Nurses' support needs in palliative care for people with dementia

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Abstract

Background: Since dementia is an incurable illness a palliative care approach for people with dementia is needed, however they are not receiving this care optimally. Understanding nursing staff needs how to provide palliative care specifically for people with dementia would facilitate the improvement of the quality of palliative care. The objective is to explore what the preferred forms of support of nursing staff in the home care and nursing home setting for providing palliative care for people with dementia are and if there are differences in these support preferences between work settings and nursing levels.

Methods: The study is a cross-sectional design based on an online questionnaire. The sample consisted of nursing staff working in either home care or nursing homes. Quantitative analyses were used to describe the demographic characteristics and support needs.

Results: The top five support needs of the nursing staff were exchanging experience with colleagues, joint casuistry discussions, classroom training, general support from the organization and a palliative expert or team to ask for advice. There were significant differences in preferences found between work settings and nursing levels. Overall preferred the UNA's and nursing home nurses organizational support less and training more.

Conclusions: Nursing staff needs in proving palliative care for people with dementia are in general training related forms of support and specific parts of the support from the institution, like resources and a palliative expert to ask for advice. The forms of support should be specified for each work setting and nursing level when implemented.

Keywords: Palliative care, People with dementia, Support needs, Nursing staff, Home care, Nursing home.

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1 Introduction

In the Netherlands, approximately 254.000 people were affected by dementia in 2016 (Volksgezondheidenzorg.info, 2019). It is expected that in 2030 the number of people with dementia would be almost doubled in size worldwide (Prince et al., 2013). Dementia can be described as a set of symptoms that may include memory loss, mood or behaviour changes and difficulties with thinking, problem-solving or language (Alzheimer's Society, 2019b). As a result of the complexity of dementia, people with dementia receive formal care from a range of health and social care services (Alzheimer's Society, 2019a). Since there is currently no curable treatment for dementia, the care services that people with dementia receive are mostly focused on relieving the symptoms (Alzheimer's Society, 2019c; Alzheimer's association, 2019). Despite, research shows that people with dementia commonly experience frequently persistent pain, especially in their last week and a substantial number of people with dementia die while experiencing a high level of suffering (Hendriks, Smalbrugge, Galindo-Garre, Hertogh, & van der Steen, 2015; Aminoff & Adunsky, 2007). Thus taken together, palliative care is needed for people with dementia.

Palliative care is a multidisciplinary holistic form of care that not only focuses on pain and symptom relief, but also on the physical, emotional and spiritual needs of the patient. The WHO's definition of palliative care in 2002 is: ''*Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*''(Sepúlveda, Marlin, Yoshida & Ullrich, 2002). Because of the complexity and heterogeneity of dementia, caregiving for people with dementia, which includes palliative care, requires specific competencies (Haaksma et al., 2018; Bolt et al., 2019). Hence, in order to enhance the quality of palliative care for people with dementia, the competencies for healthcare professionals should be tailored to dementia. When looking at the perceived competence of the caregivers that provide palliative care for people with dementia, a study of Whittaker, George Kernohan, Hasson, Howard & McLaughlin (2006) state that nursing staff themselves report a lack of competence in providing palliative care in general and a study of Robinson et al. (2014) state that caregivers lack knowledge regarding palliative care for people with dementia. Thus, the competencies of healthcare professionals with regard to providing palliative care for people with dementia should be improved.

Since nursing staff, as part of this health care staff, usually provide most of the daily care for people with dementia, they can identify early changes in the person's physical and

cognitive status and have an important role in preventing or relieving suffering (De Witt Jansen et al., 2017a). As follows, when aiming to improve the palliative care for people with dementia, there is much to gain in optimizing the palliative care provided by nursing staff (Bolt et al., 2019). Nevertheless, nursing staff experience several barriers in providing palliative care for people with dementia. A study states that the main barrier in providing palliative care for people with dementia is a lack of continuity according to healthcare professionals working in nursing homes, which entails time pressure, an increasing demand to be efficient, a lack of resources and the end-of-life transition (Midtbust, Alnes, Gjengedal & Lykkeslet, 2018). Another study shows that according to nursing staff there are multiple challenges in providing palliative care specific to people with dementia, including: making the transition to palliative care at an appropriate point in the care pathway; limited competence, skills and capability in working with people with dementia; and collaboration between teams from a variety of settings, organizations and disciplinary backgrounds (Ryan, Gardiner, Bellamy, Gott & Ingleton, 2012).

These challenges and barriers for nursing staff in providing palliative care specifically for people with dementia could indicate that nursing staff needs support in providing this care. In a study of De Veer, Francke & Poortvliet 73% of the nurses expressed the need for extra training in one or more subjects related to providing palliative care (De Veer, Francke & Poortvliet, 2003). Bolt et al. (2019) state that nursing staff needs in providing palliative care are: communication, interdisciplinary collaboration, recognizing and addressing palliative care needs, education and organizational support, training and handling challenging behaviour (Bolt et al., 2019). Another study shows that potential facilitators of nurses in providing palliative care would be external support, monthly meetings, access to a resource file and peer support (Hasson, Kernohan, Waldron, Whittaker & McLaughlin, 2008).

From these studies can be concluded that nursing staff need different forms of support to overcome the challenges and barriers to improve the quality of palliative care for people with dementia. Getting an understanding of these nursing staff needs to overcome these challenges and barriers in providing palliative care specifically for people with dementia, would facilitate the improvement of the care they provide and the tailoring of the palliative care specific for people with dementia. Although some studies already mention facilitators and forms of support that might help, there are no studies that describe specifically which support form is needed most. Moreover, these studies make no distinction between the different levels of nursing staff and the different work settings. There is there little know about the needs of nursing staff in the home care setting, while 53% of the people with

dementia receive home care (Volksgezondheidenzorg.info, 2019). Therefore, in this study the key questions are: ‘’*What are the preferred forms of support of nursing staff in the home care and nursing home setting for providing palliative care for people with dementia?*’’ and ‘’*Does the preference of support forms differ between work settings and nursing levels?’’.*

2 Method

Study design

This study has a cross-sectional design and is part of the DEDICATED (Desired Dementia Care Towards End of Life) study. DEDICATED is a four-year research and implementation project and aims to improve palliative care for people with dementia and their loved ones in both nursing homes and home care (ZonMw, 2018). The current study explores the support needs of nursing staff in providing palliative care for people with dementia using an online questionnaire, which was distributed by the online survey tool Qualtrics. In this study a secondary data analysis was performed with the collected data from the original study. The Medical Ethics Committee Zuyderland & Zuyd confirmed that the rules of Medical Research Involving Human Subjects Act were not applicable (METCZ20180079).

Study population

The study population consisted of nursing staff. Nursing staff were considered as eligible participants when they met the following inclusion criteria: 1) working in home care or nursing home; 2) classified as either uncertified nurse assistant (UNA), certified nurse assistant (CNA) or registered nurse (RN); 3) provided palliative care for people with dementia aged 65 years and older; 4) employed for at least six months; and 5) signed an informed consent form. Within the group of RNs both baccalaureate-educated and vocationally-educated were included. Within the home care setting nursing staff from a care home setting were included, because the structure of the care is the same.

Questionnaire design

The aim of the questionnaire was to explore the needs of nursing staff for providing palliative care for people with dementia. The structure of the questionnaire is based on the four themes of DEDICATED: palliative basic care and comfort, communication in the final phase of life, continuity of care and collaboration between healthcare providers (Academische Werkplaats Ouderzorg [AWO], n.d.). These themes are derived from articles of Perrar, Schmidt, Eisenmann, Cremer & Voltz (2015), IKNL/Palliactief (2017) and Van der Steen et al. (2014).

The questionnaire was developed by three researchers; JM, SP and SB. When developing the questionnaire existing questionnaires were examined; Dijkslag-Kluijver (2017) and Lazenby, Ercolano, Schulman-Green & McCorkle (2012). All the questions from the questionnaire were discussed with all members of the DEDICATED research team. After achieving consensus among the research team about the questions, they presented the questionnaire in working groups to healthcare professionals (who came from the partner organizations) to test the face validity and include their suggestions. Subsequently the questionnaire was also tested for content and language use by a test panel consisting of nurses (from the participating organizations). This test panel consisted of 2 RNs, 2 CNAs and 2 UNAs per partner organization. They furthermore assessed the feasibility of the questionnaire. All their suggestions have been included and that has ultimately resulted in the definitive questionnaire that in used in this study.

The questionnaire consists of five sections; General, Basic care and communication, Collaboration and transfer, Admission to the nursing home and Desired form of support. The general section of the survey includes the following demographic items: age; gender; work setting; how they received the questionnaire; province of workplace; current function; work experience; additional training followed in the past two years regarding palliative care and/or dementia care; the perceived quality of palliative care for people with dementia in their work team or section; and to what extent they feel able to provide palliative care to people with dementia and their loved ones. In this study is focused on the section: Desired form of support, which consists of 22 closed questions. This is about whether different forms of support are preferred by the nursing staff or not (dichotomous). The different forms of support are divided into four groups: training, technological support, emotional support and from the institution. The translated version of the questionnaire in English can be found in Appendix I.

Data collection

The recruitment for the original study was a convenience sampling method, which took place from July to October 2018. The recruitment has been at both regional and national level. On the regional level three researchers shared the hyperlink to the Qualtrics questionnaire with their linking pins from the DEDICATED partner organizations: Envida, Zuyderland and Vivantes. These organizations have a partnership with the Living Lab in Ageing & Long-Term Care (AWO) and contacts from the University Network for the Care Sector Zuid-Holland (UNC-ZH) and Scientific Centre for care and welfare (Tranzo). The dissemination tools used for this were emails, face-to-face contact and information flyers. On the national

level likewise three researchers shared the hyperlink to the Qualtrics questionnaire with their linking pins from the cooperating organizations, namely the Dutch Nurses Association (V&VN), National Survey of Care Indicators (LPZ) and Alzheimer Nederland. The dissemination tools used for this were information flyers, newsletters and websites.

Data analysis

During the secondary data analysis, the programme IBM SPSS version 25 was used to conduct the quantitative analyses. Primary outcomes entail characteristics of the participants and an overview of the support needs. Descriptive and frequency analysis were used to describe demographic characteristics (age and gender), work-related characteristics (years of experience, type of work setting and level of nursing), educational characteristics (additional training in dementia or palliative care), and perceptions about the quality of palliative care. Furthermore, a frequency analysis was conducted to order the support needs, which were presented in numbers and percentages (Support Section).

The secondary outcomes are the correlations between the different work settings and levels of nursing staff with regard to educational characteristics, perception and preferred support forms. Chi-square tests were performed to explore differences between types of work setting (NH or HC) and between levels of nursing staff (UNA, CNA and RN) in relation to additional training in palliative care/dementia care; the perception on providing palliative care as basic or specialized task (questions 8, 9 and 12 of the general section); and the support needs. Additionally, chi-square tests were performed to explore differences between types of work setting within each level of nursing staff and between levels of nursing staff within each type of work setting. Furthermore, independent t-tests were carried out to analyse the differences between nursing staff in the home care and nursing home setting in relation to the perception scores on the quality of palliative care among nurses, perception score on feeling competent to provide palliative care to people with dementia and their loved ones, and the years of experience of the nursing staff (questions 7, 10 and 11 of the general section). Moreover, ANOVA tests were used to calculate the differences between different nursing levels in relation to the perception score on quality of palliative care, perception score on feeling competent to provide palliative care to people with dementia and their loved ones, and the years of experience of the nursing staff (questions 7, 10 and 11 of the general section).

3 Results

Demographic characteristics of the participants

The study population consisted of the 366 participants. The demographics are shown in Table 1 and 2. The majority of the participants were female (96%) had a mean age of 46 years (SD=11.99) and mean working experience of 16 years (SD=10.83). About half of the participants worked in home care (54%) and the other half worked in nursing homes (46%). In the whole study population most of the nursing staff were CNA's (53%) and RN's (39%). In the home care setting the majority of the nursing staff were respectively RN's (43%) and CNA's (47%). In the nursing home setting the majority of the nursing staff were CNA's (59%). The majority of the RN's (60%) and UNA's (58%) worked in home care. About half of the CNA's worked in home care (48%) and the other half worked in nursing homes (52%).

Additional training, quality and competency in palliative and dementia care

Approximately, 50% of the study population had received additional training in either palliative or dementia care (Table 1). There was a significant difference in having had additional training in palliative care ($\chi^2 = 7.232$, $p = 0.027$) and dementia care ($\chi^2 = 6.548$, $p = 0.038$) between the nursing levels. UNA's had received significantly lower additional trainings compared to the other nursing levels. Regarding additional training in dementia care, the number of additional trainings in nursing homes were significantly higher than in home care settings ($\chi^2 = 19.124$, $p = 0.000$) (Table 2). The average rating for the perceived quality of care was a 7. Furthermore, was the average rating for the extent of competence in providing palliative care for people with dementia a 7 (Table 1). A significant difference was seen in the extent of competence in providing palliative care for people with dementia between the work settings ($t = -4.882$, $p = 0.000$). In the home care setting, nurses felt less competent compared to nurses in the nursing home setting (Table 2). Furthermore, were there no significant differences in demographic characteristics between work settings or nursing levels derived from the Chi-Square test, independent samples t-test and ANOVA test.

Table 1

Characteristics of nursing staff in home care and nursing home setting (N=366)

Demographic characteristics of nursing staff	**N = 366**
Age, mean (range)	45.80 (18-65)
Years of experience, mean (range)	15.79 (1-43)
Female gender, number (%)	351 (96)
Work setting, number (%)	
Home care	196 (54)
Nursing Home	170 (46)
Work function, number (%)	
RN	142 (39)
CNA	193 (53)
UNA	31 (9)
Additional training palliative care (% yes)	167 (46)
Additional training dementia (% yes)	179 (49)
Perceived quality of care, range	7.2 (2-10) SD=1.04
Extent of competence providing care, range	7.5 (0-10) SD=1.32
Opinion king of task, number (%)	
Basic task	267 (73)
Specialized task	99 (27)

Table 2

Characteristics of nursing staff per work setting and nursing level (N=366)

Demographic characteristics of nursing staff	**Home care (N=196)**	**Nursing home (N=170)**	**RN[a] (N=142)**	**CNA (N=193)**	**UNA (N=31)**
Age	46.92 SD=11.91	44.51 SD=11.99	42.96 SD=12.49	487.70 SD=11.34	47.03 SD=11.41
Years of experience	16.61 SD=10.83	14.86 SD=11.10	15.04 SD=10.46	16.66 SD=10.81	13.87 SD=10.22
Female gender %	97	94	94	97	97
Work setting %					
Home care	100	0	60	48	58
Nursing Home	0	100	40	52	42
Work function %					
RN	43	34	100	0	0
CNA	47	59	0	100	0
UNA	9	8	0	0	100
Additional training palliative care (% yes) **	49	42	54	41	36
Additional training dementia (% yes) * **	38	61	54	48	29
Perceived quality of care	7.1 SD=0.93	7.2 SD=1.14	7.1 SD=0.96	7.2 SD=1.12	7.2 SD=0.87
Extent of competence providing care **	7.2 SD=1.34	7.9 SD=1.20	7.5 SD=1.12	7.6 SD=1.38	7.1 SD=1.64
Opinion king of task %					
Basic task	69	77	77	69	77
Specialized task	31	23	23	31	23

[a] Within the group of RNs both baccalaureate-educated and vocationally-educated were included.

* Significant differences between work settings.

** Significant differences between nursing levels.

Support needs general

In Table 3, all support form items were ranked based on a frequency analysis. The top five support needs were exchanging experience with colleagues (50.5%), joint casuistry discussions (48.1%), classroom training (44.8%), general support from the organization (43.2%) and a palliative expert or team to ask for advice (35.8%). The bottom three support needs were emotional support from the organization (6.8%), serious gaming (4.4%) and professional emotional support (1.9%).

Table 3

Frequency support needs of total study population (N=366)

Support forms	Frequency	Ranking
Exchanging experience with colleagues (intervision moments)	***185 (50.5%)***	***1***
Joint casuistry discussions	***176 (48.1%)***	***2***
Classroom training (such as clinical lessons)	***164 (44.8%)***	***3***
General support from the organization (time, resources, sufficient staff on the floor)	***158 (43.2%)***	***4***
A palliative expert or team to ask for advice	***131 (35.8%)***	***5***
E-learning	112 (30.6%)	6
Coaching / supervision in the workplace ('coaching on the job')	106 (29.0%)	7
Electronic clients / patient file with access for all involved healthcare providers (transmural / interdisciplinary)	71 (19.4%)	8
Care processes represented in care paths (such as care path dying phase)	63 (17.2%)	9
A social map / overview of available healthcare providers	63 (17.2%)	10
Digital communication means accessible to all involved healthcare providers	54 (14.8%)	11
Digital support in the workplace (such as measuring instruments, checklists, decision-making tools, etc.)	46 (12.6%)	12
Collaboration agreements within the own organization	46 (12.6%)	13
Emotional support from direct colleagues	43 (11.7%)	14
More times when a palliative expert or team is available	41 (11.7%)	15
Mobile apps	35 (9.6%)	16
Collaboration agreements with care providers outside the organization	35 (9.6%)	17
Digital informative videos / animations / podcasts	34 (9.3%)	18
Training with the help of actors or dolls	30 (8.2%)	19
Emotional support from the organization (for example a confidential adviser)	*25 (6.8%)*	*20*
Serious gaming (games with an educational purpose)	*16 (4.4%)*	*21*
(Being referred to) professional emotional support	*7 (1.9%)*	*22*

Comparison of support needs between nursing levels

The priority support need of RN's, CNA's and UNA's were respectively; joint casuistry discussions (54.2%), exchanging experiences with colleagues (52.3%) and classroom training (51.6%) (Table 4). In comparison with the general top five, for the RN's is E-learning (36.6%) in the top five with a shared place with general support from the organization

(36.6%). For the UNA's, in comparison with the general top five, are E-learning (35.5%) and coaching/supervision in the workplace (29.0%) in the top five instead of joint casuistry discussions (12.9%) and a palliative expert or team to ask for advice (22.6%). Besides, for each nursing level is the order of the top five different from the other levels and the general top five. In comparison with the general bottom three, for the UNA's are collaboration agreements with care providers outside the organization (3.2%) and a social map/overview of available healthcare providers (3.2%) in the bottom three instead of emotional support from the organization (6.5%) and serious gaming (9.7%). For the CNA's, in comparison with the general bottom three, is collaboration agreements with care providers outside the organization (4.7%) in the bottom three instead of emotional support from the organization (9.3%). Besides, for the RN's and UNA's is the order of the bottom three different from the other levels and the general bottom three. Moreover, significant differences between the nursing levels in the preference of support forms were found. Exchanging experiences with colleagues ($\chi^2 = 6.279$, $p = 0.043$) and joint casuistry discussions ($\chi^2 = 17.615$, $p = 0.000$) were more preferred by the RN's and CNA's, than the UNA's. Electronic clients/patient file with access for all involved healthcare providers ($\chi^2 = 6.598$, $p = 0.037$), digital communication means accessible to all involved healthcare providers ($\chi^2 = 9.248$, $p = 0.010$) and collaboration agreements with care providers outside the organization ($\chi^2 = 17.418$, $p = 0.000$) were mostly preferred by the RN's and less by the CNA's and the UNA's. A palliative expert or team to ask for advice ($\chi^2 = 7.311$, $p = 0.026$) and a social map/overview of available healthcare providers ($\chi^2 = 14.506$, $p = 0.001$) were mostly preferred by the RN's, less by the CNA's and the least by the UNA's. General support from the organization ($\chi^2 = 7.385$, $p = 0.025$) was more preferred by the CNA's, than the RN's and UNA's.

Table 4

Frequency support needs in nursing levels (N=366)

Support forms	**RN[a] (N=142)**	**CNA (N=193)**	**UNA (N=31)**	**P-value**
Exchanging experience with colleagues (intervision moments)*	***75 (52.8%)***	***101 (52.3%)***	***9 (29.0%)***	***0.043***
Joint casuistry discussions*	***77 (54.2%)***	***95 (49.2%)***	4 (12.9%)	***0.000***
Classroom training (such as clinical lessons)	***54 (38.0%)***	***94 (48.7%)***	***16 (51.6%)***	0.111
General support from the organization (time, resources, sufficient staff on the floor)*	***52 (36.6%)***	***96 (49.7%)***	***10 (32.3%)***	***0.025***
A palliative expert or team to ask for advice*	***62 (43.7%)***	***62 (32.1%)***	7 (22.6%)	***0.026***
E-learning	***52 (36.6%)***	49 (25.4%)	***11 (35.5%)***	0.073
Coaching / supervision in the workplace ('coaching on the job')	42 (29.6%)	55 (28.5%)	***9 (29.0%)***	0.977

Electronic clients / patient file with access for all involved healthcare providers (transmural / interdisciplinary)*	37 (26.1%)	29 (15.0%)	5 (16.1%)	***0.037***
Care processes represented in care paths (such as care path dying phase)	33 (23.2%)	26 (13.5%)	4 (12.9%)	0.052
A social map / overview of available healthcare providers*	37 (26.1%)	25 (13.0%)	*1 (3.2%)*	***0.001***
Digital communication means accessible to all involved healthcare providers*	31 (21.8%)	20 (10.4%)	3 (9.7%)	***0.010***
Digital support in the workplace (such as measuring instruments, checklists, decision-making tools, etc.)	21 (14.8%)	21 (10.9%)	4 (12.9%)	0.565
Collaboration agreements within the own organization	19 (13.4%)	23 (11.9%)	4 (12.9%)	0.922
Emotional support from direct colleagues	14 (9.9%)	27 (14.0%)	2 (6.5%)	0.323
More times when a palliative expert or team is available	18 (12.7%)	20 (10.4%)	3 (9.7%)	0.771
Mobile apps	20 (14.1%)	13 (6.7%)	2 (6.5%)	0.064
Collaboration agreements with care providers outside the organization*	25 (17.6%)	*9 (4.7%)*	*1 (3.2%)*	***0.000***
Digital informative videos / animations / podcasts	7 (4.9%)	24 (12.4%)	3 (9.7%)	0.065
Training with the help of actors or dolls	12 (8.5%)	14 (7.3%)	4 (12.9%)	0.562
Emotional support from the organization (for example a confidential adviser)	*5 (3.5%)*	18 (9.3%)	2 (6.5%)	0.114
Serious gaming (games with an educational purpose)	*6 (4.2%)*	*7 (3.6%)*	3 (9.7%)	0.309
(Being referred to) professional emotional support	*1 (0.7%)*	*5 (2.6%)*	*1 (3.2%)*	0.394

* Significant differences between nursing levels.

[a] Within the group of RNs both baccalaureate-educated and vocationally-educated were included.

*Comparison of support needs between work setting*s

The priority support need in home care and nursing home setting were respectively; exchanging experience with colleagues and general support from the organization (Table 5). In comparison with the general top five, with the nursing home setting coaching/supervision in the workplace (35.3%) is in the top five instead of a palliative expert or team to ask for advice (30.0%). Likewise, the order of the top five of both work settings is different from each other and the general top five. In comparison with the general bottom three, with the nursing home setting collaboration agreements with care providers outside the organization (5.3%) is in the bottom three instead of emotional support from the organization (7.6%). Furthermore, significant differences between the work settings in the preference of support forms were identified. Coaching/supervision in the workplace ($\chi^2 = 6.187$, $p = 0.013$) and general support from the organization ($\chi^2 = 6.037$, $p = 0.014$) were more preferred by nurses in the nursing home setting. Electronic clients/patient file with access for all involved healthcare providers ($x^2 = 6.995$, $p = 0.008$), a palliative expert or team to ask for advice ($\chi^2 = 4.635$, $p = 0.031$), collaboration agreements within the own organization ($\chi^2 = 5.424$, $p = 0.020$), collaboration agreements with care providers outside the organization ($\chi^2 = 6.689$, $p = 0.010$) and a social map/overview of available healthcare providers ($\chi^2 = 13.558$, $p = 0.000$)

were more preferred by nurses in the home care setting.

Table 5

Frequency support needs in work settings (N=366)

Support forms	**HC (N=196)**	**NH (N=170)**	**P-value**
Exchanging experience with colleagues (intervision moments)	***101 (51.5%)***	***84 (49.4%)***	0.686
Joint casuistry discussions	***92 (46.9%)***	***84 (49.4%)***	0.637
Classroom training (such as clinical lessons)	***87 (44.4%)***	***77 (45.3%)***	0.862
General support from the organization (time, resources, sufficient staff on the floor)*	***73 (37.2%)***	***85 (50.0%)***	***0.014***
A palliative expert or team to ask for advice*	***80 (40.8%)***	51 (30.0%)	***0.031***
E-learning	66 (33.7%)	46 (27.1%)	0.171
Coaching / supervision in the workplace ('coaching on the job')*	46 (23.5%)	***60 (35.3%)***	***0.013***
Electronic clients / patient file with access for all involved healthcare providers (transmural / interdisciplinary)*	48 (24.5%)	23 (13.5%)	***0.008***
Care processes represented in care paths (such as care path dying phase)	31 (15.8%)	32 (18.8%)	0.447
A social map / overview of available healthcare providers*	47 (24.0%)	16 (9.4%)	***0.000***
Digital communication means accessible to all involved healthcare providers	35 (17.9%)	19 (11.2%)	0.072
Digital support in the workplace (such as measuring instruments, checklists, decision-making tools, etc.)	29 (14.8%)	17 (10.0%)	0.167
Collaboration agreements within the own organization*	32 (16.3%)	14 (8.2%)	***0.020***
Emotional support from direct colleagues	25 (12.8%)	18 (10.6%)	0.521
More times when a palliative expert or team is available	21 (10.7%)	20 (11.8%)	0.751
Mobile apps	19 (9.7%)	16 (9.4%)	0.927
Collaboration agreements with care providers outside the organization*	26 (13.3%)	*9 (5.3%)*	***0.010***
Digital informative videos / animations / podcasts	21 (10.7%)	13 (7.6%)	0.313
Training with the help of actors or dolls	16 (8.2%)	14 (8.2%)	0.980
Emotional support from the organization (for example a confidential adviser)	*12 (6.1%)*	13 (7.6%)	0.564
Serious gaming (games with an educational purpose)	*11 (5.6%)*	*5 (2.9%)*	0.213
(Being referred to) professional emotional support	*6 (3.1%)*	*1 (0.6%)*	0.085

* Significant differences between work settings.

Comparison of support needs between nursing levels within work settings

The priority support need within the home care setting of RN's, CNA's and UNA's were respectively; exchanging experience with colleagues and joint casuistry discussions, exchanging experience with colleagues and classroom training (Table 6). Within the home care setting, in comparison with the top five of all the RN's, for the RN's is a social map/overview of available healthcare providers (35.3%) in the top five instead of general support from the organization (31.8%). The top five's of all CNA's and UNA's are the same as the top five's of the CNA's and UNA's within the home care setting. Within the home care setting there is a significant difference between nursing levels in the preference of joint casuistry discussions ($\chi^2 = 12.496$, $p = 0.002$), a social map/overview of available healthcare

providers (χ^2 = 11.663, p = 0.003) and digital communication means accessible to all involved healthcare providers (χ^2 = 9.068, p = 0.011), they were mostly preferred by the RN's, less by the CNA's and the least by UNA's. Training with the help of actors or dolls (χ^2 = 6.125, p = 0.047) was mostly preferred by the UNA's and less by the CNA's and RN's. Electronic clients/patient file with access for all involved healthcare providers (χ^2 = 6.351, p = 0.042), 10 (χ^2 = 9.068, p = 0.011) and collaboration agreements with care providers outside the organization (χ^2 = 17.453, p = 0.000) were mostly preferred by the RN's and less by the CNA's and the UNA's. Digital informative videos/animations/podcasts (χ^2 = 8.104, p = 0.017) and emotional support from the organization (χ^2 = 6.442, p = 0.040) were more preferred by the CNA's and UNA's, than the RN's. Care processes represented in care paths (χ^2 = 6.918, p = 0.031) was more preferred by the RN's and UNA's, than the CNA's.

The priority support need within the nursing home setting of RN's, CNA's and UNA's were respectively; joint casuistry discussions, exchanging experiences with colleagues and joint casuistry discussions, and classroom training (Table 6). Within the nursing home setting, in comparison with the top five of all RN's, for the RN's is coaching/supervision in the workplace (38.6%) in the top five instead of a palliative expert or team to ask for advice (36.8%) and E-learning (36.8%). For the CNA's, in comparison with the top five of all CNA's, is coaching/supervision in the workplace (34.0%) in the top five instead of a palliative expert or team to ask for advice (27.0%). For the UNA's, in comparison with the top five of all UNA's, is a palliative expert or team to ask for advice (23.1%) and electronic clients/patient file with access for all involved healthcare providers (23.1%) in the top five. Within the nursing home setting there is a significant difference between nursing levels in the preference of joint casuistry discussions (χ^2 = 6.586, p = 0.037), it was more preferred by the RN's and CNA's, than the UNA's.

Table 6

Frequency support needs in nursing levels within work settings (N=366)

Support forms	**RN[a]**	**CNA**	**UNA**	**P-value**
Home care (N=196)	**(N=85)**	**(N=93)**	**(N=18)**	
Exchanging experiences with colleagues	***48 (56.5%)***	***48 (51.6%)***	***5 (27.8%)***	0.086
Joint casuistry discussions*	***48 (56.5%)***	***42 (45.2%)***	2 (11.1%)	***0.002***
Classroom training	***30 (35.3%)***	***46 (49.5%)***	***11 (61.1%)***	0.053
General support from the organization	27 (31.8%)	***40 (43.0%)***	***6 (33.3%)***	0.282
A palliative expert or team to ask for advice	***41 (48.2%)***	***35 (37.6%)***	4 (22.2%)	0.086
E-learning	***31 (36.5%)***	27 (29.0%)	***8 (44.4%)***	0.345
Coaching / supervision in the workplace	20 (23.5%)	21 (22.6%)	***5 (27.8%)***	0.893
Electronic clients / patient file with access for all involved healthcare providers*	28 (32.9%)	18 (19.4%)	2 (11.1%)	***0.042***

Care processes represented in care paths*	19 (22.4%)	8 (8.6%)	4 (22.2%)	***0.031***
A social map / overview of available healthcare providers*	***30 (35.3%)***	16 (17.2%)	*1 (5.6%)*	***0.003***
Digital communication means accessible to all involved healthcare providers*	23 (27.1%)	11 (11.8%)	*1 (5.6%)*	***0.011***
Digital support in the work place	16 (18.8%)	10 (10.8%)	3 (16.7%)	0.309
Collaboration agreements within the own organization	17 (20.0%)	13 (14.0%)	2 (11.1%)	0.455
Emotional support from direct colleagues	9 (10.6%)	15 (16.1%)	*1 (5.6%)*	0.342
More times when a palliative expert or team is available	9 (10.6%)	10 (10.8%)	2 (11.1%)	0.998
Mobile apps	13 (15.3%)	*4 (4.3%)*	2 (11.1%)	0.046
Collaboration agreements with care providers outside the organization*	21 (24.7%)	*5 (5.4%)*	0 (0.0%)	***0.000***
Digital informative videos / animations / podcasts*	*3 (3.5%)*	15 (16.1%)	3 (16.7%)	***0.017***
Training with the help of actors or dolls*	4 (4.7%)	8 (8.6%)	4 (22.2%)	***0.047***
Emotional support from the organization*	*1 (1.2%)*	9 (9.7%)	2 (11.1%)	***0.040***
Serious gaming	*3 (3.5%)*	*5 (5.4%)*	3 (16.7%)	0.088
Professional emotional support	*1 (1.2%)*	*4 (4.3%)*	*1 (5.6%)*	0.391
Nursing home (N=170)	**(N=57)**	**(N=100)**	**(N=13)**	
Exchanging experiences with colleagues	***27 (47.4%)***	***53 (53.0%)***	***4 (30.8%)***	0.229
Joint casuistry discussions*	***29 (50.9%)***	***53 (53.0%)***	2 (15.4%)	***0.037***
Classroom training	***24 (42.1%)***	***48 (48.0%)***	***5 (38.5%)***	0.679
General support from the organization	***25 (43.9%)***	***56 (56.0%)***	***4 (30.8%)***	0.121
A palliative expert or team to ask for advice	21 (36.8%)	27 (27.0%)	***3 (23.1%)***	0.369
E-learning	21 (36.8%)	22 (22.0%)	***3 (23.1%)***	0.125
Coaching / supervision in the workplace	***22 (38.6%)***	***34 (34.0%)***	***4 (30.8%)***	0.794
Electronic clients / patient file with access for all involved healthcare providers	9 (15.8%)	11 (11.0%)	***3 (23.1%)***	0.405
Care processes represented in care paths	14 (24.6%)	18 (18.0%)	*0 (0.0%)*	0.117
A social map / overview of available healthcare providers	7 (12.3%)	9 (9.0%)	*0 (0.0%)*	0.383
Digital communication means accessible to all involved healthcare providers	8 (14.0%)	9 (9.0%)	2 (15.4%)	0.555
Digital support in the work place	5 (8.8%)	11 (11.0%)	1 (7.7%)	0.868
Collaboration agreements within the own organization	*2 (3.5%)*	10 (10.0%)	2 (15.4%)	0.226
Emotional support from direct colleagues	5 (8.8%)	12 (12.0%)	1 (7.7%)	0.769
More times when a palliative expert or team is available	9 (15.8%)	10 (10.0%)	1 (7.7%)	0.497
Mobile apps	7 (12.3%)	9 (9.0%)	*0 (0.0%)*	0.383
Collaboration agreements with care providers outside the organization	4 (7.0%)	*4 (4.0%)*	1 (7.7%)	0.663
Digital informative videos / animations / podcasts	4 (7.0%)	9 (9.0%)	*0 (0.0%)*	0.505
Training with the help of actors or dolls	8 (14.0%)	6 (6.0%)	*0 (0.0%)*	0.113
Emotional support from the organization	4 (7.0%)	9 (9.0%)	*0 (0.0%)*	0.505
Serious gaming	*3 (5.3%)*	*2 (2.0%)*	*0 (0.0%)*	0.410
Professional emotional support	*0 (0.0%)*	*1 (1.0%)*	*0 (0.0%)*	0.703

[a] Within the group of RNs both baccalaureate-educated and vocationally-educated were included.

* Significant differences between nursing levels.

Comparison of support needs between work settings within nursing levels

The priority support need within the RN's in home care and nursing home setting were respectively; exchanging experiences with colleagues and joint casuistry discussions, and joint casuistry discussions (Table 7). Within the RN's, in comparison with the top five of all nurses in the home care setting, for the nurses in the home care setting is E-learning (36.5%) and a social map/overview of available healthcare providers (35.3%) in the top five instead of general support from the organization (31.8%). For the nurses in the nursing home setting is the top five the same in comparison to the top five of all nurses in the nursing home setting. Within the RN's there is a significant difference between work settings in the preference of training with the help of actors or dolls ($\chi^2 = 3.838$, $p = 0.050$) (Table 7), it was more preferred by nurses in the nursing home setting. Electronic clients/patient file with access for all involved healthcare providers ($\chi^2 = 5.210$, $p = 0.022$), collaboration agreements within the own organization ($\chi^2 = 8.006$, $p = 0.005$), collaboration agreements with care providers outside the organization ($\chi^2 = 7.359$, $p = 0.007$) and a social map/overview of available healthcare providers ($\chi^2 = 9.379$, $p = 0.002$) were more preferred by nurses in the home care setting.

The priority support need within the CNA's in home care and nursing home setting were respectively; exchanging experiences with colleagues, and exchanging experiences with colleagues and joint casuistry discussions (Table 7). Within the CNA's, in comparison with the top five of all nurses in the home care setting, for the nurses in the home care setting is the top five the same. For the nurses in the nursing home setting is the top five also the same in comparison with the top five of all nurses in the nursing home setting. Within the CNA's no significant difference between work setting in the preference of support needs were found.

The priority support need within the UNA's in home care and nursing home setting were both classroom training (Table 7). Within the UNA's, in comparison with the top five of all nurses in the home care setting, for the nurses in the home care setting is E-learning (44.4%) and coaching/supervision in the workplace (27.8%) in the top five instead of joint casuistry discussions (11.1%) and a palliative expert or team to ask for advice (22.2%). For the nurses in the nursing home setting, in comparison with the top five of all nurses in the nursing home setting, is a palliative expert or teams to ask for advice (23.1%), E-learning (23.1%) and electronic clients/patient file with access for all involved healthcare providers (23.1%) in the top five instead of joint casuistry discussions (15.4%). Within the UNA's no significant difference between work setting in the preference of support needs were found.

Table 7

Frequency support needs in work setting within nursing levels (N=366)

Support forms	HC	NH	P-value
RN[a] (N=142)	**(N=85)**	**(N=57)**	
Exchanging experiences with colleagues	***48 (56.5%)***	***27 (47.4%)***	0.287
Joint casuistry discussions	***48 (56.5%)***	***29 (50.9%)***	0.512
Classroom training	***30 (35.3%)***	***24 (42.1%)***	0.412
General support from the organization	27 (31.8%)	***25 (43.9%)***	0.143
A palliative expert or team to ask for advice	***41 (48.2%)***	21 (36.8%)	0.180
E-learning	***31 (36.5%)***	21 (36.8%)	0.964
Coaching / supervision in the workplace	20 (23.5%)	***22 (38.6%)***	0.054
Electronic clients / patient file with access for all involved healthcare providers*	28 (32.9%)	9 (15.8%)	***0.022***
Care processes represented in care paths	19 (22.4%)	14 (24.6%)	0.760
A social map / overview of available healthcare providers*	***30 (35.3%)***	7 (12.3%)	***0.002***
Digital communication means accessible to all involved healthcare providers	23 (27.1%)	8 (14.0%)	0.066
Digital support in the work place	16 (18.8%)	5 (8.8%)	0.098
Collaboration agreements within the own organization*	17 (20.0%)	*2 (3.5%)*	***0.005***
Emotional support from direct colleagues	9 (10.6%)	5 (8.8%)	0.722
More times when a palliative expert or team is available	9 (10.6%)	9 (15.8%)	0.361
Mobile apps	13 (15.3%)	7 (12.3%)	0.613
Collaboration agreements with care providers outside the organization*	21 (24.7%)	4 (7.0%)	***0.007***
Digital informative videos / animations / podcasts	*3 (3.5%)*	4 (7.0%)	0.347
Training with the help of actors or dolls*	4 (4.7%)	8 (14.0%)	***0.050***
Emotional support from the organization	*1 (1.2%)*	4 (7.0%)	0.064
Serious gaming	*3 (3.5%)*	*3 (5.3%)*	0.615
Professional emotional support	*1 (1.2%)*	*0 (0.0%)*	0.411
CNA (N=193)	**(N=93)**	**(N=100)**	
Exchanging experiences with colleagues	***48 (51.6%)***	***53 (53.0%)***	0.847
Joint casuistry discussions	***42 (45.2%)***	***53 (53.0%)***	0.276
Classroom training	***46 (49.5%)***	***48 (48.0%)***	0.839
General support from the organization	***40 (43.0%)***	***56 (56.0%)***	0.071
A palliative expert or team to ask for advice	***35 (37.6%)***	27 (27.0%)	0.114
E-learning	27 (29.0%)	22 (22.0%)	0.262
Coaching / supervision in the workplace	21 (22.6%)	***34 (34.0%)***	0.079
Electronic clients / patient file with access for all involved healthcare providers	18 (19.4%)	11 (11.0%)	0.105
Care processes represented in care paths	8 (8.6%)	18 (18.0%)	0.056
A social map / overview of available healthcare providers	16 (17.2%)	9 (9.0%)	0.090
Digital communication means accessible to all involved healthcare providers	11 (11.8%)	9 (9.0%)	0.520
Digital support in the work place	10 (10.8%)	11 (11.0%)	0.956
Collaboration agreements within the own organization	13 (14.0%)	10 (10.0%)	0.394
Emotional support from direct colleagues	15 (16.1%)	12 (12.0%)	0.409
More times when a palliative expert or team is available	10 (10.8%)	10 (10.0%)	0.864
Mobile apps	*4 (4.3%)*	9 (9.0%)	0.193
Collaboration agreements with care providers outside the organization	*5 (5.4%)*	*4 (4.0%)*	0.650
Digital informative videos / animations / podcasts	15 (16.1%)	9 (9.0%)	0.134
Training with the help of actors or dolls	8 (8.6%)	6 (6.0%)	0.486
Emotional support from the organization	9 (9.7%)	9 (9.0%)	0.872
Serious gaming	*5 (5.4%)*	*2 (2.0%)*	0.210

Professional emotional support	*4 (4.3%)*	*1 (1.0%)*	0.149
UNA (N=31)	**(N=18)**	**(N=13)**	
Exchanging experiences with colleagues	***5 (27.8%)***	***4 (30.8%)***	0.856
Joint casuistry discussions	2 (11.1%)	2 (15.4%)	0.726
Classroom training	***11 (61.1%)***	***5 (38.5%)***	0.213
General support from the organization	***6 (33.3%)***	***4 (30.8%)***	0.880
A palliative expert or team to ask for advice	4 (22.2%)	***3 (23.1%)***	0.955
E-learning	***8 (44.4%)***	***3 (23.1%)***	0.220
Coaching / supervision in the workplace	***5 (27.8%)***	***4 (30.8%)***	0.856
Electronic clients / patient file with access for all involved healthcare providers	2 (11.1%)	***3 (23.1%)***	0.371
Care processes represented in care paths	4 (22.2%)	*0 (0.0%)*	0.069
A social map / overview of available healthcare providers	*1 (5.6%)*	*0 (0.0%)*	0.388
Digital communication means accessible to all involved healthcare providers	*1 (5.6%)*	2 (15.4%)	0.361
Digital support in the work place	3 (16.7%)	1 (7.7%)	0.462
Collaboration agreements within the own organization	2 (11.1%)	2 (15.4%)	0.726
Emotional support from direct colleagues	*1 (5.6%)*	1 (7.7%)	0.811
More times when a palliative expert or team is available	2 (11.1%)	1 (7.7%)	0.751
Mobile apps	2 (11.1%)	*0 (0.0%)*	0.214
Collaboration agreements with care providers outside the organization	*0 (0.0%)*	1 (7.7%)	0.232
Digital informative videos / animations / podcasts	3 (16.7%)	*0 (0.0%)*	0.121
Training with the help of actors or dolls	4 (22.2%)	*0 (0.0%)*	0.069
Emotional support from the organization	2 (11.1%)	*0 (0.0%)*	0.214
Serious gaming	3 (16.7%)	*0 (0.0%)*	0.121
Professional emotional support	*1 (5.6%)*	*0 (0.0%)*	0.388

[a] Within the group of RNs both baccalaureate-educated and vocationally-educated were included.

* Significant differences between nursing levels or work settings.

4 Discussion

The objective of this study was to explore what the preferred forms of support are of nursing staff in the home care and nursing home setting for providing palliative care for people with dementia and if there are differences in these support preferences between work settings and nursing levels. The results of this study show that the most preferred support needs were exchanging experience with colleagues, joint casuistry discussions, classroom training, general support from the organization and a palliative expert or team to ask for advice. Furthermore, the least preferred support needs were emotional support from the organization, serious gaming and professional emotional support. Regarding differences between nursing levels, the UNA's preferred E-learning and coaching/supervision in the workplace above joint casuistry discussions and a palliative expert or team to ask for advice. Additionally, the UNA's preferred collaboration agreements with care providers outside the organization and a social map/overview of available healthcare providers below emotional support from the organization and serious gaming, while the CNA's only preferred collaboration agreements

with care providers outside the organization below emotional support from the organization. Moreover, concerning the differences between work settings, the nurses in the nursing home setting preferred coaching/supervision in the workplace above a palliative expert or team to ask for advice and collaboration agreements with care providers outside the organization below emotional support from the organization. Additionally, when looking within a certain work setting the preferences of the nursing levels were different from the preferences of the nursing levels when looking at all work setting at the same time. The same goes for the work setting when looking within a certain nursing level in comparison when looking at all nursing levels at the same time.

Apart from this study of Bolt et al., that is part of DEDICATED, there are no studies that specifically looked at the support needs of nursing staff that provides palliative care for people with dementia. Moreover, the other studies discussed had a different study population or did not research the needs of nursing staff but something related. Regarding training related support forms, in the study of Bolt et al. they discuss subjects nursing staff would like more training in. For example skills and knowledge on pain recognition and management, entailing monitoring and reporting treatment response and side effects. In our study ways of receiving training are discussed, for example classroom training, exchanging experiences with colleagues and joint casuistry discussions. Thus, both studies state that training is an important nursing staff need, though discuss it in different ways. For further research could be advised to also research subject nurses would like training in. The study of De Witt Jansen et al. (2017b) likewise state that a needs-based training to support practice development is required for registered nurses working in nursing homes that care for people with advanced dementia. Moreover, the study of Whittaker, George Kernohan, Hasson, Howard & McLaughlin (2006) also state that nursing home staff in general need more education and training in palliative care. The reason they give for this is that respondents reported a lack of competence in providing palliative care and only 30% had obtained formal training in palliative care related subjects. In this study the competence score had an average score of 7.5, and 42% of the nurses that worked in a nursing home had obtained additional training in palliative care. Because our study also shows a high preference of training, it indicates that despite the nurses of our study feel quite competent in providing the care, there is still room and a need for improvement in the competence of providing palliative care through training. Furthermore, according to Ryan et al. (2012) nurses experience three main challenges in providing palliative care specific to people with dementia. One of these challenges is limited competence, skills and capability in working with people with dementia (Ryan et al., 2012).

According to Fraser & Greenhalgh (2001) education and training should enhance the competence, skills and capability. Thus, if the nursing staff that provides palliative care for people with dementia receiving training it should improve the competence, skills and capability in working with people with dementia when the training is developed based on Fraser & Greenhalgh (2001). So, this would take away one of the three main barriers nurses experience in providing palliative care for people with dementia according to Ryan et al. (2012).

The forms of receiving training from our study appear to be communicative ways of sharing information with colleagues and other disciplines to learn from it, especially exchanging experience with colleagues and joint casuistry discussions. Regarding communication in Bolt et al., they focused on communication with the individual with dementia, in contrast with our questionnaire that only focused on communicative aspects with healthcare providers. It could be advised to include in further research additionally the communication with regard to the individual with dementia. Furthermore, the study of Hasson et al. (2008) state that potential facilitators for link nurses in nursing homes for providing palliative care would include monthly meetings, which is also a communicative way of sharing information with colleagues and/or other disciplines.

Additionally, Bolt et al. reported a poor collaboration with other disciplines and a need for interdisciplinary collaboration. In our study a need for joint casuistry discussions and a palliative expert or team to ask for advice were reported as very preferred. A palliative expert or teams to ask for advice is a kind of interdisciplinary collaboration and a joint casuistry discussion could be either interdisciplinary or only in one discipline. But in contrast, the support forms of collaboration agreements within the own organization and with care providers outside the organization were not very preferred. The need for a palliative expert or team to ask for advice is also in line with the study of Hasson et al. (2008), that states link nurses would like external support. Moreover, according to the study of Ryan et al. (2012) one of the three challenges in providing palliative care to people with dementia is the collaboration between teams form a variety of settings, organizations and disciplinary backgrounds, maybe because collaboration can be challenging nurses do not prefer collaboration agreements. From this could be concluded that nurses mainly prefer collaboration that arises freely and is not laid down in an agreement.

With regard to organizational support Bolt et al. give in their scoping review as example understaffing, a heavy workload, limited time. In our study as an example of general support from the organization was given time, resources and sufficient staff on the floor.

Hence, the forms of organizational support of our study are largely the same as Bolt et al. Additionally, the study of Midtbust et al. (2018) looked at all healthcare professionals that provide palliative care for people with severe dementia and they recommended among other things organizational changes. In the study of Midbust et al. they mention as an example of an organizational change a higher proportion of permanent employees. However, in this study examples of organizational support that was preferred were time, resources and sufficient staff on the floor. This difference between organizational support preference could be explained that nursing staff in specific have different needs in organizational support than all healthcare professionals on average. Moreover, the study of De Witt Jansen et al. (2017b) showed that the barriers arising from organizational factors varied across work settings. In our study also small differences in organizational support preferences are seen. So the organizational support needs deduced from our study should be specified to the nursing levels and work settings.

Regarding to the differences found in our study between the nursing levels and work settings in support forms, no other studies had researched this yet. No explanation for these differences could be found in other studies. But the differences between the nursing levels could potentially be explained by the difference in educational level and tasks the different nursing levels perform. The differences between the work settings could also be explained by the differences in tasks in each work setting has to be performed. Since both of these factors were not assessed in our study, no clear explanation of these differences in preference can be derived from our study.

This study furthermore had some strengths and limitations. This study's main strength is exploring the difference in the preference of support forms between nursing levels and work settings. The study population consisted of 336 nurses, this is a relatively large number of participants compared to other studies. Likewise, the sample of nurses working in the home care setting is relatively large. On the other hand, were the UNA's underrepresented, because they were 9% of the study population compared to 39% of RN's and 53% of CNA's. Furthermore, the majority of RN's and UNA's worked in home care and the majority of CNA's worked in nursing homes. Moreover, is there a high chance of selection bias, it could be that only nurses with an interest in palliative care for people with dementia responded on the questionnaire. Also is the questionnaire not validated. Besides, here were 22 forms of support presented in the questionnaire, it could be that a form of support that wasn't presented in the questionnaire would be important as well. As example Bolt et al. documented needs in recognizing and addressing palliative care needs, and handling challenging behaviour.

Conclusion

Nursing staff needs in proving palliative care for people with dementia are in general training related forms of support and specific parts of the support from the institution, like resources and a palliative expert to ask for advice. Most nurses do not prefer emotional related support forms, also the technological related support forms were not very preferred either. The forms of support should be specified for each work setting and nursing level when implemented.

Recommendations

From this research can be deduced that when developing support forms for nursing staff in providing palliative care for people with dementia the support forms should focus on training and general forms of support from the organization. There should be less of a focus on emotional and technological forms of support. Moreover, when developing support forms there should be taken into account that the different nursing levels and work setting in some amount differ in what forms of support they prefer or do not prefer. Nevertheless, it would be very helpful for the development of efficient support forms for nursing staff in providing palliative care for people with dementia to know the underlying reasons behind the preference of the different support needs. In this way the support forms could be more focused on what works for each different nursing level and works setting and have a better chance at helping the nursing staff in providing good quality palliative care for people specified to dementia. This research could be done by interviewing the nursing staff or via focus groups per work setting and nursing level and ask about their needs in support forms and why they prefer something more or less than the other support forms. As a result, according to the outcomes from those interviews or focus groups could the support forms be adjusted to optimally meet the needs of the nursing staff specified to the nursing level and work setting.

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Appendix I

Questionnaire for nurses:

Providing palliative care to people with dementia

Background

This questionnaire is part of the "**DEDICATED: Desired dementia care towards end of life"** project, focused on palliative care for people with dementia and their loved ones. For more information, you can visit our website: www.dedicated-awo.eu

By **palliative care**, we mean care that is aimed at increasing the comfort and quality of life of people with an incurable disease and their loved ones. People with dementia will not get better anymore, and are therefore qualified for palliative care from diagnosis onwards. This includes attention to physical, psychological, social and spiritual care needs, and talking about future wishes and needs in care on time.

Why do we ask you to fill in this questionnaire?

To improve the quality of palliative care for people with dementia, we first want to map what is needed by you when providing palliative care to people with dementia. **Our opinion therefore matters. We would like to know your needs.**

For who?

The questionnaire can be completed by nursing staff (levels 2, 3, 4, 5 or 6), working for at least 6 months with elderly people with dementia (<65) in the nursing home or in home care.

How to fill in?

When answering this questionnaire, it is about **your own personal experience**. We get that situations vary, but try to answer what you experience in most cases. The estimated time to fill in this questionnaire is 15 minutes.

Your answers will only be used for the purpose of the research and **cannot be traced to anyone**. By completing and sending this questionnaire, you consent to the confidential use of your answers for research purposes. For questions or comments, you can contact one of the researchers:

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Feedback: The results of this survey are used within the DEDICATED project. A summary of results will be fed back.

Thank you in advance for your time and compliance!

A. General

1. What is your age?

2. What is your gender?

- ❑ Female
- ❑ Male

3. In which setting do you currently work mainly?

- ❑ Home care
- ❑ Nursing home
- ❑ Care home
- ❑ General practice
- ❑ Hospice
- ❑ Hospital
- ❑ Other, namely …

4. How did you receive this questionnaire?

- ❑ Partner of the project (Envida, Zuyderland, Vivantes)
- ❑ V&VN (Dutch Nurses Association)
- ❑ LPZ (National Survey of Care Indicators)
- ❑ Alzheimer Nederland
- ❑ Other

5. In which province do you currently work?

- ❑ Limburg
- ❑ Noord-Brabant
- ❑ Zeeland
- ❑ Zuid-Holland
- ❑ Noord-Holland
- ❑ Utrecht
- ❑ Gelderland
- ❑ Flevoland
- ❑ Overijssel
- ❑ Drenthe
- ❑ Friesland
- ❑ Groningen

6. What is your current position?

- ❑ Nursing specialist
- ❑ Nursing level 6
- ❑ Nursing level 5
- ❑ Nursing level 4
- ❑ Caring level 3
- ❑ Caring / helping level 2
- ❑ Other, namely …

7. How many years of experience do you have in working with people with dementia?

8. Have you followed additional training in the field of palliative care in the last two years?*

- ❑ No
- ❑ Yes, namely:

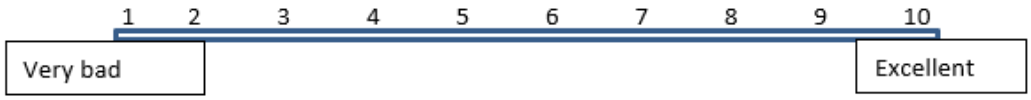
* By additional training we mean courses, clinical lessons, skills training, workshops or curriculums of **at least 2 hours**.

9. Have you followed additional training in the field of dementia care in the past two years?*

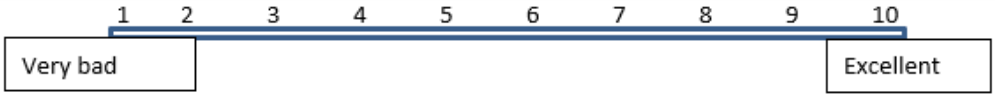
- ❑ No
- ❑ Yes, namely:

* By additional training we mean courses, clinical lessons, skills training, workshops or curriculums of **at least 2 hours**.

10. What do you think of the quality of palliative care for people with dementia within your department or team?



11. To what extent do you feel able to provide palliative care to people with dementia and their loved ones?



12. In my opinion, providing palliative care is...

- ❑ ... a basic task for all nursing and care staff with a basic education.
- ❑ ... a task for nursing and care staff specialized in palliative care.

B. Basiszorg en communicatie

Of the following options, could you please indicate in which you think you need support in palliative care for people with dementia (multiple answers possible). This can involve a need for practical matters, but also for knowledge or, for example, emotional support or contact moments.

In providing palliative care to people with dementia and their loved ones, I need more skills or support in the field of...

Symptom management		
1.	... the daily care / care (ADL and IADL)	☐
2.	... recognizing and dealing with certain behaviours, such as unrest or aggression	☐
3.	... recognizing and dealing with emotions, such as sadness, fear or anger	☐
4.	... recognizing and increasing physical comfort	☐
5.	... recognizing discomfort and dealing with pain	☐
6.	... communicating with people with severe dementia	☐
7.	... dealing with faith and questions of life	☐
8.	... the use of (validated) measuring instruments when for example when measuring symptoms	☐
9.	... recognizing the (start of the) end-of-life phase	☐
10.	... guiding people with dementia and their loved ones in the dying phase	☐
11.	... the involvement of loved ones in the entire care process	☐
12.	... supporting relatives (immediately) after death	☐
13.	... getting the space and opportunity to get to know the people with dementia and their loved ones well	☐
14.	... making me feel more comfortable working with people with dementia	☐
15.	... making me feel more comfortable dealing with loved ones	☐
16.	... my personal contribution to the valuable daily activities of people with dementia	☐
Communication about the end of life		
17.	... feeling comfortable talking about the end of life with people with dementia and their loved ones	☐
18.	...estimating a good time to start a conversation about the end of life	☐
19.	... having a conversation about the end of life	☐
20.	... involving people with dementia in end-of-life decisions	☐

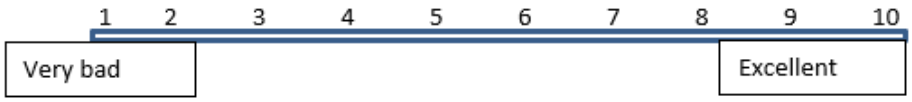
21.	… involving loved ones in end-of-life decisions	☐
22.	… dealing with disagreements between loved ones about end-of-life care	☐
23.	… guiding people with dementia and their loved ones in noting wishes around the end of their life	☐
24.	… being able to retrieve noted agreements about the end of life	☐

25. Can you indicate what your top 3 is that you need from your selected options, with number 1 being the most preferred?

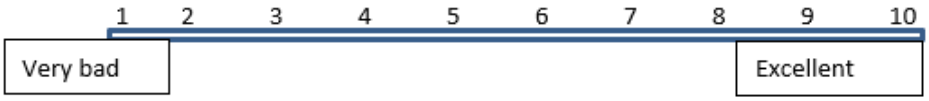
1.
2.
3.

C. Collaboration and transfer (admission to the nursing home)

1. Can you give a grade for the quality of collaboration with colleagues within your own discipline?

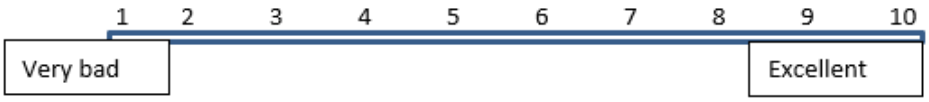


2. Can you give a grade for the quality of collaboration with colleagues from other disciplines?



❑ I don't have to deal with this in my job.

3. Can you give a grade for the quality of collaboration with colleagues from institutions other than the one in which you work?



❑ I don't have to deal with this in my job.

Of the following options, could you please indicate what your needs are in collaboration with other care providers in palliative care for people with dementia (multiple answers possible). This may be a need for practical matters, but also for knowledge or, for example, emotional support or contact moments.

In providing palliative care to people with dementia and their loved ones, I need more skills or support in the field of…

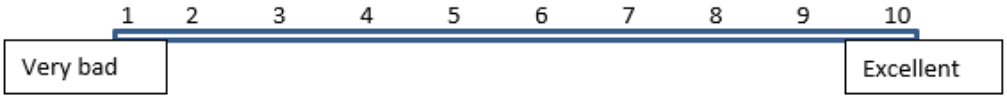
Colllaboration	
4. … the availability of one clear contact person for people with dementia and their loved ones	☐
5. … the availability of one clear contact person for myself	☐
6. … clarity about the tasks of all care providers	☐
7. … clarity about who is responsible for which task	☐
8. … more skills or support in working together as one team	☐
9. … more skills or support in working together, like tips and advice in coordinating care agreements between care providers and a team	☐
10. … consultation with colleagues within my own discipline	☐
11. … consultation with colleagues from other disciplines	☐
12. … consultation with colleagues outside my own institution	☐
13. … tips and advice on how to involve people with dementia and / or their loved ones in interdisciplinary consultations	☐
14. … clarity about where healthcare agreements are recorded	☐
15. … clarity about how care agreements are passed on	☐
16. … feeling safe in implementing care agreements made (for example, a non-CPR policy)	☐
17. … discuss regularly and adjust care agreements if necessary	☐
18. … being able to approach other disciplines directly within my own organization	☐
19. … being able to approach other disciplines directly outside my own organization	☐
20. … a clear information transfer	☐

21. Can you indicate what your top 3 is that you need from your selected options, with number 1 being the most preferred?

1.
2.
3.

D. Admission to the nursing home

1. **Extramura**l: Can you give a grade for the content of the nurse transfer as issued at your institution?
2. **Intramural**: Can you give a grade for the content of the nurse transfer as it is received at your institution?



❑ This is not applicable within my function of work.

Of the following options, could you please indicate what you need when admitting people with dementia from home to the nursing home (multiple answers possible)? This may be a need for practical matters, but also for knowledge or, for example, emotional support or contact moments.

When providing palliative care for people with dementia and their loved ones, I need ...

Upon admission to the nursing home		
3.	... insight into the coordination of the recording (who arranges what)	☐
4.	... one point of contact in the coordination of the recording	☐
5.	... tips and advice to guide relatives and people with dementia in admission	☐
6.	... tips and advice to prepare myself for a admission	☐
7.	... tips and advice for a warm, personal transfer	☐
8.	... standard guidelines for the content of the transfer	☐
9.	... clarity about agreements made earlier about end-of-life wishes	☐
10.	... clarity about where agreements made earlier about end of life wishes can be found	☐
11.	... a visit to the nursing home, together with people with dementia and / or loved ones, before the admission **Extramural**	☐
12.	... a visit to people with dementia in their home situation, before the admission **Intramural**	☐
13.	... tips and advice on how to contribute to a personal and warm welcome **Intramural**	☐

14. Can you indicate what your top 3 is that you need from your selected options, with number 1 being the most preferred?

1.
2.
3.

E. Desired form of support

Of the following options, could you please indicate which form of support you especially need to have in providing palliative care for people with dementia (multiple answers possible)?
In the aforementioned aspects of palliative care for people with dementia, I would like to receive support in the form of...

Training		
1.	... classroom training (such as clinical lessons)	☐
2.	... e-learning	☐
3.	... coaching / supervision in the workplace ('coaching on the job')	☐
4.	... exchanging experience with colleagues (intervision moments)	☐
5.	... joint casuistry discussions	☐
6.	... training with the help of actors or dolls	☐

Technological support		
7.	... mobile apps	☐
8.	... serious gaming (games with an educational purpose)	☐
9.	... electronic clients / patient file with access for all involved healthcare providers (transmural / interdisciplinary)	☐
10.	... digital communication means accessible to all involved healthcare providers	☐
11.	... digital informative videos / animations / podcasts	☐
12.	... digital support in the work place (such as measuring instruments, checklists, decision-making tools, etc.	☐
Emotional support		
13.	... emotional support from direct colleagues	☐
14.	... emotional support from the organization (for example a confidential adviser)	☐
15.	... (being referred to) professional emotional support	☐
From the institution		
16.	... a palliative expert or team to ask for advice	☐
17.	... more times when a palliative expert or team is available	☐
18.	... care processes represented in care paths (such as care path dying phase)	☐
19.	... collaboration agreements within the own organization	☐
20.	... collaboration agreements with care providers outside the organization	☐
21.	... a social map / overview of available healthcare providers	☐
22.	... general support from the organization (time, resources, sufficient staff on the floor)	☐

23. Can you indicate what your top 3 is in these forms of support from your selected options, with number 1 being the most preferred?

1.
2.
3.

24. Are there any other topics in palliative care for people with dementia that you would like support for? Then we kindly ask you to fill it in below and possibly supplement it with the desired form of support.

25. If you have more time to do your work, for what would you use that time?