, resources, staffing)	158 (43)
A palliative care expert or team to ask for advise	131 (36)
E-learning	112 (30)
Coaching/supervision on the work floor (coaching on the job)	106 (29)
Electronic client or patient files with access by all involved caregivers	71 (19)
Care processes depicted in care paths (e.g., care path dying phase)	63 (17)
A guide to or overview of available care providers	63 (17)[c]
Digital communication medium with access by all involved caregivers	54 (15)
Digital support on the work floor (e.g., measuring instruments, checklists)	46 (13)
Collaboration agreements within own organization	46 (13)
Emotional support from direct colleagues	43 (12)
More opportune moments to consult a palliative care expert or team	41 (11)
Collaboration agreements with professionals outside own organization	35 (10)[b]
Mobile apps	35 (10)
Digital informative movies, animations, or podcasts	34 (9)
Training by means of actors or puppets	30 (8)
Emotional support from the organization (e.g., trustees)	25 (7)
Serious gaming (games with an educative goal)	16 (4)
(Being referred to) professional emotional support	7 (2)

[a]The preferred forms of support section was at the end of the questionnaire. The smaller sample size is due to respondents that prematurely withdrew from completing the questionnaire, after finishing at least the caregiving and end-of-life communication items.
[b]Significant differences between educational levels. Details are shown in Table S3.
[c]Significant differences between educational levels and settings. Details are shown in Table S3.

most frequently reported need in end-of-life communication. Nursing staff preferred opportunities for peer-to-peer learning and "real life" exchange with colleagues. Nursing staff with different educational levels and working in home care or in the nursing home reported mostly the same needs.

The findings suggest that increasing feelings of competence among nursing staff may require interventions that focus on dealing with challenging behaviors and pain in particular. Difficulties in dealing with behaviors likely relate to difficulties in communication, and both require familiarity with the individual (Bolt, van der Steen, Schols, Zwakhalen, Pieters, & Meijers, 2019). Certain behaviors may be due to underlying pain (Malara et al., 2016; Pieper et al., 2013), and communication difficulties leave staff unsure about interpreting individual care needs (Midtbust, Alnes, Gjengedal, & Lykkeslet, 2018a; Monroe, Parish, & Mion, 2015). The finding that nursing staff want to devote personal attention and make a connection with the individual further supports previous statements about the importance of a person-centered approach in dementia care (Kitwood & Bredin, 1992) and in palliative care for persons with dementia (Bolt, van der Steen, Schols, Zwakhalen, Pieters, & Meijers, 2019; van der Steen et al., 2014). However, as in this study, nursing staff previously expressed concerns on how to achieve this with increasing work demands, scarce resources, and a lack of time (Midtbust, Alnes, Gjengedal, & Lykkeslet, 2018b; Smythe et al., 2017). Initiatives aimed at increasing competence and person-centered palliative care may require reconsideration of the organizational culture of long-term care and awareness about palliative care for persons with dementia to be successful (Kaplan et al., 2010; Midtbust et al., 2018b; Sommerbakk, Haugen, Tjora, Kaasa, & Hjermstad, 2016).

Dealing with disagreement between family members in decision making about care and treatment was a prominent issue for nursing staff from both settings. Nursing staff may encounter families that are unwilling to comply with advance directives or decisions that are not in the person's best interest as perceived by staff (Hill, Savundranayagam, Zecevic, & Kloseck, 2018). A comparison of six European countries demonstrated that achieving full consensus (as perceived by nurses) about end-of-life care and treatments of nursing home residents among all involved in care agreements ranged from 60% in Finland to 86% in England, with the Netherlands rating in between with 78% (ten Koppel et al., 2018). Conflict between family members or between staff and family may result from poor communication or families' lack of understanding or disagreement about appropriate care and treatment, and forms a barrier to effective palliative care for persons with dementia (Erel et al., 2017; Lopez, 2007). Current findings also highlight a particular need for competencies in dealing with family conflicts in end-of-life decision making emotionally. This underexposed topic is an important direction for future research and for the development of interventions.

Overall, home care staff felt less competent than nursing home staff in providing palliative care for persons with dementia. Moreover, home care staff less frequently indicated that they had had additional

Table 4. Descriptions and Frequencies of Main Categories in Answers to the Open-Ended Question: "If you had more time to do your work, what would you use it for?" (n = 238)

Main categories	Description (subcategories)	Example citation	Frequency[a]
Devoting personal attention	Investing in person-centered care, nearness, familiarity, meaningful activities, connecting to the people cared for and sensory stimulation; complying with individual wishes	"Attention, listening, warm care for the resident"	198
Supporting families	Having conversations; providing information and explanations; providing emotional support (also during the dying process)	"Attention for loved ones who are present during the dying process"	68
Safeguarding quality of care	Creating a calm atmosphere and taking one's time to provide good care; having care matters in order; being well-prepared	"Updating care files/work plans to maintain/improve quality of care"	49
Deepening one's knowledge	Getting (self)educated; obtaining information; deepening one's understanding of cases	"Staying up-to-date with literature, newsletters"	16
Exchanging and reflecting on experiences with colleagues	Discussing cases; learning from or acting as a supervisor for colleagues; communicating and collaborating with colleagues within and outside one's own discipline.	"Discussing clients or general cases with colleagues"	15

[a](Fragments within) single answers could contribute to establishing multiple categories.

training in dementia care, and they reported more support needs in communicating with and feeling comfortable in caring for persons with (severe) dementia. These findings are important, and they point out that more training on dementia and end-of-life care is needed, in particular for home care staff (D'Astous et al., 2019). The population cared for at home might differ from the nursing home population, possibly requiring different levels of competence from nursing staff. Nonetheless, Hasson and Arnetz (2008) found that in Sweden both settings involve similar care tasks and that staff from both settings have similar development needs. Correspondingly, the current findings point to similar needs across the settings, which may have important implications for the development of interventions that target both settings.

Self-perceived competence did not differ between the different educational levels. Similarly, a previous study found that educational level did not predict self-perceived competence among home care staff (Grönroos, & Perälä, 2008). Self-assessment of competence is valued in nursing (Fereday & Muir-Cochrane, 2006), Nonetheless, the concept of competence is ill defined, and it has been argued that nurses cannot judge what they ought to know and what they do and do not know (Cowan, Norman, & Coopamah, 2005). Higher-educated nursing staff are generally more trained in self-reflection and might be more conscious of their own competence and incompetence, which may explain the findings.

In both settings, the rapid digitalization of health care challenges nursing staff's technological skills and induces changes in care practice (Konttila et al., 2019).

Considering forms of support, instead of endorsing the use of apps or other technological aides, nursing staff emphasize the need for having "real" conversations and exchanging knowledge and experiences with colleagues. This is an important finding considering the contemporary digital era. There is sufficient literature highlighting the value of peer learning among undergraduate nurses, suggesting it contributes to critical thinking, facilitates a safe learning environment, and raises feelings of being emotionally supported (Irvine, Williams, & McKenna, 2018; Nelwati, Abdullah, & Chan, 2018). Less is known about formal and informal peer-to-peer learning among employed nursing staff. Particularly when caring for people with complex care needs, sharing experiences and reflecting with peers might be essential for emotional and informational support and to overcome challenges in caregiving. Future research may explore the shaping of efficient peer learning among nursing staff within an increasingly technology-driven work environment.

Limitations

This study is limited by its nonrandom sampling technique, which was administered to comply with the General Data Protection Regulation (Official Journal of the European Union, 2018). Self-selection bias might have occurred (e.g., a special interest in palliative care or dementia), diminishing generalizability of the findings to the entire population of interest (Etikan, Musa, & Alkassim, 2016). Nonetheless, a partial-response analysis suggests that partial responders (who may

share characteristics with nonresponders) were similar, although more experienced and certified or registered staff were more likely to respond fully. The representation of certified nurse assistants is consistent with the general staffing levels in Dutch long-term care (Arbeid in Zorg en Welzijn [AZW], 2016; Backhaus et al., 2017). The mean age and proportion of females in the sample are comparable to national statistics (AZW, 2016). This study does not provide information on the reliability of the questionnaire. The goal of the current study was to rank nursing staff's needs by counting item frequencies, rather than measuring a single construct for individual needs. Different forms of reliability (i.e., internal consistency, inter-rater, test-retest) were considered unsuitable, and parallel form reliability data were not obtained in this study as no equivalent instrument existed.

Conclusions

Nursing staff with varying educational levels and working in the nursing home or home setting reported similar support needs in providing palliative care for persons with dementia. Dealing with challenging behaviors, pain, and family conflict were the most pressing support needs for proper caregiving. Nursing staff expressed a desire to connect with persons with dementia when imagining they would be given more time for caregiving. Organizational support and awareness is needed to enable nursing staff to devote personal attention and to establish meaningful care relationships. Nursing staff preferred and emphasized the need for peer-to-peer learning and exchanging knowledge and experiences with colleagues. Professionalizing palliative care for persons with dementia in both settings requires consideration of explicit needs and preferences for support. To increase the competence of nursing staff in providing palliative care for persons with dementia, interventions with a similar focus may address the needs of a heterogeneous group of nurses and nurse assistants, working in the home or nursing home setting.

Acknowledgments

Clinical Resources

- Alzheimer's Association. Professionals. https://www.alz.org/professionals
- European Association for Palliative Care. Palliative care for older people: Better practices. https://www.eapcnet.eu/eapc-groups/archives/task-forces-archives/older-people-better-practices
- Marie Curie. Palliative care knowledge zone. https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web site:

Table S1. Questionnaire.

Table S2. Frequencies of Reported Needs in Descending Order (Total) and Specified per Educational Level and Setting.

Table S3. Frequencies of Preferred Forms of Support in Descending Order (Total) and Specified per Educational Level and Setting.

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