Needs of nurses in the interprofessional collaboration in palliative care for people with dementia

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Abstract

Background. Dementia is a progressive, incurable, neurocognitive disorder which affects activities of daily living and social functioning. Patients with a disease leading to an imminent death, such as dementia, are in need of palliative care to address the patient and relatives concerns and needs. Interprofessional collaboration is key in providing quality palliative care for people with dementia. An optimally functioning interprofessional team requires excellent training, communication and a description of the tasks and responsibilities of each team member. However, often communication problems are prevalent among staff, leading to poor team collaboration, disagreements, and stress, especially with staff members who are not trained in palliative care. This study explores the needs of nursing staff across different disciplines that provide palliative care when having to collaborate with professionals within and outside of their own discipline. Research questions: 1. What are the perceived needs of nurses when collaborating with other nurses and healthcare professionals in the palliative care for people in the home care and nursing home setting? 2. Do the perceived needs of these nurses differ within the home care and nursing home settings and among nursing levels?
Method. The study is a cross-sectional secondary data analysis of a questionnaire. The population consisted of nursing staff working in home care or nursing homes (n=384). Chi-square tests, independent t-test and one-way ANOVA have been conducted in the data analysis.
Results. The overall the top five needs identified by nurses when providing palliative care for people with dementia are: the availability of one clear contact person for people with dementia and their loved ones, a clear information transfer, being able to approach other disciplines directly within their own organization, clarity about who is responsible for which task and clarity about the tasks of all care providers. There were significant differences in perceived needs between care settings.
Conclusion. This study explored the needs of nurses during interprofessional collaboration when providing palliative care for people with dementia. Insight in the needs can be used to further develop high quality patient-centred care. More research is needed to understand causes of the identified needs.

Keywords: Palliative care, interprofessional collaboration, dementia, nursing staff, home care, nursing home

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1. Introduction

As the world's population increases in age, the number of people living with dementia is continuously growing. In 2010 an estimated 35.6 million people above the age of 60 years worldwide lived with dementia. This number is expected to double by 2030 due to the rising numbers of older adults (Prince et al., 2013). In the Netherlands the prevalence of dementia is estimated to be around 270.000 of whom 70,000 reside in nursing home settings (Alzheimer Nederland, 2017).

Dementia is a progressive, incurable, neurocognitive disorder which affects activities of daily living and social functioning (World Health Organisation, 2016). There are several different types of dementia with Alzheimer's disease being the most common (60-70%). Symptoms of dementia can vary according to the part of the brain that is damaged and presents as impairment in multiple facets of cognitive function such as memory, learning, language, social cognition, executive function, and perceptual motor skills (American Psychiatric Association, 2013). Patients with a disease leading to an imminent death, such as dementia, are in need of palliative care to address the patient and relatives concerns and needs. Palliative care is defined by the World Health Organization (2012) 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.' In a Delphi study several different domains were defined that were associated with giving optimal palliative care in older people with dementia (van der Steen et al., 2014). There was an immediate and full consensus on the following eight domains including: person centred care, communication and shared decision making; optimal treatment of symptoms and providing comfort setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues. To provide the care that is required an interprofessional team composed of physicians, nurses, physician assistants, social workers, psychologists, therapists, health educators, other allied health professionals and support staff is needed (Galvin, Valois, & Zweig, 2014). In general research on the collaboration between healthcare professionals is scarce and complicated by the use of carried terms (interdisciplinary collaboration, multidisciplinary coordination, trans-professional teamwork), which has resulted in conceptual confusion within the field (Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017). For the purpose of this paper the term interprofessional collaboration (IPC) is used to describe said terms. IPC is defined by as the process by which

different health and social care professional groups work together to improve quality of care. IPC involves regular negotiation and inter-action between professionals, which values the expertise and con-tributions that various healthcare professionals bring to patientcare (Reeves et al., 2017).

Most of the daily care provided for people with advanced dementia is done by working staff in home care or long-term care facilities. Nurses that are working on daily basis with people with dementia often familiarize themselves with usual behavioural patterns, routines and preferences of the people whom they care for. They are often first to detect and act upon changes in the person's physical and cognitive stats to prevent or alleviate suffering (De Witt Jansen et al., 2017). Because of this they have a key position when it comes to IPC. However, due to the complex nature of care for people with dementia, nurses face a variety of problems during IPC. A scoping review on barriers to palliative care for advanced dementia showed that communication problems are prevalent among staff, leading to poor team collaboration, disagreements, and stress, especially with staff members who were not trained in palliative care (Erel, Marcus, & Dekeyser-Ganz, 2017). Moreover time pressure, funding mechanisms, integration of services, and diffused responsibility were found to be a cause of conflict between decision-makers and a cause of tension leading to a lack of trust, disorganized care, and hesitancy to address a palliative approach. Furthermore a scoping review on the needs of nursing staff in providing palliative care for people with dementia at home or in long-term care facilities concluded that nursing staff reported poor collaboration with other disciplines (physicians/other nursing staff members) as a barrier to effective palliative care provision (Bolt et al., 2019). Next to that assistants reported feelings of being unsupported by other staff and being excluded from multidisciplinary team meetings, which raised concerns about missing out on critical information about patients from other discipline. The barriers nurses experience during IPC likely have a negative effect on delivering high-quality palliative care. An integral understanding on how nurses experience IPC during the delivery of palliative care for people with dementia is therefore necessary.

This study explores the needs of nursing staff across different disciplines that provide palliative care when having to collaborate with professionals within and outside of their own discipline. Furthermore, it gives insight in how nurses in different disciplines evaluate the quality of the collaboration with professionals within and outside of their own discipline as well as professionals from different institutions. This study is part of the Desired Dementia Care Towards Ends of Life (DEDICATED) project that was established in 2017 in the Netherlands. The overall goal of the DEDICATED project is to improve the quality of end of

life care for people with dementia receiving long term care in the home setting or in the nursing home setting (ZonMw, 2018.). The main research questions of this study are: 1. What are the perceived needs of nurses when collaborating with other nurses and healthcare professionals in the palliative care for people in the home care and nursing home setting? 2. Do the perceived needs of these nurses differ within the home care and nursing home settings and among 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. The current study explores the interprofessional collaboration 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. The online questionnaire was distributed among nursing staff using the online survey software Qualtrics.. 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 (HC) or nursing home (NH); 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. In the group of RN both baccalaureate-educated (In Dutch: HBO-opgeleid) as well as vocationally-educated (In Dutch: MBO-opgeleid) were included.

Questionnaire design

Aim of the questionnaire was to determine the needs of nursing staff for providing palliative care for people with dementia. The structure of the questionnaire is based on the four main themes of the DEDICATED project:, basic palliative care and comfort, communication during the end-of-life phase and the continuity of care and collaboration between health care providers. These themes have been derived from the following sources: Perrar, Schmidt, Eisenmann, Cremer, & Volt, 2015; IKNL/Palliactief 2017; van der Steen et al., 2014. The questionnaire has been developed by researchers JM, SP and SB and is partially based on

current existing questionnaires (Dijkslag-Kluijver 2017; Lazenby, Ercolano, Schulman-Green, & McCorkle 2012). First a consensus was reached on all questions in the questionnaire after they were thoroughly discussed with all members of the DEDICATED research team. Secondly the questions were presented in work groups of healthcare professionals of partner organisations of the DEDICATED study to test the face validity. Suggestions provided in these work groups have been taken into account. Next the questionnaire was tested by a test panel of nurses currently working in the palliative healthcare setting (2 RN, 2CNA and 2 UNA for each partner organisation). They tested the feasibility of the questionnaire by looking at the content as well as the language used in the questionnaire. All suggestions made have been taken into account while developing the final version of the questionnaire, as used in this study. The questionnaire consists of five different sections;. General information, 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 is focussed on only the collaboration section. The section on collaboration consists of two different parts as can be found in Appendix I. Part one consist of 3 questions on the experienced IPC which can be answered with a score on Likert-scale ranging from 1 to 10 (1 being very poor and 10 being excellent). Part two consists of 20 dichotomous items on nursing needs of IPC.

Data collection

Recruitment of the study population was not random due to the inclusion criteria of the study which required a convenience sampling method. Recruitment lasted from July until and including October 2018. Recruitment has been on regional as well as national level. On a regional level, three researches shared the hyperlink to the Qualtrics questionnaire with linking pins from the DEDICATED partner organisations. The partner organisations are Envida, Zuyderland and Vivantes. These organisations have collaboration contracts with the Living Lab in Ageing & Long-Term care (AWO) and have linking pins with the University Network for the Care Sector Zuid-Holland (UNC-ZH) and Scientific Centre for care and welfare (Tranzo). The dissemination tools used during this process were emails, face-to-face contacts and information flyers. On a national level the three researchers shared the hyperlink

to the Qualtrics questionnaire with linking pins of the collaborating organisations Dutch Nurses' Association (V&VN), National Survey of Care Indicators (LPZ) and Alzheimer Nederland. The used dissemination tools in this process were information flyers, newsletters and websites.

Data analysis

The secondary data analyses has been generated using the IBM SPSS statistics version 25. Primary outcomes entail characteristics of the participants and an overview of the collaboration needs. 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 is conducted to order the needs of nurses on IPC as answered in section C. Secondary outcomes were generated to test differences between settings and nursing levels. 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). We carried out independent t-tests to analyse the perception score on quality of palliative care among nurses from home care and nursing home. Moreover, ANOVA tests were used to calculate the differences between different nursing levels as well as for the analysis of the perception score on quality of palliative care and the extent to which nurses feel capable to provide palliative care to people with dementia and their loved ones.

3. Results

Demographic characteristic of the participants

The total study population consisted of 384 participants. Demographics are shown in Table 1 and 2. Participants in this study were primarily female (96.1%), had a mean age of 45.7 years and have on average been working 15.78 years with people suffering from dementia. Overall more people worked in the home care setting (53.9%) than in nursing homes (46.1%). Furthermore most nurses were CNA's (53.1%), followed by RN's (38.8%) and UNA being last (8.1%). Of the population 45.8% had additional training in palliative care in the last two years and 49% had additional training in dementia care in the last two years. The mean score of perceived quality of care was 7.13. The mean score of to what extend the nurses felt competent to provide care was 7.51. Moreover the majority of the population thinks that providing palliative care is a basic task for all nursing and care staff with a basic education (74.0%) versus palliative care being seen as a task for specialized care staff (26.0%).

Table 1. *Demographic characteristics overall population*

Demographic characteristics of nursing staff	**N = 384**
Mean age, range	45.71 (18-65) SD = 12.06
Female gender, number (%)	369 (96.1)
Years of experience, range	15.78 (0.75-43) SD = 10.86
Work setting, number (%)	
Home care	207 (53.9)
Nursing Home	177 (46.1)
Work function, number (%)	
RN[a]	149 (38,8)
CNA	204 (53,1)
UNA	31 (8,1)
Additional training palliative care (% yes)	176 (45.8)
Additional training dementia (% yes)	188 (49.0)
Perceived quality of care, range	7.13 (1-10) SD = 1.13
Extent of competence to provide care, range	7.51 (0-10) SD = 1,37
Palliative care being basic / specialized task, number (%)	
Basic task	284 (74.0)
Specialized task	100 (26.0)

Table 2. *Demographic characteristics in work settings and nursing levels*

Demographic characteristics of nursing staff	**Home care (N=207)**	**Nursing home (N=177)**	**RN (N=149)**	**CNA (N=204)**	**UNA (N=31)**
Mean age	46.86 SD=11.96	44.36 SD=12.06	42.91 SD=12.51	47.55 SD=11.47	47.03 SD=11.41
Female gender %	202 (97.6)	167 (94.4)	141 (94.6)	198 (97.1)	30 (96.8)
Year of experience	16.60 SD=11.06	14.82 SD=10.57	14.90 SD=10.82	16.70 SD=10.82	13.87 SD=10.22
Work setting %					
Home care	100	0	91 (61)	98 (48.1)	18 (58.0)
Nursing Home	0	100	58 (38.9)	106 (52.0)	13 (41.9)
Work function %					
RN[1]	91 (44.0)	58 (32.8)	149 (100)	0	0
CNA	98 (47.3)	106 (59.9)	0	204 (100)	0
UNA	18 (8.7)	13 (7.2)	0	0	31 (100)
Additional training palliative care (% yes) **	102 (49.3)	74 (41.8)	81 (54.4)	84 (41.2)	11 (35.5)
Additional training dementia (% yes) * **	79 (38.2)	109 (61.6)	81 (54.4)	98 (48.0)	9 (29.0)
Perceived quality of care	7.08 SD = 1.06	7.19 SD = 1.19	7.1 SD= 0.97	7.15 SD = 1.27	7.19 SD = 0.87
Extent of competence to provide care *	7.19 SD = 1.43	7.88 SD = 1.20	7.51 SD = 1.11	7.57 SD = 1.48	7.10 SD=1.640
Palliative care being basic / specialized task, number (%)					
Basic task	147 (71)	137 (77.4)	116 (77.9)		114 (70.6)

Specialized task	60 (29.0)	40 (22.6)	22 (22.1)	60 (29.4)

[1] Within the group of RNs both baccalaureate-educated and vocationally-educated were included.
* Significant differences between work setting.

** Significant differences between nursing levels.

Additional training, perceived quality of care and competence in proving care

A Chi-square test of independence was calculated comparing if the participants had received additional palliative care training or training in dementia care in the last two years and whether palliative care is seen as a basic or a specialized task in different care settings and in different nursing levels. A significant difference was found for additional training for palliative care in different nursing levels χ^2 (2, N=384)= 7.49, $p < .05$. Furthermore a significant difference was found for additional training for dementia care in different settings χ^2 (1, N=384) = 20.94, $p < .05$ and in different nursing levels χ^2 (2, N=384) = 6.74 $p < .05$. No significant difference was found for additional palliative care training in care settings χ^2 (1, N=384) = 2.14, $p > 0.05$) and no significant difference was found in palliative care being a basic or specialized task in care settings χ^2 (1, N=384) = 2.02, $p > 0.05$ and in nursing levels χ^2 (2, N=384) = 2.57, $p > .05$.

An independent-samples t-test was conducted to determine significant differences on the perception of the quality of palliative care within the department or team and to what extent to the participants feel able to provide palliative care to people with dementia and their loved ones in care settings. A significant difference was found in the extent to which the participants feel able to provide palliative care to people with dementia and their loved ones between home care (M=7.19, SD=1.42) and nursing home setting (M=7.88, SD=1.12); t (382)= -5.07, $p < .05$. To test differences in nursing levels for the same two items a one-way ANOVA was conducted. No significant effect was found of nursing levels on the perception of the quality of palliative care F (2, 370) = .160, $p > .05$ and no significant effect was found of nursing levels on the extent to which the participants feel able to provide palliative care to people with dementia and their loved ones F (2, 381) = 1.642, $p > .05$.

General needs of participants within IPC

Needs of the participants within IPC of the total study population are listed in Table 3 and ranked on frequency. The top 5 needs were respectively: the availability of one clear contact person for people with dementia and their loved ones (37.5%), a clear information transfer of information (37.2%), being able to approach other directly within my own organization

(31%), clarity about who is responsible for which task (30.7%) and clarity about the tasks of all care providers (30.5%).

Table 3. *Frequency needs within IPC of total study population*

Needs within IPC	**Frequency (n=384)**	**Ranking**
The availability of one clear contact person for people with dementia and their loved ones	**144 (37.5%)**	**1**
A clear transfer of information	**143 (37.2%)**	**2**
Being able to approach other disciplines directly within my own organization	**119 (31.0%)**	**3**
Clarity about who is responsible for which task	**118 (30.7%)**	**4**
Clarity about the tasks of all care providers	**117 (30.5%)**	**5**
Tips and advice in coordinating care agreements between care providers	115 (29.9%)	6
Being able to approach other disciplines directly outside my own organization	102 (26.6%)	7
More skills or support in working together as one team	101 (26.3%)	8
Regularly discuss and adjust care agreements if necessary	100 (26.0%)	9
Tips and advice on how to involve people with dementia and / or their loved ones in interprofessional consultations	98 (25.5%)	10
Consultation with colleagues within my own discipline	83 (21.6%)	11
Consultation with colleagues from other disciplines	83 (21.6%)	12
Feeling safe in implementing care agreements that have been made (for example, a non-CPR policy)	71 (18.5%)	13
The availability of one clear contact person for myself	67 (17.4%)	14
Clarity about how care agreements are recorded	63 (16.4%)	15
Clarity about where care agreements are recorded	61 (15.9%)	16
Consultation with colleagues outside my own institution	45 (11,7%)	17

Needs of participants within IPC in care settings.

In Table 4 the needs within IPC in home care and nursing home setting are shown. The top five for the home care setting is respectively: the availability of one clear contact person for people with dementia and their loved ones (47.8%), clarity about the tasks of all care providers (39.6%), a clear information transfer (38.6%), being able to approach other disciplines directly outside my own organization (34.8%) and clarity about who is responsible for which task (34.3%). The top five for the nursing home setting is respectively: a clear information transfer (35.6%), being able to approach other disciplines within my own organisation (32.2%), more skills and support in working together as one team (31.1%), clarity about who is responsible for which task (26.6%) and tips and advice in coordinating care agreements between care providers (26.0%).

A Chi-square test was conducted to determine significant differences between settings for each of the items listed in Table 4. Significant differences between settings were found for the

availability of one clear contact person for people with dementia and their loved ones χ^2 (1, N=384) = 20.431, $p < .05$, clarity about the tasks of all care providers χ^2 (1, N=384) = 17.73, $p < .05$, being able to approach other disciplines directly outside my own organization χ^2 (1, N=384) = 15.56, $p < .05$, the availability of one clear contact persons for myself χ^2 (1, N=384) = 4.52, $p < .05$, clarity about where healthcare agreements are recorded χ^2 (1, N=384) = 3.97, $p < .05$ and consultation with colleagues outside my own institution χ^2 (1, N=384) = 9.62, $p < .05$.

Table 4. *Needs within IPC in home care and nursing home setting*

Needs within IPC	**HC (N=207)**	**NH (N=177)**
*The availability of one clear contact person for people with dementia and their loved ones **	99 (47.8%)	45 (25.4%)
A clear information transfer	80 (38.6%)	63 (35.6%)
Being able to approach other disciplines directly within my own organization	62 (30.0%)	57 (32.2%)
Clarity about who is responsible for which task	71 (34.3%)	47 (26.6%)
*Clarity about the tasks of all care providers **	82 (39.6%)	35 (19.8%)
Tips and advice in coordinating care agreements between care providers	69 (33.3%)	46 (26.0)
Being able to approach other disciplines directly outside my own organization*	72 (34.8%)	30 (16.9%)
More skills or support in working together as one team	46 (22.2%)	55 (31.1%)
Regularly discuss and adjust care agreements if necessary	61 (29.5%)	39 (22.0%)
Tips and advice on how to involve people with dementia and / or their loved ones in interprofessional consultations	57 (27.5%)	41 (23.2%)
Consultation with colleagues within my own discipline	44 (21.3%)	39 (22.0%)
Consultation with colleagues from other disciplines	51 (24.6%)	32 (18.1%)
Feeling safe in implementing care agreements that have been made (for example, a non-CPR policy)	43 (20.8%)	28 (15.8%)
The availability of one clear contact person for myself *	44 (21.3%)	23 (13.0)
Clarity about how care agreements are recorded	40 (19.3%)	23 (13.0%)
Clarity about where care agreements are recorded *	40 (19.3%)	21 (11.9%)
Consultation with colleagues outside my own institution*	34 (16.4%)	11 (6.2%)

*Significant differences between setting

Needs of participants within IPC in different nursing levels.

In Table 5 the needs within IPC in nursing levels (RN, CNA, UNA) are shown. The top five for the RN nursing level is respectively: being able to approach other disciplines directly outside my own organization (56.9%), the availability of one clear contact person for people with dementia and their loved ones (44.3%), a clear information transfer (38.9%), clarity about who is responsible for which task (33.6%) and tips and advice in coordinating care agreements between care providers (30.2%). The top five for CNA nursing level is respectively: a clear information transfer (36.3%), clarity about the tasks of all care providers (35.8%), the availability of one clear contact person for people with dementia and their loved

ones (33.8%), being able to approach other disciplines directly within my own organization (33.8%) and tips and advice in coordinating care agreements between care providers (on shared place)(30.9%). The top five for UNA nurses is respectively: a clear information transfer (35.5%), tips and advice on how to involve people with dementia and / or their loved ones in interprofessional consultations (32.3%), the availability of one clear contact person for people with dementia and their loved ones (29.0%), clarity about the tasks of all care providers (29%) and clarity about who is responsible for which task (on shared place) (25.8%)

A Chi-square test was conducted to determine significant differences between nursing levels for each of the items listed in Table 5. Significant differences between nursing levels were found for being able to approach other disciplines directly outside my own organization χ^2 (2, N=384) = 25.50, $p < .05$, clarity about how care agreements are recorded χ^2 (2, N=384) = 6.18, $p < .05$ and consultation with colleagues outside my own institution χ^2 (2, N=384) = 10.32, $p < .05$.

Table 5. Needs within IPC in nursing levels

Needs within IPC	**RN[1] (N=149)**	**CNA (N=204)**	**UNA (N=31)**
The availability of one clear contact person for people with dementia and their loved ones	***66 (44.3%)***	***69 (33.8%)***	***9 (29.0%)***
A clear information transfer	***58 (38.9%)***	***74 (36.3%)***	11 (35.5%)
Being able to approach other disciplines directly within my own organization	***44 (29.5%)***	***69 (33.8%)***	***6 (19.4%)***
Clarity about who is responsible for which task	***50 (33.6%)***	***60 (29.4%)***	***8 (25.8%)***
Clarity about the tasks of all care providers	***35 (23.5%)***	***73 (35.8%)***	9 (29.0%)
Tips and advice in coordinating care agreements between care providers	45 (30.2%)	63 (30.9%)	7 (22.6%)
Being able to approach other disciplines directly outside my own organization*	58 (56.9%)	44 (21.6%)	0 (0%)
More skills or support in working together as one team	30 (20.1%)	63 (30.9%)	8 (25.8%)
Regularly discuss and adjust care agreements if necessary	30 (20.1%)	63 (30.9%)	7 (22.6%)
Tips and advice on how to involve people with dementia and / or their loved ones in interprofessional consultations	38 (25.5%)	50 (24.5%)	10 (32.3%)
Consultation with colleagues within my own discipline	25 (16.8%)	53 (26.0%)	5 (16.1%)
Consultation with colleagues from other disciplines	35 (23.5%)	44 (21.6%)	4 (12.9%)
Feeling safe in implementing care agreements that have been made (for example, a non-CPR policy)	24 (16.1%)	40 (19.6%)	7 (22.6%)
The availability of one clear contact person for myself	22 (14.8%)	39 (19.1%)	6 (19.4%)
Clarity about how care agreements are recorded *	22 (14.8%)	36 (17.6%)	5 (16.1%)
Clarity about where care agreements are recorded	23 (15.4%)	32 (15.7%)	6 (19.4%)
Consultation with colleagues outside my own institution *	27 (18.1%)	17 (8.3%)	1 (3.2%)

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

Significant differences in needs split for setting and nursing level

A Chi-square test was conducted to determine differences in needs within IPC for the different nursing levels in the NH and HC setting (Table 6). Significant differences in needs have been found for: the clarity about the tasks of all care provider $\chi 2$ (2, N=384) = 8.40, $p < .05$, 2 $\chi 2$ (2, N=384), consultation with colleagues within my own discipline $\chi 2$ (2, N=384) = 7.46 $p < .05$, consultation with colleagues outside my own institution $\chi 2$ (2, N=384) = 25.497, $p < .05$, and being able to approach other disciplines directly outside my own organization $\chi 2$ (2, N=384) = 20.49, $p < .05$. In the nursing home setting no significant differences have been found. Furthermore a Chi-square test was conducted to determine differences in needs within IPC in the HC and NH setting for each of the nursing levels (Table 7). In the group of RN significant differences have been found for: the availability of one clear contact person for people with dementia and their loved ones $\chi 2$ (1, N=384) = 5.12, $p < .05$, being able to approach other disciplines directly outside my own organization $\chi 2$ (1, N=384) = 10.89, $p < .05$ and consultation with colleagues outside my own institution $\chi 2$ (1, N=384) = 5.78, $p < .05$. In the group of CNA significant differences has been found for: the availability of one clear contact person for people with dementia and their loved ones $\chi 2$ (1, N=384) = 12.33, $p < .05$, clarity about the tasks of all care providers $\chi 2$ (1, N=384) = 14.29, feeling safe in implementing care agreements made (for example, a non-CPR policy) $\chi 2$ (1, N=384) = 4.17, $p < .05$, being able to approach other disciplines directly outside my own organization $\chi 2$ (1, N=384) = 3.99, $p < .05$ and tips and advice in coordinating care agreements between care providers $\chi 2$ (1, N=384) = 4.17, $p < .0$. In the group of UNA significant differences have been found for: clarity about the tasks of all care providers $\chi 2$ (1, N=384) = 4.95, $p < .05$, clarity about how care agreements are passed on $\chi 2$ (1, N=384) = 4.31, $p < .05$ and consultation with colleagues within my own discipline $\chi 2$ (1, N=384) = 4.31, $p < .05$.

Table 6. *Significant differences in needs between nursing levels in care settings*

Needs within IPC			
Home care (N=207)	**RN[1] (N=91)**	**CNA (N=98)**	**UNA (N=18)**
Clarity about the tasks of all care providers	26 (28.6%)	48 (49.0%)	8 (44.4%)
Consultation with colleagues within my own discipline	12 (13.2%	27 (27.6%)	5 (27.8%)
Consultation with colleagues outside my own institution	22 (24.2%)	11 (11.2%)	1 (5.6%)
Being able to approach other disciplines directly outside my own organization	45 (49.5%)	27 (27.6%)	0 (0%)
Nursing home (N=177)	**(N=58)**	**(N=106)**	**(N=13)**
-	-	-	-

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

Table 7. *Significant differences in needs between care settings in nursing levels*

Needs within IPC		
RN[1] (N=149)	**HC (N=91)**	**NH (N=58)**
The availability of one clear contact person for people with dementia and their loved ones	47 (51.6%)	19 (32.8%)
Being able to approach other disciplines directly outside my own organization	45 (49.5%)	13 (22.4%)
Consultation with colleagues outside my own institution	22 (24.2%)	5 (8.6%)
CNA (N=204)	**HC (N=98)**	**NH (N=106)**
The availability of one clear contact person for people with dementia and their loved ones	45 (45.9%)	24 (22.6%)
Clarity about the tasks of all care providers *	48 (49.0%)	25 (23.6%)
Feeling safe in implementing care agreements made (for example, a non-CPR policy)	25 (25.5%)	15 (14.2%)
Being able to approach other disciplines directly outside my own organization[7]	27 (27.6%)	17 (16.0%)
Tips and advice in coordinating care agreements between care providers[8]	37 (37.8%)	26 (24.5%)
UNA (N=31)	**HC (N=18)**	**NH (N=13)**
Clarity about the tasks of all care providers	8 (44.4%)	1 (7.7%)
Clarity about how care agreements are passed on	5 (27.8%)	0 (0%)
Consultation with colleagues within my own discipline	5 (27.8%)	0 (0%)

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

4. Discussion

In this study a secondary data analysis has been performed to determine the perceived needs of nurses when collaborating with other nurses and healthcare professionals in the palliative care for people with dementia (n=384). The analysis was used to determine differences in the perceived needs in interprofessional collaboration (IPC) of the nurses within the home care (HC) and nursing home (NH) setting and among thee nursing levels being: registered nurse (RN), certified nurse assistant (CNA) and uncertified nurse assistant (UNA). In this study barriers to high-quality palliative dementia care have been conceptualized as needs. A high need of a certain aspect of IPC corresponds with the aspect being a barrier in providing high-quality palliative dementia care.

The results of this study show that overall the top five needs identified by nurses when providing palliative care for people with dementia are: the availability of one clear contact person for people with dementia and their loved ones, a clear information transfer, being able to approach other disciplines directly within their own organization, clarity about who is responsible for which task and clarity about the tasks of all care providers. Consultation with colleagues outside of their own institution, clarity about where health agreements are recorded and clarity about how care agreements are recorded have been perceived least often as a need. When comparing the HC and the NH setting there is a significant difference in how nurses

perceive ‘the availability of one clear contact person for people with dementia and their loved ones’ as a need. Nurses perceived this aspect of IPC almost twice more often as a need in the HC setting (47.8%) as opposed to the NH setting (25.4%). The same accounts for the ‘clarity about the task of all care providers’ which is also perceived almost twice more often as a need in the HC setting (39.6%) as opposed to the NH setting (19.8%). Although there is an overall significant difference between care settings for ‘the availability of one clear contact person for people with dementia and their loved ones’ this difference is only significant for the group of RN and CNA. In the group of RN in the HC setting, 51.6% identify this aspect of IPC as a need as opposed to 32.8% in the NH setting. In the group of CNA in the HC setting, 45.9% identified it as a need as opposed to 22.6% in the NH setting. The difference between settings for the ‘clarity about the tasks of all care providers’ is only significant for the group of CNA and UNA. Of the group CNA in HC setting, 29.0% perceived this aspect of IPC as a need as opposed to 23.6% in NH setting. Of the group UNA this difference was even greater with 44.4% identifying it as a need in HC setting as opposed to only 7.7% in NH setting.

In the overall top five of perceived needs in IPC there are no overall significant differences among the three nursing levels. However, there is a significant difference in ‘being able to approach other disciplines directly outside my own organisation’ which is far more often perceived as a need by RN (56.9%) as opposed to CNA (21.6%) and UNA (0.0%). Presumably this difference is caused by the nature of the tasks of RN when proving palliative care for people with dementia. Due to the higher level of education it is likely that that the group of RN has to collaborate more often with professionals from other disciplines outside of their own organisation as opposed to the group of CNA and UNA causing this aspect of IPC to be more often perceived as a barrier for RN.

Interprofessional collaboration is suggested to be the cornerstone of hospice and palliative care throughout the world (Lysaght Hurley, Barg, Strumpf, & Ersek, 2015). An optimally functioning interprofessional team requires excellent training, communication and a description of the tasks and responsibilities of each team member (Vissers et al., 2013). A study that examined professional communication in interprofessional team meetings also found communication to be a key aspect to successfully provide good patient care (Bokhour, 2006). Another qualitative study on team interactions in specialized palliative care teams found characteristics of interprofessional teams to be competence, communication, and organization. Competence was mirrored in education, collaboration, approach, and support within the team; while communication was described as key to being a team, resolving conflict, and executing palliative care (Klarare, Hagelin, Furst, & Fossum, 2013). Due to

communication being so important in interprofessional collaboration it can also form a barrier and negatively affect palliative care team functioning when it is suboptimal (Goldsmith, Wittenberg-Lyles, Rodriguez, & Sanchez-Reilly, 2010). Three barrier's within IPC found in this study; 'the availability of one clear contact person for people with dementia and their loved ones', the barrier 'a clear information transfer' and 'being able to approach other disciplines directly within their own organization', are most likely caused by poor communication. It can be assumed that these barriers are caused by communication breakdowns. Though communication is of critical importance to the interprofessional collaboration and the patient it is understandable that miscommunication can occur. Patients who receive palliative care and their families are often overwhelmed and vulnerable. It is important that the interprofessional team responds to the patient and family when a breakdown in communication happens (Goldsmith et al., 2010). Having one clear contact for people with dementia and their loved ones, a clear information transfer and the ability for nurses to approach other disciplines directly within the organisation are therefore key to provide high quality palliative care. Other important barriers to overcome that became apparent in this study are the clarity about who is responsible for which task and clarity about the tasks of all care providers. A key aspect of effective interdisciplinary care is to be knowledgeable about other team members' disciplines, as well as to recognize and understand each discipline's perspective about patient care plans and goals (Goldsmith et al., 2010). Improving this will most likely help improve the clarity about the tasks of care providers and clarity who is responsible for which task.

A conceptual framework that could help view interprofessional collaboration is Bronstein's two part model (Bronstein, 2003). Bronstein's two-part model of optimal interprofessional collaboration describes generic components for positive collaboration between social workers and other disciplines (Ronald, Hooper, Head, Evans-Andris, & Estes, 2018). The first part of the model lists five core interprofessional processes, which embody team collaboration: interdependence, newly created professional activities, flexibility, collective ownership of goals, and reflection on process. The second part of the model describes influences on interprofessional collaboration: professional role, structural characteristics, personal characteristics, and history of collaboration (Ronald et al., 2018). When these influences exist, interprofessional collaboration is supported; when they are missing, barriers occur which impede effective interdisciplinary collaboration (Ronald et al., 2018). Understanding the underlying components of IPC can be useful in understanding the barriers perceived by the nurses that provide palliative care to people with dementia.

This study has several strengths and limitations. First of all the group that have filled in the questionnaire consisted of 384 nurses which makes it a relatively large study population when compared to similar studies in this field. Furthermore data collection has been on both regional and national level. The results of this study are therefore more reliable and represent the nurses working in the field of palliative care for people with dementia more accurately. One of the limitations of this study is the use of a self-developed questionnaire. Even though the feasibility of the questionnaire was extensively tested, more research is needed to conclude if the questionnaire is reliable and valid. However, due to the explorative nature of this study, having used a self-developed questionnaire brought us new insights in the needs of nurses in interprofessional collaboration. Moreover the questionnaire had a fixed list of needs in interprofessional collaboration that the nurses could select if they perceived it as a need. Because no qualitative component was added to this list, information on different needs other than those listed is therefore not available. Another limitation is that the inclusion criteria of the study required a convenience sampling method which made it not possible to randomize. Furthermore, selection bias might have occurred due to the questionnaire being shared online and it is unknown if potentially a certain group of nurses was more willing to fill in the questionnaire than others.

Further recommendations

This study shows that even though palliative care for people with dementia is on the right track (the quality of care was perceived by nurses as 7.13 (1-10)), there is plenty of room for improvement. In this study several aspects of interprofessional collaboration have been identified as a barrier but a lot remains unknown on the underlying cause of these barriers. This study can hopefully be used as a foundation for further research. More insight is needed in the barriers that occur during interprofessional collaboration in the palliative care for people with dementia. Effective collaborative care models could be created to deal with these challenges in order to improve the collaboration of interprofessional palliative care teams to sustain high quality patient-centred and family-centred care. Furthermore some aspects of interprofessional collaboration are more often identified as a need in the home care setting as opposed to the nursing home setting. More research on what is causing this difference needs to be done. It is likely that on certain aspects of interprofessional collaboration nurses in the home care setting can learn from nurses in the nursing home setting.

5. Conclusion

It can be concluded that overall nurses in the palliative care for people with dementia have the need for a clear task distribution of all care providers and clarity about who is responsible for which task. Furthermore there is need for one clear contact person for people with dementia and their loved ones, the need for a clear information transfer and need for being able to approach other disciplines directly within their own organizations. There are significant differences between the home care and the nursing home setting although it remains unclear what the underlying cause is for these differences. Research on this topic remains scarce and therefore further research needs to be done to improve high-quality palliative care for people with dementia in the home care and nursing home setting.

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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:

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:

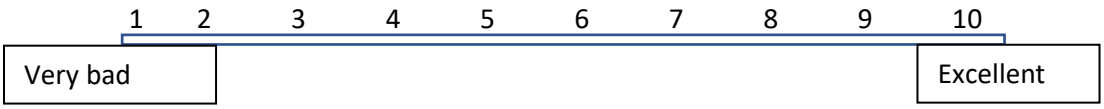
* By additional training we mean courses, clinical lessons, skills training, workshops or curriculums of **at least 2 hours**.

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

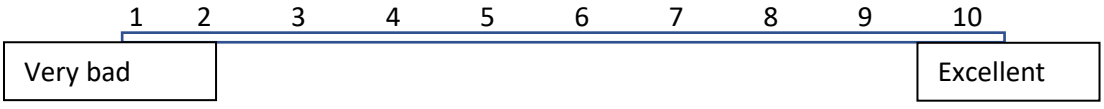
- ❑ No
- ❑ Yes, namely:

* 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. 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…

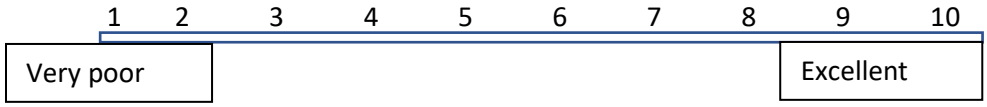
Symptoom management		
1.	… the daily care / care (ADL and IADL)	☐
2.	… recognizing and dealing with certain behaviors, such as unrest or aggression	☐
3.	… recognizing and dealing with emotions, such as sadness, fear or anger	☐
4.	… recognizing and increasing physical comfort	☐
5.	… recognizing discomfort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

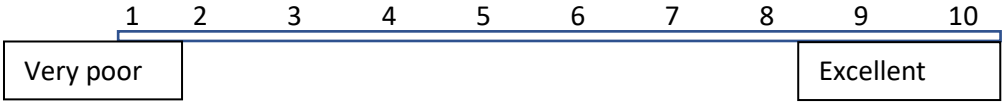
1.
2.
3.

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?

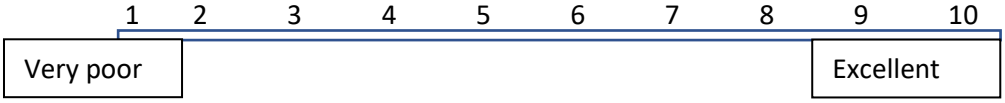


2. Can you give a grade for the quality of collaboration with colleagues from other disciplines?



❑ 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	☐

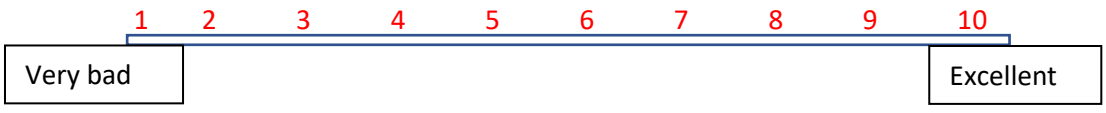
Can you indicate what your top 3 is from the options above, with number 1 being the most important one?

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?