Nurses' needs in providing palliative care for people with dementia during the transition from home care to a nursing home

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03-07-2019

Background. Palliative care can help with providing a higher quality of life in patients with dementia. However, during transition from home to a nursing home palliative care is fragmented and continuity is sometimes lacking. Discontinuity of palliative care can result in negative health outcomes such as hospitalisation and mortality. In providing palliative care nursing staff are most often closest related to the patients. Therefore, in this study, the needs of nurses working in home care and nursing homes are examined to improve continuous palliative care during the transition of dementia patients from home to the nursing home setting.

Method. The study is a secondary data-analysis of a cross-sectional design based on an online questionnaire. The sample consisted of nursing staff working in home care or nursing homes. The data of characteristics and transition needs was analysed through frequency analysis, chi-square tests, independent t-test and one-way ANOVA.

Results. 370 nurses participated in the study of which 53.5% worked in home care. The most prioritized need of nurses in home care is one point of contact in the coordination of transition. The most prioritized need of nurses in a nursing home is a visit to the people with dementia in their home situation, before transition. Furthermore, significance differences were found in the needs of nurses between different levels and work settings.

Conclusion. The needs of nurses should be looked at individually per work setting and nursing level. Acting according to these needs can result in improved and continuous palliative care for people suffering from dementia and their loved ones.

Keywords: Palliative care, transition needs, people with dementia, nursing staff, nursing home, home care.

Index

1. Introduction

Fifty million people worldwide with are suffering from dementia. Moreover, every year nearly ten million people all over the world are diagnosed with it. Expected is that this number will triple by 2050 (World Health Organization, 2017). Dementia is a disease characterized by deterioration in memory, thinking, behavior and decline in the ability to perform everyday activities. The most common cause of dementia is Alzheimer's disease, followed by vascular dementia as the second most common cause and dementia with Lewy bodies (DLB) as third most common (World Health Organization, 2017). The population suffering from this disease is very vulnerable and requires complex care needs with the input of multiple health professionals, such as general practitioners, registered nurses, geriatricians and care assistants (Hickman, Neville, Fischer, Davidson, & Phillips, 2016). As nowadays, no curable treatments are foreseen for dementia, so focus on the quality of life for those people is important. Palliative care can help with providing this high(er) quality of life.

There is already a widespread agreement that in the advanced phase of dementia, palliative care should be provided (Erel, Marcus, & Dekeyser-Ganz, 2017). Despite this recognition, and the importance of palliative care in all phases of dementia, there is still a large number of people with dementia who fail to receive this kind of care (Erel et al., 2017). The importance of this care has risen due to reports showing the poor-quality care for people with dementia at the end of their life (Davies et al., 2014). According the World Health Organization (2012), palliative care can be defined as: '*an approach that improves the quality of life of patients and their families facing the problem 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*.' Important domains to palliative care for people suffering from dementia are, according to experts: person-centred care, continuity of care, communication and shared decision making and optimal treatment of symptoms and providing comfort (van der Steen et al., 2014). Failure to recognize dementia as a terminal illness, poor communication and the organizational culture of some nursing homes are recognized as barriers to the provision of palliative end-of-life care (Rose & Lopez, 2012). Besides, the same study shows that guidance is needed for professional caregivers with limited experiences in palliative caregiving. During the final stages of life, people suffering from dementia account for one of the most vulnerable groups of people in care. Adequate care practices are necessary to guarantee the best possible well-being at the final stage of life for these patients (Aaltonen et al., 2014).

In the Netherlands, more than half (55%) of the people with dementia are still living independently at home (Poos, Gijsen, Meijer, & Van Bommel, 2018). In the earlier stages of dementia, care is often provided by family members (Rose & Lopez, 2012). However, this informal care can result in physical, emotional and economic pressures, and although part of the people suffering from dementia wants to stay at home, 92% of all registered dementia patients in the Netherlands eventually died in a nursing home (Houttekier et al., 2010).

The decision to transfer people with dementia from their home to a nursing home is a complex but also an inevitable one, influenced by available resources and characteristics from both the patient and the caregiver(s) (Verbeek et al., 2012). There are several reasons that can lead up to the decision of a transition. Reasons can be medical problems that come along with a dementia patient, burden of family caregivers and, according to the study of Ouslander, Zarit, Orr, and Muira (1990), incontinence. This transition however, is prolonged due to the wishes of people and the aging in place policies, resulting in negative health outcomes for informal caregivers, such as sleep disturbances, depressive symptoms and poorer self-rating of overall health status. These negative health outcomes pile up and informal caregivers get overworked and burned out (Rose & Lopez, 2012). If this takes place and the person with dementia or their loved ones did not prepare for or anticipated on a possible transition to a nursing home in the future, these transition often happen rapidly. As a result, a crisis situation occurs. This while a transfer is a complex process, in which multiple health professionals are (or should be) involved. It is a challenge to the patients, their families and the healthcare providers, and each adds to the risk of medical errors and inefficiency (Callahan et al., 2012). An important part of the transition is the continuity of palliative care, and during this movement across settings and between providers the palliative care should take place without interruption (Hirschman & Hodgson, 2018). Nevertheless, the risk of fragmented care increases during every transition. An effective transition with a continuity of palliative care requires face-to-face and unambiguous communication between former and new professional caregivers and patient and families (Saag et al., 2018; van der Steen et al., 2014). When this is not accomplished, fragmented palliative care can lead to the negative experience of poor outcomes such as hospital-acquired complications, morbidity, mortality, and excess health care expenditures (Hirschman & Hodgson, 2018).

In a nursing home as well as in home care, nurses are most often the closest to the patient from all the involved healthcare professionals (Camicia & Lutz, 2016). They interact with the patient and the family, most often acquiring important information about the patient and their needs as well as the needs and shortcomings of their loved ones. This information

can be used in the development and evaluation of a transition plan of a person living with dementia. With this information, nurses can identify and communicate possible barriers to the plan (Camicia & Lutz, 2016). Hence, nurses play a key role in the wellbeing of people living with dementia during the transfer and the provision of palliative care. Therefore, the focus of this study is on these nurses and their needs in order to provide continues palliative care during a transition. Accordingly, the research question of this study is: What are the needs of nurses during the transition phase from home to the nursing home in patients with dementia in a palliative phase and do these preferences differ between nursing level and work setting?

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 transition 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, the data was already collected as described above, and a secondary data analysis has been performed. The Medical Ethics Committee Zuyderland & Zuyd confirmed that the rules of Medical Research Involving Human Subjects Act were not applicable (METCZ20180079).

Study population

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 RN we included both baccalaureate-educated and vocationally-educated nurses.

Questionnaire design

The questionnaire was designed to investigate the needs of nursing staff in providing palliative care for people with dementia. The four themes of DEDICATED is the basis of the questionnaire. Those themes are derived from the following three sources: Perrar, Schmidt, Eisenmann, Cremer, and Voltz (2015); IKNL/Palliactief (2017); van der Steen et al. (2014). This new developed questionnaire was partly created by consulting multiple sources

(Dijkslag-Kluijver, 2017; Lazenby, M., Ercolano, E., Schulman-Green, D., & McCorkle, R., 2012). The questionnaire was developed by three researchers (JM, SP & SB). All the questions were discussed with the entire DEDICATED team. After the research team reached consensus about all items, the questionnaire was discussed in working groups consisting of healthcare professionals from DEDICATED partner organizations in workgroups. They tested the face validity and any comments regarding the questionnaire were taken into consideration. Furthermore, the questionnaires were tested by a test panel consisting of nurses (2 RN, 2 CNA, 2 UNA from every partner organization) regarding content and language use. They tested the feasibility of the questionnaire. Their comments were also taken into consideration. That eventually led to the final questionnaire as used in this study.

The questionnaire consists of five different sections: a general part; basic care and communication; collaboration ; admission to the nursing home; and desired form of support. The general section of the survey includes the following items: age; gender; work setting; how they received 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. This study focusses on the survey section admission to the nursing home. This section contains one rating scale question about the perception on the transition (on a 0-10 scale) and nine dichotomous questions about several aspects during transitions such as coordination, guidance during admission and warm handoff between home care and nursing home. The complete questionnaire can be found in appendix I.

Data Collection

The recruitment method during the study was on a non-random base and lasted from July till October 2018. It was non-randomized due to the inclusion criteria of the study which required a convenience sampling method. The recruitment has been both on a regional and national level. On a regional level, the three researchers of the study shared the hyperlink of the Qualtrics questionnaire with their linking pins from the DEDICATED partner organizations. Those being: Envida, Zuyderland and Vivantes. These organisation at their turn have cooperation contracts with the Living Lab in Ageing & Long-Term Care (AWO) and contact persons from University Network for the Care Sector Zuid-Holland (UNC-ZH) and the Scientific Center for care and wellfare (Tranzo). The dissemination tools used during this process were emails, face-to-face contacts and information flyers. Nationally, the three

researchers also shared the hyperlink of the Qualtrics questionnaire with linking pins from the cooperating organizations, being the Dutch Nurses' Association (V&VN), National Survey of Care Indicators (LPZ) and Alzheimer Nederland. De used dissemination tools in this process have been information flyers, newsletters and websites.

Data Analysis

During the secondary data analysis conducted in this study, IBM SPSS version 25 was used for the quantitative analysis. Primary outcomes entail characteristics of the participants and an overview of the transition needs. Secondary outcomes include differences between types of healthcare settings and levels of nursing. Descriptive analysis was used to describe demographic characteristics (sex and gender), work-related characteristics (years of experience, type of healthcare setting and level of nursing), educational characteristics (additional training in dementia or palliative care), and perceptions about the quality of palliative care. Furthermore, a frequentation analysis was conducted to order the needs and presented in both numbers and percentages. This was also used to indicate a top 5 of nurses' needs. Subsequently, Chi-square tests were performed to explore differences among types of healthcare setting (NH or HC) and within levels of nursing (UNA, CNA and RN) in additional dementia training, additional palliative care training, perception on providing palliative care and the nurses' needs regarding transitions. We carried out independent t-tests to analyse the perception score on quality of palliative care among nurses from home care and nursing home as well as for the perception score on feeling competent to provide palliative care and the perception score on information during a transfer. Moreover, a one-way ANOVA was used to calculate the differences between different nursing levels for the analysis of the perception score on quality of palliative care, the analysis of the perception score on feeling competent to provide palliative care and for the perception score on information during a transfer.

3. Results

Demographic characteristics of the participants

The study population consisted of the 370 participants. In Table 1, the demographic characteristics of the overall participants are shown. The majority of the participants were female (95.9%), the mean age was 45.9 years and the mean working experience 15.75 years. In the overall study population, most of the nursing staff were Certified nurse assistants (CNA), as well as when divided in home care and nursing home settings. The average age of

home care nurses is 47 years in and 44.5 years in nursing home nurses, as can be seen in table 2. The vast majority of the nurses is woman in both settings.

Additional training and Competency in palliative care and dementia.

Approximately, 45.7% of the study population had received additional training in palliative care, 48.6% in dementia care (Table 1). A chi-square analysis showed that nurses in home care followed significantly less additional dementia training than nurses in nursing homes (χ^2 = 19.776, p = 0.000). There was no significant difference between the two settings and additional training in the field of palliative care. Furthermore, between the level of nurses both the difference between dementia training within the levels and the palliative care training differed significantly (χ^2 = 6.611, p = 0.037 and χ^2 = 7.131. p = 0.028 respectively).

Table 1. Characteristics overall population

	Overall (N=370)
Age (average)	45.9 [18-65] SD = 11.99
Female gender, number (%)	95.9
in which setting do you currently work mainly? (percentage mainly working in nursing homes)	46.5
Years of experience working in dementia care(average)	15.75 [0.75-43] SD = 10.80
Did follow additional training in the field of palliative care in the past two years (percentage)	45.7
Did follow additional training in the field of dementia in the past two years (percentage)	48.6
Grade for the quality of palliative care in the department or team	7.14 [1-10] SD = 1.12
Nursing level	
Uncertified nurse assistant (UNA)	N= 31
Certified nurse assistant (CNA)	N= 197
Registered nurse (RN)	N= 142

A one-way ANOVA test was preformed and showed that there where no significant differences found between nursing level and: grading for the provided quality of palliative

care for people with dementia in ones team/floor; how capable one feels to provide palliative care to people with dementia and their loved ones; years of experience in working with people with dementia and grading for the content of the nurse transfer as issued within your institution. For the differences between settings on the same factors as mentioned above, a independent samples t-test was used to identify significant differences. Only 'feeling capable to provide palliative care to people with dementia and their loved ones' differed significantly ($t = -4.996$, $p = 0.000$) between home care and nursing home.

Table 2. Characteristics divided by setting

	Home Care (N=198)	**Nursing Home (N=172)**
Age (average)	47.0 [18-65] SD = 11.91	44.5 [19-64] SD = 11.98
Female gender, number (%)	97.5	94.2
in which setting do you currently work mainly? (percentage mainly working in nursing homes)	16.7	100
Years of experience working in dementia care (average)	16.6 [0.75-40] SD = 11.05	14.8 [1-43] SD = 10.45
Did follow additional training in the field of palliative care in the past two years (percentage)	49	41.9
Did follow additional training in the field of dementia in the past two years (percentage)	37.9	61.0
Grade for the quality of palliative care in the department or team	7.1 [1-10] SD = 1.03	7.2 [2-10] SD = 1.20
Nursing level		
Uncertified nurse assistant (UNA)	N=18	N=13
Certified nurse assistant (CNA)	N=95	N=102
Registered nurse (RN)	N=85	N=57

Table 3. Characteristics divided by nursing level

	RN (N=142)	**CNA (N=197)**	**UNA (N=31)**
Age (average)	42.96 [18-63] SD = 12.49	47.78 [21-65] SD = 11.34	47.03 [19-64] SD = 11.41
Female gender, number (%)	94.4	97.0	96.8
in which setting do you currently work mainly? (percentage mainly working in nursing homes)	40.1	51.8	41.9
Years of experience working in dementia care (average)	15.04 [1-40] SD = 10.94	16.57 [0.75-43] SD = 10.77	13.87 [1-35] SD = 10.22
Did follow additional training in the field of palliative care in the past two years (percentage)	54.2	41.1	35.5
Did follow additional training in the field of dementia in the past two years (percentage)	54.2	47.7	29.0
Grade for the quality of palliative care in the department or team	7.1 [4-9] SD = 0.96	7.16 [1-10] SD = 1.255	7.19 [5-9] SD = 0.873

With the use of a frequency analysis, the overall ranking of the needs of all level nurses in both settings is produced and shown in table 4. The overall most prioritized need is 'Clarity about agreements made earlier about end-of-life wishes (extramural) and where these can be found (intramural)'. The least prioritized need for all nurses combined are 'tips and advice to prepare myself for a transition.'

Table 4. The overall needs of nurses of all levels and both settings.

Overall (N=370)	**Frequency (%)**	**Ranking**
Clarity about agreements made earlier about end-of-life wishes (extramural) and where these can be found (intramural)	156 (42.2)	1.
A visit to the nursing home together with people with dementia and / or loved ones, before the admission (extramural) or a visit to people with dementia in their home situation, before the admission (intramural)	155 (41.9)	2.
Tips and advice to guide relatives and people with dementia in admission	146 (39.5)	3.

One point of contact in the coordination of the recording	132 (35.7)	4.
Insight into the coordination of the recording (who arranges what)	116 (31.4)	5.
Tips and advice for a warm, personal transfer	114 (30.8)	6
Standard guidelines for the content of the transfer	99 (26.8)	7.
Tips and advice to prepare myself for a transition	56 (15.1)	8.

A ranking of the needs of nurses, divided by setting, is established with a frequency analysis and shown in table 5. The priority need for nurses working in home care is 'One point of contact in de coordination of transition'. The priority with regard to the needs for nurses working in a nursing home is 'A visit to the people with dementia in their home situation, before transition'. The need that is least prioritized according to the nurses in both categories is 'Tips and advice to prepare myself for a transition'. With the use of a chi-square analysis (significance of 0.05), the differences between settings are analysed. Significance differences were found between settings and the need for: 'one point of contact in the coordination of transition' ($\chi^2 = 15.963$, $p = 0.000$); 'tips and advice to guide loved ones and people with dementia during a transition' ($\chi^2 = 5.374$, $p = 0.020$); 'tips and advice for a warm, personal transfer' ($\chi^2 = 4.123$, $p = 0.042$) and the needs for a visit to either the people at home (intramural) or a visit to the nursing home (extramural) ($\chi^2 = 9.970$, $p = 0.002$).

Table 5. Ranking of nurses' needs divided by setting

Home care	**Frequency (%)**	**Ranking**	**Nursing home**	**Frequency (%)**	**Ranking**
One point of contact in the coordination of transition	89 (44.9)	1.	A visit to the people with dementia in their home situation, before transition (intramural)	87 (50.6)	1.
Tips and advice to guide loved ones and people with dementia during a transition	89 (44.9)	2.	Tips and advice to contribute to a personal and warm welcome (intramural)	77 (20.8)	2.
Clarity about agreements made earlier about wishes around the end of life	81 (40.9)	3.	Clarity about where to find earlier made agreements	75 (43.6)	3.

			about wishes around the end of life		
Tips and advice to provide a warm and personal transition	70 (35.4)	4.	Tips and advice to guide loved ones and people with dementia during a transition	57 (33.1)	4.
A visit to the nursing home together with people with dementia and/or their loved ones, before transition (extramural)	68 (34.3)	5.	Insight into the coordination (who takes care of what)	49 (28.5)	5.
Insight into the coordination (who takes care of what)	67 (33.8)	6.	Tips and advice to provide a warm and personal transition	44 (25.6)	6.
Standard guidelines for the content of the transition	59 (29.8)	7.	One point of contact in de coordination of transition	43 (25.0)	7.
Tips and advice to prepare myself for a transition	27 (13.6)	8.	Standard guidelines for the content of the transition	40 (23.3)	8.
			Tips and advice to prepare myself for a transition	29 (16.9)	9.

Using a chi-square analysis with a significance of 0.05, the needs of all participants, divided by nursing level is shown. Significance differences between nursing levels have been found in 'Tips and advice to prepare myself for a transition' ($\chi^2 = 6.624$, $p = 0.036$) and in 'A visit to the nursing home together with people with dementia and / or loved ones, before the admission (extramural) or a visit to people with dementia in their home situation, before the admission (intramural)' ($\chi^2 = 9.625$, $p = 0.008$). The top 3 needs in are made bolt and cursive for per levels of nurses in the table.

Table 6. Needs of all nurses divided by nursing level.

Needs overall (N=370)	**Registered nurse Frequency (%)**	**Certified nurse assistant Frequency (%)**	**Nurse assistant Frequency (%)**

Clarity about agreements made earlier about end-of-life wishes (extramural) and where these can be found (intramural)	46 (32.4)	*63 (54.3)*	*7 (22.6)*
One point of contact in de coordination of transition	***60 (42.3)***	*64 (32.5)*	*8 (25.8)*
Tips and advice to guide loved ones and people with dementia during a transition	50 (35.2)	***83 (42.1)***	***13 (41.9)***
Tips and advice to prepare myself for a transition	13 (9.2)	38 (19.3)	5 (16.1)
Tips and advice to provide a warm and personal transition	*48 (33.8)*	55 (27.9)	***11 (35.5)***
Standard guidelines for the content of the transition	47 (33.1)	47 (23.9)	*5 (16.1)*
Clarity about agreements made earlier about wishes around the end of life (extramural) and where to find them (intramural)	***64 (45.1)***	**80 (40.6)**	***12 (38.7)***
A visit to the nursing home together with people with dementia and / or loved ones, before the admission (extramural) or a visit to people with dementia in their home situation, before the admission (intramural)	**60 (42.3)**	**90 (45.7)**	5 (16.1)

A Chi-square analysis with a significance of 0.05 shows in table 7 that the need of 'Insight into the coordination (who takes care of what)' ($\chi^2 = 6.732$, $p = 0.035$); 'One point of contact in de coordination of transition'($\chi^2 = 12.046$, $p = 0.002$); 'Tips and advice to prepare myself for a transition ($\chi^2 = 6.732$, $p = 0.035$); 'Tips and advice to provide a warm and personal transition ($\chi^2 = 17.574$, $p = 0.000$); 'Standard guidelines for the content of the transition' ($\chi^2 = 7.742$, $p = 0.021$) and 'Clarity about agreements made earlier about wishes around the end of life' ($\chi^2 = 8.936$, $p = 0.011$) differed significantly between the level of nurses in home care. The top 3 needs in home care are made bolt and cursive for per levels of nurses in the table.

Table 7. Needs of nurses in home care divided by nursing level

Needs in home care	**Registered nurse Frequency (%)**	**Certified nurse assistant Frequency (%)**	**Uncertified nurse assistant Frequency (%)**
Insight into the coordination (who takes care of what)	31 (21.8)	***24 (30.9)***	***3 (9.7)***
One point of contact in de coordination of transition	***44 (31.0)***	***34 (17.3)***	***3 (9.7)***
Tips and advice to guide loved ones and people with dementia during a transition	34 (23.9)	***35 (17.8)***	***4 (12.9)***

Tips and advice to prepare myself for a transition	6 (4.2)	12 (6.1)	0 (0.0)
Tips and advice to provide a warm and personal transition	***37 (26.1)***	19 (9.6)	***3 (9.7)***
Standard guidelines for the content of the transition	29 (20.4)	20 (10.2)	***3 (9.7)***
Clarity about agreements made earlier about wishes around the end of life (home care)	***35 (24.6)***	26 (13.2)	***3 (9.7)***
A visit to the nursing home together with people with dementia and/or their loved ones, before transition (extramural)	22 (15.5)	28 (14.2)	1 (3.2)

A Chi-square analysis with a significance of 0.05 shows in table 8 that the need of 'Tips and advice to guide loved ones and people with dementia during a transition' (χ^2 =10.788, p = 0.005); 'Tips and advice to prepare myself for a transition' (χ^2 = 7.382, p = 0.025); 'Tips and advice to provide a warm and personal transition' (χ^2 = 10.428, p = 0.005) and 'Tips and advice to contribute to a personal and warm welcome' (χ^2 = 6.764, p = 0.034) differed significantly between the level of nurses in nursing homes. Just as in table 7, the top 3 needs of nurses in nursing homes is made bold and cursive for all levels.

Table 8. Need of nurses in nursing homes divided by nursing level

Needs in nursing homes	**Registered nurse Frequency (%)**	**Certified nurse assistant Frequency (%)**	**Uncertified nurse assistant Frequency (%)**
Insight into the coordination (who takes care of what)	15 (10.6)	39 (19.8)	4 (12.9)
One point of contact in de coordination of transition	16 (11.3)	30 (15.2)	5 (16.1)
Tips and advice to guide loved ones and people with dementia during a transition	16 (11.3)	***48 (24.4)***	***9 (29.0)***
Tips and advice to prepare myself for a transition	7 (4.9)	26 (13.2)	5 (16.1)
Tips and advice to provide a warm and personal transition	11 (7.7)	36 (18.3)	8 (25.8)
Standard guidelines for the content of the transition	18 (12.7)	27 (13.7)	2 (6.5)

Clarity about where to find earlier made agreements about wishes around the end of life	***29 (20.4)***	***54 (27.4)***	***9 (29.0)***
A visit to the people with dementia in their home situation, before transition (intramural)	***38 (26.8)***	***62 (31.5)***	4 (12.9)
Tips and advice to contribute to a personal and warm welcome	***22 (15.5)***	44 (22.3)	***11 (35.5)***

4. Discussion

The objective of this study is to have insight in the needs of nurses in providing continues palliative care for patients with dementia in transition from home to the nursing home setting. Furthermore, the differences between nursing level and work setting were examined. The most prioritized need of nurses in home care is to have one clear point of contact in the coordination of transition. The most prioritized need of nurses in a nursing home is to have a visit to the people with dementia in their home situation, before the transition. A significant difference was found between the amount of additional training followed in the fields of both palliative care as well as dementia care between the level of nurses. Registered nurses have followed significantly more training than certified nurse assistants and uncertified nurse assistants. Besides, within the groups of (un)certified nurse assistants, less than fifty percent has followed additional training in both fields. This is striking since they are the biggest group working with the patients. The difference can be explained by the tasks of the different nurses and their education level. Registered nurses have more tasks with regard to healthcare and the wellbeing of the patients and have had a higher education level. This education could also involve or require additional training, or due to the more extended tasks of the registered nurses, additional training is more urgent. This research also shows that nurses working in a nursing home significantly feel more capable to provide palliative care to people with dementia and their loved ones. This might be explainable by the difference between the number of additional dementia trainings followed between the settings, where nurses in home care followed significantly less additional training. Additionally, it is to assume that people with severe dementia most often live in a nursing home instead of at home. Therefore, home care nurses have less experience in working with people with severe dementia. This lack of experience could result in feeling less capable than nursing home nurses.

Interestingly, the overall least prioritized need of all nurses taken together is to receive tips and advice to prepare oneself for a upcoming transition. This while, as mentioned above,

home care nurses feel significantly less capable of providing palliative care in comparison with nursing home nurses. Besides, when looking at the division based on setting, less than half of the nurses in both settings have followed any additional training in the field of palliative or dementia care. Nevertheless, this study suggest that nurses themselves do feel prepared for a transition, as tips and advice for this are least prioritized. Even more, not one uncertified nurse assistant working in home care feels the need to receive these kind of tips and advice. Of all the nurses, not divided by setting nor level, 42.2 percent has indicated to have the need for more clarity with regard to end-of-life wishes of the patients as well as where those wishes/agreements of a patients can be found. This suggests that almost half of the nurses in this study working in home care or nursing homes is not sure about or does not know where to find the final wishes of a patient. For registered nurses working in home care, a clear first person of contact in the coordination of a transition was the most urgent need in providing continues palliative care. (Un)certified nurse assistants found this the second most important need, they prioritized the need for tips and advice to guide people with dementia and their loved ones during a transition. This once again could also result from the variety in tasks between the different nursing levels. The most prioritized need for registered nurses and certified nurse assistants working in a nursing home is to have a visit to the people with dementia while they are still living at home. However, only four uncertified nurse assistants saw this visit as a need to improve palliative care. This could suggest that uncertified nurse assistants are not as much involved in the transition but only come into play when the people with dementia are placed in the nursing home. This suggestion is supported by the finding that the most prioritized need for uncertified nurse assistants are tips and advice to contribute to a personal and warm welcome, when the people with dementia arrive to the nursing home.

Our study already suggested the importance of adequate training in the shape of the need for tips and advice in different kind of sections. The upcoming studies ones more confirm this importance. The study of Beck, Ortigara, Mercer, and Shue (1999) looked at the needs of nurses providing palliative care. This study suggested that barriers limiting the caregiving effectiveness of certified nurse assistants are a low salary, minimal long-term benefits and insufficient training. Although in this study the questionnaire did not included questions regarding ones wage and work benefits, insufficient training can result in a need for tips and advice. For instance, the need for tips and advice for the guidance of people with dementia and their loved ones during a transition was ranked third in the needs of certified nurse assistants in nursing home and second in home care certified nurse assistants. Besides, it was the third prioritized need when taken all nurses together. The study of Sung, Chang, and

Tsai (2005) states that the consideration of the needs of nurses in long-term dementia care is essential, and they identified five factors of needs: monetary, working environment, the relationship with residents, gratification and training opportunity. The study of Redman, White, Ryan, and Hennrikus (1995) found in a survey of 108 palliative care nurses that the opportunity to improved training was the most prioritized need among the nurses. Our study suggest that tips and advices are more needed in home care since nurses in that setting have significantly prioritized the need for it more often than nurses in nursing homes. Wallerstedt and Andershed (2007) found that insufficient cooperation, time, support and resources resulted in dissatisfaction of the nine nurses providing palliative care in their study. Contact with patients and relatives resulted in satisfaction among the nurses, as well as functional collegial cooperation. As mentioned before, the most prioritized need among nursing home nurses is a visit to the people with dementia in their home situation, before the transition to a nursing home. This can be linked to the contact with patients and relatives as found in the above mentioned study. In the study of Dunne, Sullivan, and Kernohan (2005) communication is looked at as an effective way whilst dealing with emotional reaction of the patient and their loved ones. This is perceived as difficult by the home care nurses in the study. Although the study is about patients with cancer and a transition is not necessarily discussed, it does relate to our finding that the need ranked second by home care nurses is the need to receive tips and advice to guide loved ones and people with dementia during a transition. This guidance can be engaged with emotions of the patients who might not want to move out of their house or overburdened loved ones. The same goes for nursing home nurses, who prioritized the need for tips and advice to the contribution of a personal and warm welcome for the new resident second. Also linked with the same need, the nurses in the study of Dunne et al. (2005) mentioned that they needed training in dealing with the loved ones of the patient. Especially in dealing with children and adolescents. The study concluded with the need of an adequate communication network between various professional groups. This is also supported by the results in the ranking of needs in our study, as the most prioritized need of all nurses together is linked with adequate communication to provide clarity about end-of-life wishes and where these wishes can be found. Besides, to have clarity in who the first person of contact during a transition is, is the most prioritized need by home care nurses. This clarity is also based on proper communication. The study of Bolt et al. (2019) looked into the needs of nurses providing palliative care in nursing homes and home care and found several needs comparable to the needs found in this study. For instance, they found that nurses have unmet needs with regards to interdisciplinary collaboration, training and education, and

information exchange with other nurses. Besides, the study found that nursing staff has difficulties with recognizing and addressing physical needs and handling physical discomfort. Additional training in palliative and dementia care could overcome these difficulties, and as our study shows, there is still much to be gained with regard to the number of nurses (in all levels) to follow this additional training.

370 nurses filled in our questionnaire which is a relatively large study population compared to other studies in this field. This is a strength of the study. As a result, the findings of the study can be seen as more reliable and representable. Besides, the relatively large number of home care nurses is noteworthy, since not many studies have looked at home care nurses providing palliative care. Most of the interviewed nurses where female. This is the case in more studies done regarding nurses, indicating that our study population is representable for the population of nurses (Brodaty, Draper, & Low, 2003).

A possible limitation of this study is the validity of the questionnaire. Despite the fact that several parties were involved in the development of the questionnaire, a widely used and established questionnaire would have improved the validity and would made the study results more reliable. However, the study for which the questionnaire was used was explorative and used to indicate the needs of nurses, not to measure a specific outcome. Selection bias could have occurred in the study. Although there was no selection in to which nurses the questionnaire was send to, nurses who are more interested in (improving) palliative care will most likely be more interested in the questionnaire. Another limitation is the low number of uncertified nurse assistants in the study. If the number of uncertified nurse assistants were more comparable with the number of certified nurse assistants and registered nurses the study would have been more reliable.

Implications in practice and conclusion

Interestingly, the priority need for nurses working in home care, to have a clear first person to contact in de coordination of transition is ranked seventh in the needs for nurses working in nursing homes. For those nurses working in nursing homes, their priority need is to have a visit to the people with dementia in their home situation, before the actual transition occurs. This whilst the other way around, being a visit to the nursing home together with people with dementia and/or their loved ones before the transition, is ranked fifth in the needs for nurses working in home care. This suggests that the needs for nurses working in home care differs from the needs of nurses in nursing homes and therefore should be approached separately in practice. This also accounts for the difference in level between nurses. In this

study, certified nurse assistants and registered nurses in a nursing home setting have the same most prioritized need, whereas uncertified nurse assistants in the same setting have a different number one need. For the home care setting, all three nursing levels have a different prioritized need. Applying this knowledge to practice, it indicates that all needs of nurses between different settings as well as different levels should be approached individually. Besides, providing training with regards to palliative and dementia care can help with the improvement and continuity of palliative care. Therefore, the possibilities of providing training should be investigated within both settings. Especially certified nurse assistants and uncertified nurse assistants should be the focus of these trainings, since less that fifty percent of these nursing levels has had any additional training in the field of dementia or palliative care.

With regards to the research question, this study suggest that all needs of nurses vary between different levels and settings. When looking to the needs in nursing homes, registered nurses' most prioritized need is to have a visit to the people with dementia in their home situation, before the transition occurs. The same accounts for certified nurse assistant. For Uncertified nurse assistants, the need for tips and advice in order to contribute to a personal and warm welcome of the residents is the most prioritized need. In home care, the most prioritized need for registered nurses is to have one clear first contact person in de coordination of the transition of a person. For both uncertified nurse assistants and certified nurse assistant the priority need is to receive tips and advice to guide loved ones and people with dementia during a transition.

To conclude, the possibility for registered nurses and certified nurse assistants working in nursing home settings to perform home visit before the transition to a nursing home should be explored in practice to improve the continuity of qualitative palliative care. Furthermore, a training with regard to the arrival of a person with dementia to a nursing home should be arranged for the uncertified nurse assistant in nursing homes. This training should include tips and advice to contribute to a warm welcome. In home care, more clarity is needed with regards to the coordination of a transition. One clear first contact person during such a transition could improve continuity of palliative care. Besides, for uncertified nurse assistants tips and advice for the guidance during such a transition should be provided in the form of a training.

Further recommendations

More research is needed for the improvement of palliative care for people suffering from dementia. In those studies, the focus should be on the transition and settling down of the

patient. This study already gives an insight with regard to the nurses, but a transition is a interprofessional event. Therefore, the needs of other parties should also be included in future research. When the needs of all parties involved are taken into account, we expect that major steps can be taken to improve palliative care and its continuity. On the other hand, as was also suggested by other studies and is endorsed by this study, communication is key. Not only with one explicit person as a point of contact during a transition or clarity about earlier made agreements and where to find them, but also with the nurses. The conversation must be introduced into with nurses about their needs. In order to improve the continuity in palliative care, nurses' wishes and shortcomings in providing palliative care should be explored. For this, communication with the nurses in both nursing homes and home care settings is required. This study already showed the differences between nursing settings and levels. Furthermore, it is also almost assumable that there are also differences on personal levels, and without communication, those needs can not be identified.

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Appendix I: The questionnaire

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?

1 2 3 4 5 6 7 8 9 10

Very bad — Excellent

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

1 2 3 4 5 6 7 8 9 10

Very bad — Excellent

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. Basic care and communication

Please cross of the box from the options below 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…

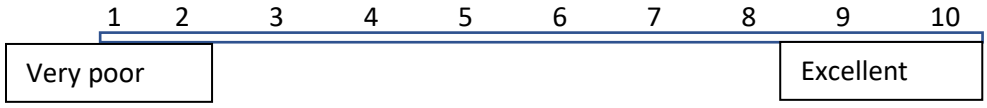
Symptoom management		
1.	… the daily care / care (ADL and IADL)	☐
2.	… recognizing and dealing with certain behaviors, such as unrest or aggression	☐
3.	… recognizing and dealing with emotions, such as sadness, fear or anger	☐
4.	… recognizing and increasing physical comfort	☐
5.	… recognizing discomfort 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	☐
Communicatie over het levenseinde		
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	☐

Can you indicate what your top 3 is from the options above, with number 1 being the most important one?

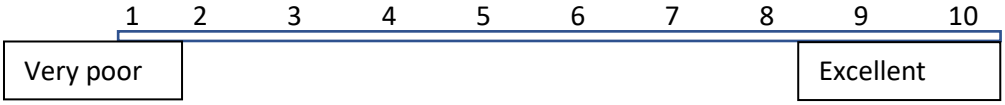
1.
2.
3.

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?

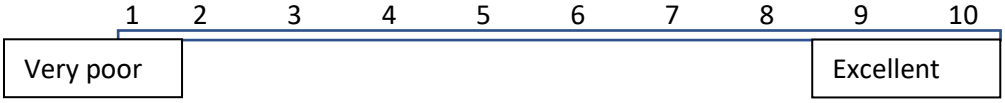


2. Can you give a grade for the quality of collaboration with colleagues from other disciplines?



❑ 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.

Please cross the box from the options below 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…

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

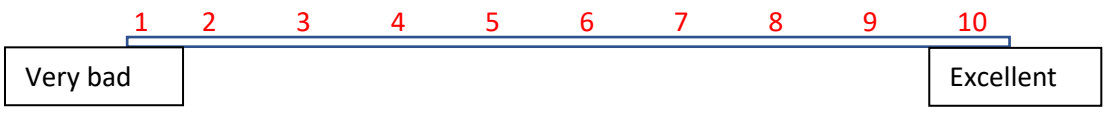
Can you indicate what your top 3 is from the options above, with number 1 being the most important one?

1.
2.
3.

D. Admission to the nursing home

1. **Extramural**: 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

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

D. 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?