The relationship between inter-professional collaboration in end-of-life dementia care and peaceful dying – Loved ones' experiences

Desired Dementia Care Towards End of Life

I. Mujezinovic, I6118567

Thesis supervisor: Dr. J. M. M. Meijers

Second examiner: Dr. S. M. G Zwakhalen

Department of Health Services Research

April - July

Master Healthcare Policy, Innovation and Management

Faculty of Health, Medicine and Life Sciences (FHML)

Maastricht University

July 5th, 2019

Foreword

During my Bachelor in Health Sciences and Master in Healthcare, Policy, Innovation and Management, my interest in dementia and dementia care has grown. As a loved one of a person with dementia, I understand how valuable the experiences of loved ones can be in improving the dementia care. Furthermore, I consider a peaceful death to be an important aspect of life. I hope this study, conducted in the context of completing my Master, can contribute to an improved inter-professional collaboration in end-of-life dementia care, through adjusting it to the needs of loved ones. This will hopefully contribute to persons with dementia dying more peacefully in the future.

I would like to thank my thesis supervisor, Dr. Meijers, for the guidance and feedback during the establishment of this thesis. I would also like to thank C. Kemai for the guidance, feedback and collaboration during the establishment of this thesis.

Abstract

Background: Palliative care may help address complex needs and concerns, and increase comfort in persons with dementia and their loved ones. Palliative dementia care requires loved ones, as proxy decision makers, to be involved in collaboration with different professionals. The percentage of loved ones indicating that the person with dementia has died peacefully is a quality indicator of palliative care. Therefore, understanding loved ones' needs in the inter-professional collaboration may improve palliative care and contribute to persons with dementia dying peacefully.

Objective: To explore loved ones' needs and challenges regarding inter-professional collaboration in end-of-life dementia care in nursing home and home care settings and explore the relationship between their experiences and how they perceived peaceful dying of the person with dementia.

Methods: Secondary data from the Desired Dementia Care Towards End of Life study was analyzed. Loved ones' experiences with inter-professional collaboration were gathered through semi-structured interviews and analyzed using NVivo software. Peaceful dying was assessed using a single item from the Quality of Dying in Long-Term Care instrument. The relationship between the experiences with inter-professional collaboration in both settings and dying peacefully was analyzed descriptively.

Results: The experiences of thirty-two participants (n=24 NH and n=8 HC) were categorized into two themes: (1) loved ones' involvement in the collaboration with HCPs and (2) loved ones' perceptions of collaboration among HCPs. (1) Participants from both settings found it important to be informed. Whereas, participants from the home care setting were actively engaged and involved by HCPs, participants from the nursing home setting had more varied experiences. (2) Loved ones in both settings were aware of an information exchange between mainly doctors and nurses, but overall had little insight in the structural collaboration between different HCPs. HCPs' seemed to contribute positively to loved ones perceiving the death of the person with dementia as peaceful, by having a good communication among HCPs, being available and competent, and by actively involving loved ones and listening to them. Loved ones seemed to contribute positively by compensating for HCPs' negative input or being involved regardless of HCPs' input, through active engagement in: relaying information between HCPs, initiating contact with whichever available HCP, executing care tasks, or coordinating care.

Conclusion: Loved ones' active engagement in the care for the person with dementia in nursing homes settings, either as a compensation for HCPs' passive attitude in involving them, by being involved by HCPs, or regardless of HCPs' attitude, is related to a peaceful death of the person with dementia, as perceived by loved ones.

Keywords: Dementia, end-of-life care, loved ones' experiences, nursing home, home care, inter-professional collaboration, dying peacefully

Contents

1. Introduction

1.1 Background

The prevalence of dementia in the Netherlands has increased significantly since 1990 (Poos, Meijer & Willemse, 2015) and is expected to increase further by 115 percent by 2040 (Rijksinstituut voor Volksgezondheid en Milieu, 2018; Volksgezondheidenzorg, 2015), as the population is ageing due to an increase in average life expectancy (Vanderleyden, 2015). Dementia is a life-limiting disease with varying courses of physical and cognitive deterioration (Lee & Chodosh, 2009), characterized by memory loss, and impaired cognitive abilities and behavioral changes that interfere with daily functioning (Alzheimer Association, 2018). Since no cure for dementia is foreseen in the near future, many people will die with or due to dementia (van der Steen et al., 2014). Therefore, a palliative approach focusing on quality of life and comfort is recommended, particularly in advanced stages of dementia (van der Steen et al., 2014). Even in earlier stages, palliative care may help address complex needs and concerns of persons with dementia and their loved ones (van der Steen et al., 2014) and improve their quality of life (van der Steen, 2010).

In the Netherlands, palliative care is mainly provided by general practitioners and nursing staff (Nederlandse Zorgautoriteit, 2018), at home and in facilities such as nursing homes, hospitals, and hospices (Zorgwijzer, 2017). The Dutch quality framework for palliative care (Kwaliteitskader palliatieve zorg Nederland) defines palliative care as: “Care that improves quality of life for patients and their relatives that have to deal with a life-threatening condition or vulnerability, by preventing and mitigating suffering, through early signalling and thoughtful assessment and treatment of problems of physical, psychical, social or spiritual nature. During the course of sickness or vulnerability, palliative care focuses on retaining autonomy, access to information and choice options” (IKNL, 2017). This multidimensional approach in palliative care requires inter-professional collaboration between different healthcare professionals (HCPs) to address the complicated care demands in dementia and assure continuity of care (Eisenmann, Schmidt, Voltz & Perrar, 2016; Erel, Marcus, Dekeyser-Ganz, 2017; Lloyd-Williams, Abba, & Crowther, 2014). The importance of adequate inter-professional collaboration is highlighted in the Dutch Dementia Deltaplan (n.d) and the National Program of Palliative Care of the Ministry of Health (VWS) (Alzheimer Nederland, 2015). Inter-professional collaboration is best described by the definition provided by the World Health Organization (2010): “Multiple health workers from different professional backgrounds work together with patients, families, caregivers and communities to deliver the highest quality of care”.

Inter-professional collaboration in palliative dementia care requires involvement of volunteers, patients (Eisenmann et al., 2016; Erel et al., 2017; Lloyd-Williams et al., 2014), and especially loved ones, as they often take on an active role as a proxy decision-maker, since active decision-making may be hampered by cognitive impairments in later stages of dementia (Samsi & Manthorpe, 2013; Shanley, Fetherstonhaugh, McAuliffle, Bauer & Beattle, 2017). The cognitive and functional deterioration associated with dementia may furthermore inflict anticipatory grief before actual bereavement in loved ones (Kiely, Prigerson & Mitchell, 2008; Arruda & Paun, 2017) and differentiate their end-of-life care needs and experiences from those of loved ones of persons with other disabilities or illnesses (Hebert & Schulz, 2006). These experiences and the extent to which loved ones are satisfied with end-of-life care may influence their grief reactions before and after bereavement (Kiely et al., 2008; Arruda & Paun, 2017).

1.2 Problem statement

Loved ones of persons with dementia prefer continuity of living arrangements and caregivers (van der Steen, Dekker, Gijsberts, Vermeulen & Mahler, 2017; van der Steen et al., 2014). Contrastingly, palliative care for persons with dementia is often fragmented (Bökberg, Ahlstrom, Karlsson, Hallberg & Janlov, 2014; Davies et al., 2014) and insufficiently adjusted to the needs of both the person with dementia and their loved ones (Teno et al., 2004). The fragmentation of care can be time consuming and may lead to frustration among loved ones, increased healthcare costs, and poor quality of care (Aaltonen et al., 2014).

Quality of care can be assessed through quality indicators, which are measurable and explicitly defined items referring to the structure, processes or outcomes of care (Campbell, Braspenning, Hutchinson & Marshall, 2002; Donabedian, 1988). These are increasingly used to compare quality scores across care providers and initiate quality improvements (Campbell, Roland & Buetow, 2000). In recent years, there has been a growing interest in quality indicators for palliative care (De Roo et al., 2013). An example of a quality indicator referring to outcomes of palliative care (Claessen et al., 2011) and quality of dying is 'the percentage of relatives who indicate that the patient died peacefully' (van Soest-Poortvliet et al., 2011). Dying peacefully is a broad concept and involves spiritual well-being and meaningfulness of life (van Soest-Poortvliet et al., 2011), which may be reflected in calmness, nearness to one's beloved and experiences of inner harmony or tranquility (De Roo et al., 2014). Research shows that only half of the nursing home residents with dementia die peacefully, as perceived by their loved ones (De Roo et al., 2014). Fragmented care might be one of the factors compromising dying peacefully (De Roo et al., 2015).

Understanding the needs regarding inter-professional collaboration of those closest to persons dying with dementia may inform unique requirements for the provision of palliative care that may contribute to quality of life and eventually dying peacefully

(Thompson & Roger, 2014). Several studies have explored loved ones' experiences with regards to inter-professional collaboration in end-of-life dementia care. According to these studies, amongst others, loved ones find it important to receive clear and continuous information (Dahlke et al., 2018), and to have a permanent contact person serving as a facilitator for the communication with HCPs (Stephan, Möhler, Renom-Guiteras & Meyer, 2015). According to Stephan et al. (2015) loved ones' experiences can be categorized into two layers of inter-professional collaboration: collaboration between HCPs and informal caregivers, and collaboration among HCPs.

Furthermore, several studies regarding end-of-life dementia care (de Roo et al., 2015; de Roo et al., 2014), peaceful dying of persons with dementia (van der Steen, 2010; van der Steen et al., 2017), and one study on the associations between unpleasant experiences with end-of-life-dementia care and dying peacefully (Bolt, Verbeek, Meijers & van der Steen, 2019) have been conducted. However, the specific relationship between loved ones' experiences with inter-professional collaboration and how they perceive peaceful dying of the person with dementia has not been explored.

1.3 Research objective and question

The objective of this study was to explore loved ones' needs and challenges in the inter-professional collaboration in end-of-life dementia care in home care and nursing home settings, and explore the specific relationship between loved ones' experiences and how they perceived peaceful dying of the persons with dementia. This study will contribute to the body of evidence on palliative dementia care and may inform the establishment of inter-professional collaborative strategies, practice recommendations and interventions aiming to enhance the quality of palliative dementia care. The current paper covered the following main research question: What is the relationship between the experiences of loved ones with the inter-professional collaboration in end-of-life dementia care and peaceful dying of the persons with dementia?

In order to answer the main research question, the following sub questions were formulated:

1. What are the experiences of loved ones with the inter-professional collaboration in the end-of-life care for persons with dementia in nursing home and home care settings?
2. What are differences between nursing home and home care settings in: the experiences of loved ones with the inter-professional collaboration, and the relationship between these experiences and how they perceived peaceful dying of the person with dementia?

2. Methodology

This study is part of the Desired Dementia Care Towards End of Life (DEDICATED) project. This research and implementation project aims at improving palliative care for persons with dementia and their loved ones in both nursing home and home care settings. DEDICATED is guided by four overarching themes, distilled from a white paper of the European Association for Palliative Care (EAPC) (van der Steen et al., 2014), a literature review on the needs of persons suffering from dementia at the end of life (Perrar, Schmidt, Eisenmann, Cremer, & Voltz, 2015), and a Dutch quality framework for palliative care (IKNL, 2017). The four themes involve: (daily) caregiving, end of life communication as a part of Advanced Care Planning, transmural collaboration in transitions of care, and inter-professional collaboration. This study focused on inter-professional collaboration.

2.1 Research nature, type and design

In order to explore the relationship between the experiences of loved ones with the inter-professional collaboration and how they perceived peaceful dying of persons with dementia, a mixed methods design was used. Cross-sectional, secondary qualitative data from semi-structured interviews and quantitative data from a single questionnaire item were combined. A mixed method design is used to gain a better understanding and more comprehensive answers to research issues compared to using either quantitative or qualitative approaches on its own. The strengths of this design offset the weaknesses of quantitative and qualitative research when used individually (Creswell & Clark, 2007).

2.2 Sample

Three nursing home and home care organizations, Zuyderland Zorg, Envida and Vivantes, located in the Southern region of the Netherlands, participated in the DEDICATED project. Managers of these organizations agreed upon the organization's role in recruiting and informing potential participants about the study. To recruit a heterogeneous sample of eligible participants, comprising both male and female participants covering a broad age range and cultural diversity, a purposive sampling method was used (Boeije, 2005). The aim was to include bereaved loved ones most closely involved in the care for the persons with dementia, by contacting the designated informal caregiver and inquiring whether they or another individual were most closely involved in the care. In case of the latter, contact information of this individual was requested. Besides being most closely involved in the care, to be considered eligible for the study, the person with dementia had to be at least 65 years old at the time of death. Additionally, the death had to have taken place within the past six months, but no earlier than six weeks ago (due to the emotional impact of interviewing) in one of the three participating nursing homes or at home having received home care by one of these organizations. Individuals were not eligible if they had insufficient understanding of the Dutch language or dialect and were physically or psychologically unable to take part in an interview. In order to participate, all individuals considered eligible, needed to provide informed consent.

2.3 Data collection

The secondary, cross-sectional data used in this study was gathered through qualitative interviews and quantitative questionnaires conducted between February and July 2018. Semi-structured in-depth interviews, covering the four themes described previously, were conducted by two researchers, trained in performing qualitative interviews. Interviews provide an opportunity to gain insight into a topic through the perspective, experiences and language of the persons involved (Boeije, 2005), as participants are encouraged to talk freely and reveal information that might have stayed hidden otherwise (Hargie, 2010). The place and time of the interviews depended on participants' preferences, but preferably took place in their home settings. Participants were given the opportunity to take breaks and end participation at any time. The interviews were audio-recorded and transcribed according to the clean read verbatim method.

2.3.1 Outcome measures

Demographic variables derived preceding the interviews, included participants' age, gender, education level and familial relationship with the deceased. Moreover, participants were inquired about the duration of stay in the nursing home or of received home care, any transfers during the last three months of life, information on end-of-life communication, age, gender and cause of death of the deceased person with dementia.

This secondary data analysis focused on loved ones' experiences with inter-professional collaboration, gathered through the interview questions, which reflected: the different involved disciplines, their collaboration and communication, and the involvement of loved ones (Appendix 1).

Participants of the interviews were furthermore requested to assess the peaceful dying of the person with dementia, by filling in an item from the Quality of Dying in Long-Term Care (QOD-LTC) instrument (Munn et al., 2007). The item concerned the last month of life and was measured on a 5-point Likert-type scale (1 = not at all; 2 = a little bit; 3 = a moderate amount; 4 = quite a bit; and 5 = completely), with higher scores indicating a more peaceful death.

2.4 Data analysis

Descriptive statistics of demographic data and the dying peacefully item from the QOD-LTC were generated and analysed using IBM SPSS statistics version 25.0 (IBM Corp, Armonk, NY). Furthermore, a possible association between the type of care setting and scores on the dying peacefully item was investigated through a Chi-Square test.

The qualitative data of the verbatim transcribed interviews were analysed by two authors (I. M and C. K.) with a critical realism (CR) approach using NVivo 12 software. CR originates as a scientific alternative to positivism and constructivism (Fletcher, 2017). One of the most relevant tenets of CR is that the nature of reality (ontology) is not reducible to our knowledge of reality (epistemology), as human knowledge captures a small part of vaster reality. Theories can thus help get closer to reality. Ontology in CR is stratified into three levels. The first level is the empirical, which is the realm of events, mediated through the filter of human experience and interpretation. At this level social ideas, meanings, decisions and actions occur, which can be causal. The middle level consists of the actual, where there is no filter of human experience. Events occur regardless of the experience or interpretation and can often be different from what is observed at the empirical level (Danermark, Ekstrom & Jakobsen, 2005). The third level is the real, where causal mechanisms exist, which produce events appearing at the empirical level (Fletcher, 2017).

Following the CR stratification, the data analysis process consists of deduction, induction, abduction and retroduction. Prior to the data analysis, the two layers of collaboration mentioned previously (collaboration between HCPs and informal caregivers, and collaboration among HCPs) were drawn from literature (Stephan et al., 2015) (deduction), and formed the two main themes and theoretical codes (Saldaña, 2015). The data analysis began with the search for demi-regularities, which are tendencies or patterns in loved ones' experiences. These demi-regularities formed the initial codes and sub-codes (induction) within the two themes (Saldaña, 2015). The codes and sub-codes based on loved ones' experiences were then re-described (abduction) using theoretical concepts (Stephan et al., 2015; Dahlke et al., 2018). Finally, contextual conditions for causal mechanisms to take effect and result in the observed trends were identified (retroduction) (Fletcher, 2017). To cluster the codes in comprehensive categories, axial coding was performed (Saldaña, 2015). The authors independently coded interviews in four cycles and compared their coding series during interim meetings to broaden, adjust or add codes according to induction, abduction and retroduction. Any discrepancies were discussed to reach consensus. The codes and categories were discussed during peer debriefing sessions, leading to further alterations and the final coding scheme.

In analysing loved ones' experiences with the inter-professional collaboration, a distinction was made between nursing home and home care settings. Furthermore, experiences were categorised per indicated score on the dying peacefully item of the QOD-LTC and patterns were identified for both settings in relation to a negative (not at all and a little bit) or positive (quite a bit and completely) category of agreement to the statement that the loved with dementia has died peacefully.

2.5 Reliability and trustworthiness

The total item extracted from the QOD-LTC, of which dying peacefully is a sub item, has an acceptable reliability with a Cronbach's alpha of 0.76 (Munn et al., 2007).

The credibility of the qualitative data collection was enhanced during the formation of the interview guide by reviewing relevant literature in search for existing, valid and reliable questions. As no existing questions were found, preliminary questions were set up through a brainstorm session with healthcare professionals from the collaborating organizations and other experts (patients, representatives, informal caregivers, educators, etc.). This set of questions was discussed with a team of researchers until consensus was reached upon five questions per theme, thereby enhancing the face validity. The interview guides have been tested by means of two mock interviews with patient representatives. Credibility was furthermore enhanced by conducting the data analysis with two researchers (I.M and C.K), who were both not involved in the data collection (Graneheim & Lundman, 2004). Finally, the coding framework was grounded from the interview data, rather than set up a priori, developed by author (I.M., C.K., and J.M.M) consensus and discussed during several peer debriefing sessions, contributing to the credibility (Thomas, 2006). Dependability, the degree to which data remains the same over time, is enhanced during the data collection by conducting the interviews with two interviewers and taking notes right after the interviews, to prevent information loss (Boeije, 2005), and by performing the analysis in a time period of two months. To ensure transferability, the extent to which findings can be transferred to other groups or settings, it was sought to describe the data collection, analysis procedures and results as detailed as possible. The above mentioned steps have contributed to the trustworthiness of this study (Flick, 2006).

2.6 Ethical considerations and ethics approval

The interview study of the DEDICATED project is line with the principles of the Declaration of Helsinki (64th WMA General Assembly, Fortaleza, Brazil, October 2013) of the World Medical Association (WMA). The Medical Research Involving Human Subjects Act (in Dutch: Wet Medisch-wetenschappelijk Onderzoek met Mensen) does not apply to the study. However, as it is a protocol to assess all studies of Maastricht University and Zuyderland, METC (Heerlen) has assessed and approved the study protocol for the interviews (METCZ20180026). Furthermore, all interviewees have provided their written informed consent. Except from possible emotional reactions to questions, neither serious risks, nor benefits were associated with participation.

Confidentiality and the voluntary nature of participation of all study activities, as well at the possibility to withdraw participation at any time, were explained to the participants. In order to safeguard confidentiality and to prevent identification of the participants, the data has been collected anonymously. The item of the QOD-LTC was derived anonymously and has been linked to each interview through a code, which has not been linked to any identifiable personal data of the participants. This is in line with the Personal Data Protection Act (Wbp).

The anonymous transcripts were secured during the course of this study and original data and all copies were returned to the researcher at the end of the period. Furthermore, all original data and copies were deleted. The research ethical committee of FHML has reviewed the research proposal of the current study and provided approval after having classified the project as low-risk. This study adhered to the principles of professional scientific conduct as stated in the 'Netherlands Code of Conduct for Scientific Integrity' and 'Regulation for Scientific Integrity at Maastricht University'.

3. Results

In total, thirty-two loved ones bereaved of a person with dementia, participated in the study (Table 1). The participants' mean age was 62.0 (standard deviation = 9.3, range 44.0, 87.0). Twenty-two participants (68.3%) were female. The participants most frequently (71.9%) were a daughter or son (in law) and a legal representative of their loved one in seventeen cases (53.1%). The mean age of the persons with dementia was 86.6 (standard deviation = 6.3, range 70.0, 97.0), and twenty-three (71.9%) were female. Eight persons (25.0%) have received home care, while 24 (75.0%) have received nursing home care, most frequently (37.5%) during the last one to two years of their lives. The death of the person with dementia most frequently was expected (65.5%), occurred due to an unknown cause (40.6%), in a nursing home setting (78.1%).

Table 1. Characteristics of the participants and the persons with dementia

	Count (n)	Percentage (%)
Participants characteristics		
Gender		
Female	22	68.8
Highest completed education		
Pre-vocational secondary and general secondary education	9	28.2
Secondary vocational education	11	34.4
Higher general secondary and pre-university education	4	12.5
Higher vocational education and University	8	25.0
Relation to person with dementia		
Son or daughter (in law)	23	71.9
Partner	3	9.4
Cousin	3	9.4
Brother or sister (in law)	1	3.1
Other	2	6.3
Legal representative [1]		
Yes	17	53.1
No	12	37.5
Person with dementia characteristics		
Gender		
Female	23	71.9
Type of care		
Nursing home care	22	75.0
Legally represented [1]		
Yes	22	68.8
No	7	21.9
Length of nursing home stay or home care provision		
<1 month	2	6.3
1-6 months	6	18.8
6-12 months	3	9.4
1-2 years	12	37.5
2-5 years	9	28.1

1. Missing = 9.4%

Table 1. (Continued)

	Count (n)	Percentage (%)
Admission during last three months		
Yes	12	37.5
Death expected by loved one		

Yes	21	65.6
Place of death		
Nursing home	25	78.1
Home	4	12.5
Hospital	3	9.4
Cause of death according to loved one		
Unknown	13	40.6
Abstinence of food/fluids	5	15.6
Complications after falling incident	3	9.4
Pneumonia	2	6.3
Swallowing difficulties, infection(s), cancer or stroke[2]	4	12.4
Other	5	15.6

[2] One indication per each death cause category

3.1 Themes in inter-professional collaboration

The thirty two interviews were qualitatively analyzed according to two main themes: loved ones' involvement in the collaboration with HCPs, and loved ones' perceptions of the collaboration among HCPs.

3.1.1 Theme 1: Loved ones' involvement in the collaboration with HCPs

The first theme regards loved ones' involvement in the collaboration with HCPs (Figure 1) and is divided into three subthemes: loved ones involvement in the collaboration (1A), factors influencing the level of involvement (1B), and factors influencing the communication between loved ones and HCPs (1C).

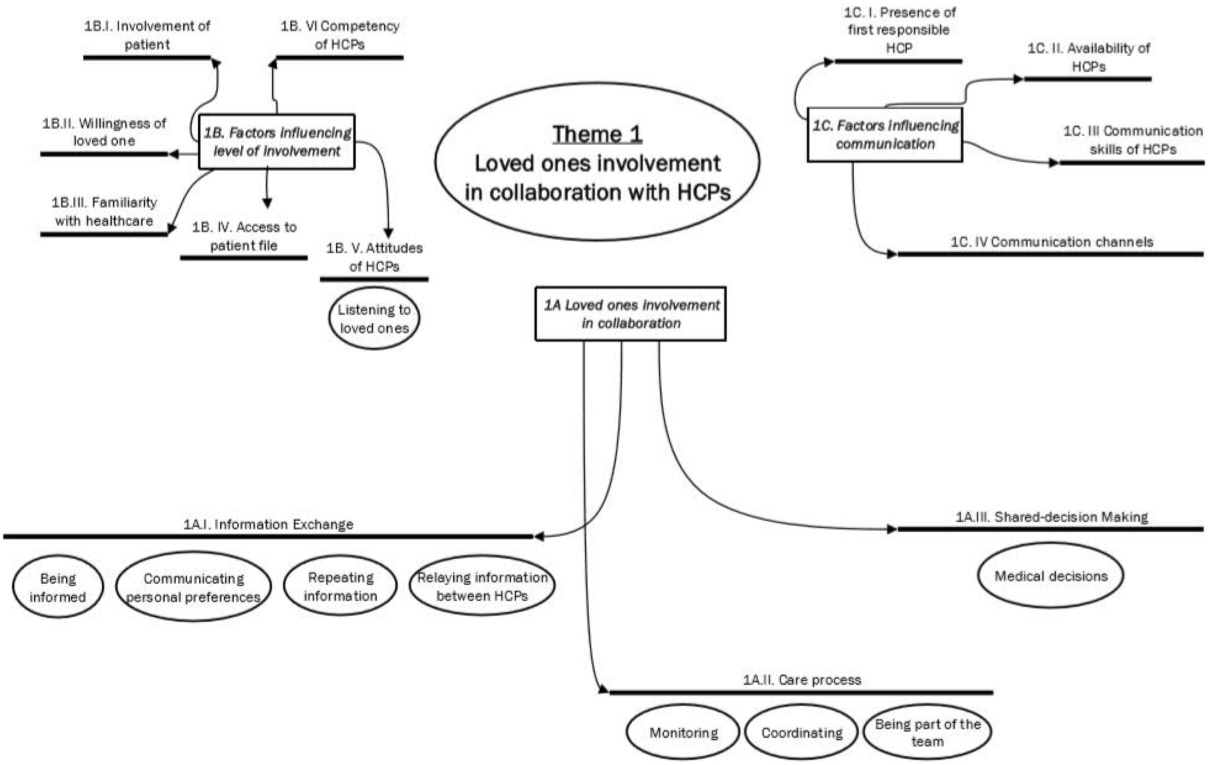

Figure 1. Theme 1: loved ones' involvement in the collaboration with HCPs

Loved ones' involvement (1A)

In the collaboration with HCPs, loved ones can be involved in the information exchange (1A.I), the care process (1A.II) and shared decision making (1A.III). In both nursing home and home care setting, participants were actively engaged in some roles in the collaboration. Even though overall all were actively engaged, only three of the twenty-four participants of whom loved ones had received nursing home care (NH participants) felt to have been in control. The eight participants of whom loved ones had received home care (HC participants) overall felt to have been in control.

Information exchange (1A.I)

Loved ones can be involved in the information exchange by: being informed about the health status or changes in care and medication, indicating personal preferences regarding the care for the person with dementia, repeating information to HCPs, and actively relaying information between different HCPs.

Overall, the participants of both settings found it important to be informed about the current health status, changes in care provision, medical decisions, and the process of dementia and dying. The NH participants' experiences on extent to which they were informed varied and were overall more negative. Seven NH participants indicated to have been actively informed by the HCPs. The following statement emphasizes that being informed made the participants feel as taking part of the care for their loved one:

> "They included us by explaining how it worked" Participant 32

HC participants mainly needed information on the course of dementia and process of dying. With regards to information on dementia, one participant stated the following:

> "That piece of information about the clinical picture helped us. We are doctors ourselves, but it still helps to get a clear explanation of this change; that those moments and hours of clarity are part of dementia." Participant 18

One HC participant was not aware of the deadly course of dementia.

While six NH participants indicated to have actively relayed information, all HC participants were engaged in in relaying information. One participant stated the following:

> "I used to be there often and you are a bit of a report yourself." Participant 29

The experiences with regards to repeating information varied among NH participants, whereas HC participants were overall not in need of repeating information.

Finally, most NH participants had indicated care preferences. There were no evident examples of indication of care preferences among the HC participants.

Care process (1A.II)

Loved ones can be involved in the care process by: monitoring the health status and care, coordinating care by making arrangements, and feeling to be part of the team.

Most NH participants overall had a monitoring role with regards to medication and food intake, their loved ones' health status and hygiene. The following statement illustrates the monitoring role with regards to medication intake:

> "If you'd happen to be there, like we were and ask: 'Is mom also getting her urinary infection medication today?' 'Oh, I don't know.' Then they would look in the cart. 'Oh yes, yes'. But hadn't she said that—" Participant 15

Some participants indicated negative experiences with the amount of monitoring needed.

Furthermore, some NH participants took on a coordinating role. HC participants overall seemed to be engaged in monitoring and coordinating. However, less evident examples are given. One participant in particular took up an active role. With regards to monitoring, the participant stated the following:

> "In that sense I did not need her (doctor) anymore. I knew what it was and with the first TIA, when he blacked out, I called her in and afterwards I'd only inform her about it. I said: 'Is it okay if I only inform you and not call you in anymore?' And she was fine with that." Participant 22

Whereas some NH indicated to have been or felt to have been a part of the team, all HC participants indicated some type of teamwork with the nurses. One participant stated the following:

> "...We worked so nice together." Participant 26

Shared decision making (1A.III)

Finally, loved ones can be involved in shared decision making by taking part of medical decision making. NH participants overall wanted to take part of medical decision making. However, some participants experienced difficulties. Shared decision making in HC participants mostly regarded sedation, food intake or admission to a hospital.

Factors influencing level of involvement (1B)

Loved ones' level of involvement can be influenced by: the involvement of the person with dementia in the care (1B.I), their willingness to be involved (1B.II), their familiarity with the healthcare sector through work experience (1B.III), access to patient files (1B.IV), HCPs' passive or active attitude in involving loved ones (1B.V), including listening to and taking into account what loved ones say, and the perceived HCPs' competency in providing the care (1B.VI).

Majority of NH participants indicated that the person with dementia was involved by indicating their preferences or attending meetings. Five participants indicated that the person with dementia was not involved, either due to a progressed state of dementia or due to lack of HPCs' initiative in involving them. HC participants indicated that the person with dementia was involved by indicating preferences in all cases. In one case the persons with dementia had an active role in monitoring their own health status:

> "Their file was there and he kept track of it completely and filled it in himself. He wanted to keep track of that himself." Participant 27

In two cases the persons with dementia were not informed about their diagnosis:

> "I avoided the topic that he was sick, I didn't want him to notice." Participant 28

Furthermore, all NH participants seemed willing to be part of the care of their loved one, except for one participant who was an ex-partner, but was actively involved regardless of his willingness. All HC participants seemed to be willing to be take part in the care of the person with dementia.

Thirdly, eight NH and three HC participants were familiar with the healthcare sector, which seemed to have an influence on their active involvement, especially in coordinating care. One HC participant stated the following:

> “They said that they had an occupational therapist. I said: Sorry, I already called in mine. I trusted her and we always had good discussions about our clients, so I wanted her for my husband.” Participant 22

Furthermore, five NH participants indicated to have seen a patient record and to have suggested adjustments to the care plan. The HC participants overall had access to the client file and could make adjustments themselves:

> “It was documented in the map and we as caregivers could write in it. I would read what was written in it before; we would just read it from each other.” Participant 18

The attitudes of HCPs could also have influenced participants’ involvement. Whereas the HC participants were overall positive about the HCPs’ proactive attitude in involving them and their loved ones, the experiences of NH participants with the attitudes of HCPs varied. Passive HCPs’ attitude has led to NH participants initiating contact to acquire information, additionally monitor the health status and medication intake, or to not being involved in decision making. HCPs’ proactive attitudes could have an effect on whether the participants felt in control, as shown by the following stated answer to the question whether the HC participant felt to have been in control:

> “Yes, because they asked everything.” Participant 26

Listening and taking into account what the participants had to say is part of a proactive HCPs’ attitude. The NH participants’ experiences with regards to being listened to varied, with the majority (n=16) indicating overall positive experiences. Some participants indicated that the extent to which they were listened to differed per HCP. Not being listened to has led to repetition of care preferences in some cases, which was considered to be exhausting, and in one participant it has led to taking a more passive role in indicating preferences. HC participants overall had positive experiences with feeling listened to. One participant stated the following:

> “We only had to ask and it was taken care of.” Participant 24

The link between being listened to and feeling in control is shown in the following stated answer of one HC participant to the question whether they felt to have been in control:

> “When you said things, they were taken into account” Participant 29

Finally, HCPs’ competency level could have impacted the participants’ involvement.
HC participants overall had positive experiences with the competency of professionals. One negative experience regarded a geriatrician having called the person with dementia to schedule appointments (Participant 26). The participant had immediately filed a complaint to the responsible agency. NH participants were overall positive of the

competency of the regular HCPs, but felt that they had too little time. Participants' negative experiences with HCPs' competency mostly regarded the interns or substitutes, which led to a more active monitoring role. HC and NH participants had indicated to see a distinction between professionals who were fit for the job and those who were not, which mostly depended on how they treated the person with dementia:

> "You see a difference in certain people; they have the gift to do it." Participant 32

Factors influencing communication between loved ones and HCPs (1C)

The communication between loved ones and HCPs can be influenced by: the presence of a first responsible HCP (1C.I), the availability or approachability of HCPs (1C.II), HCPs' communication skills (1C.III), and the communication channels between loved ones and HCPs (1C.IV).

Twenty-one NH and six HC participants had a first responsible HCP. One HC participant found the absence of the first responsible HCP unpleasant and indicated the following:

> "You are in between all these different sections and then it is a shame that you don't have a regular guide, where you can come to." Participant 24

The NH participants overall found if important for this professional to be available and take action based on what they had indicated to them, for example by contacting or coordinating other HCPs. In ten cases NH participants indicated that either the first responsible HCP was not often available or that they were replaced. In some cases this was regarded as unpleasant, but most participants would speak to other HCPs instead. The HC participants indicated positive experiences regarding their first responsible HCP or seemed to not have needed one, as they would contact other HCPs.

Furthermore, the availability or approachability of HCPs could influence the communication. Besides the unavailability of the first responsible HCP that some NH participants indicated, they furthermore mostly indicated low availability of doctors, mainly through long waiting lists for an appointment or by doctors not being in office. Twelve participants had positive experiences with the HCPs' availability. One participant stated the following:

> "I could walk right into that office and ask things and I would immediately be assisted." Participant 3

HC participants' experiences with the availability and approachability of HCPs were overall positive and mainly regarded the short communication lines with nurses, which the participants could also approach in informal fashions:

> "We exchanged numbers...We sent her that via Facebook and she did not mind at all..." Participant 27

Besides these informal communication fashions, the client file, which each client in home care gets, formed the main communication channel between HC participants and HCPs. They all shared positive experiences with regards to this file, which functioned as a tool for keeping track of their loved one’s health status and writing down personal notes or to-do lists. Two participants initiated the use of a notebook for the nurses and in daycare. Other communication channels between HC or NH participants and HCPs were face-to-face communication, phone calls and mails. NH participants furthermore had meetings with HCPs most frequently twice a year, which they considered insufficient.

Finally, HCPs’ communication skills could have influenced the communication with the loved ones. Three NH participants in particular indicated negative experiences. In two cases the nurse would start conflicts between siblings by approaching them in a different manner or sharing personal information. In the third case the participant was being contradicted and stated the following:

> “When I or the kids would say something, it would always get contradicted. It really bothered me and still does.” Participant 25

Other NH and all HC participants mainly indicated positive experiences with the nurses’ personal approach and the connection they had. However, some participants indicated to be in need of more clear and direct communication. The NH participants needed clear communication regarding their loved one’s health status. One participant stated the following:

> “You want clarity; you’re doubting all the time if she is doing all right or not…You just want honesty…Don’t prevaricate, just give me clarity.” Participant 6

The HC participants were in need of clear and direct communication with regards to the course of dementia and the process of dying:

> “No one said: he’s dying and now I think it wouldn’t have been bad at all if some would have said that. Just totally clear: this is the end.” Participant 18

3.1.2 Theme 2: Loved ones' perceptions of the collaboration among HCPs

The second theme regards loved ones' perceptions of the collaboration among HCPs (Figure 2) and is divided into three subthemes: Loved ones' insight in the structural collaboration level between HCPs (2A), the perceived outcomes of information exchange among HCPs (2B), and factors influencing the information exchange (2C).

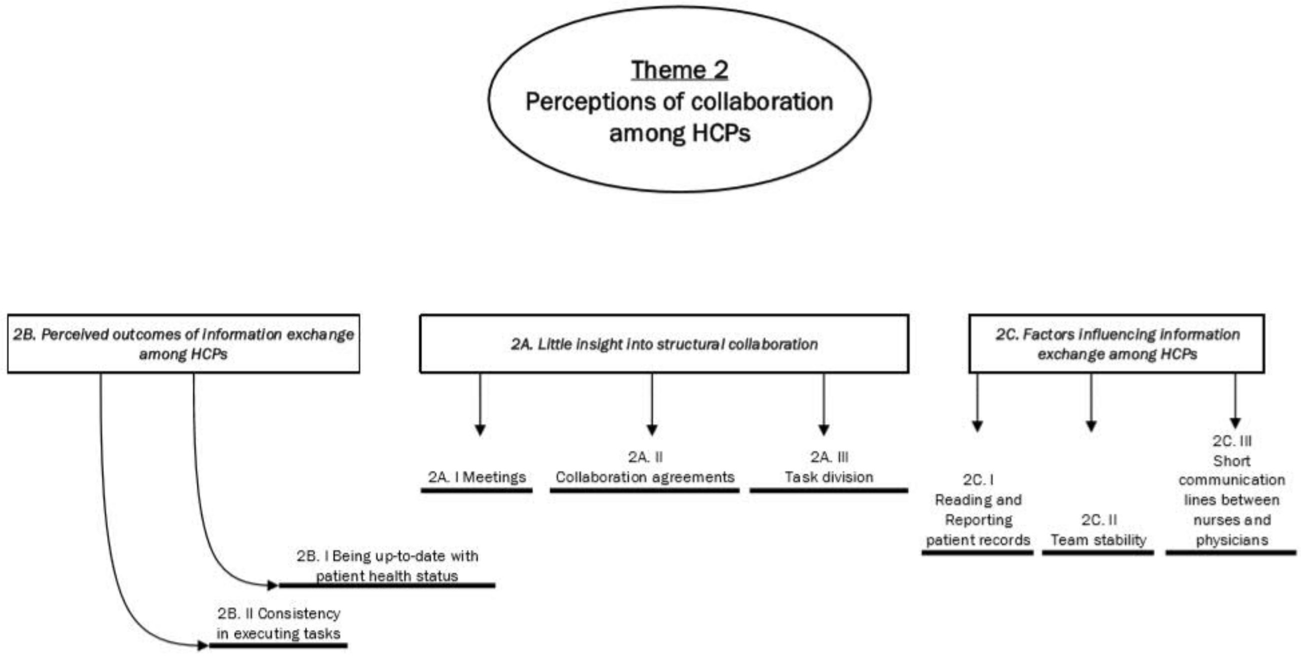

Figure 2. Theme 2: loved ones' perceptions of the collaboration among HCPs

Insight into structural collaboration level (2A)

The insight into the structural collaboration level between HCPs regards the meetings (2A.I), collaboration agreements (2A.II) and task division (2A.III) among different HCPs. Overall, the NH and HC participants had little insight into the structural collaboration between HCPs.

Overall, participants from both settings, except for one NH participant, were not aware of the meetings between different HCPs. Most NH participants, however, were aware of the information exchange between doctors and nurses. In some cases the participants were informed about the information exchange and sometimes the information exchange would take place in the presence of the participant:

> "She and the doctor would go to the office together, and they would type it into the computer and discuss how or what. It would be in the same room my aunt and we were in." Participant 10

HC participants were overall aware of the communication between different HCPs through the client file as a communication channel and less aware of other types of information exchange. One participant stated the following:

> "The map was the spine of the care." Participant 29

One HC participant indicated to not know whether the different HCPs were even aware of each other's work. Furthermore, six NH and two HC participants were aware of the existence of collaboration agreements. According to these HC participants, the agreements were administered in the client file. While four NH participants indicated there was a clear task division, the HC participants overall indicated that everybody was aware of their task, which according to some, was administered in the client file as well.

Perceived outcomes of information exchange among HCPs(2B)

The perceived outcomes of information exchange regard being up-to-date about the current health situation of the person with dementia (2B.I) and consistency in executing care tasks (2B.II). Overall, NH and HC participants had positive experiences with HCPs being up to date with their loved ones' current health status. One NH participant stated the following:

> "At the end, everybody knew what was going on." Participant 13

Whereas most HC participants had positive experiences with regards to the consistency in the execution of care tasks, most NH participants had negative experiences. One NH participant stated the following:

> "The pain medication; one would give it to her and the other one wouldn't." Participant 7

Factors influencing information exchange among HCPs (2C)

The information exchange between HCPs can be influenced by the reading of and reporting in patient records (2C.I), team stability (2C.II) and the communication lines between HCPs (2C.III).

Overall, the HC participants indicated positive experiences with the HCPs reading and reporting in the client file. One HC participant stated the following with regards to HCPs reading the client file:

> "The file was always read a day in advance…And if they were not there for a couple of days, they would read through those days and they would read the care plan, and of course if I was there, I could tell it." Participant 22

The NH participants overall had more negative experiences with regards to HCPs reading the patient record, which mostly resulted in not being aware of personal preferences. One participant indicated positive experiences with the HCPs reading the patient record until a change in the care would take place. Most negative experiences were due to substitutes or HCPs' lack of time. One participant stated the following:

> "…it is very hard for people who are lying in bed very sick, like my father; when a face they don't recognize comes in, and the face does not even know what to do." Participant 19

Regarding the team stability, all participants agreed upon the importance of consistency in the group of HCPs working with their loved ones. One NH participant stated the following:

> “Look, every person living there has their own baggage and script, so to speak. The regular personnel knew all of that, and they (substitutes) did not of course. Participant 15

The participants stated that their loved one enjoyed recognizing the HCPs. One NH participant stated the following:

> “I think it is nicer for the people on the departments when they keep seeing familiar faces. Switch once in a while, but leave the permanent workers. When she (name) would walk in; my mother would have a smile from here to there and back. That’s a pleasure.” Participant 7

Even though they would have liked to have the same group of HCPs, all NH participants except for two, experienced great staff turnover. Furthermore, they all experienced shortage of staff. The HC participants indicated to have had the same group of HCPs eventually:

> “…at a certain point he had five regular ones and of course he had his sweet hearts; the ones he rather had. That was amazing, because then I would say: that one or that one is coming. That was good, he found that amazing.” Participant 22

One HC participant viewed the substitution as a positive aspect:

> “But what makes it hard is that many different people would always come in and they (persons with dementia) struggled with that. But on the other side that was good, because, imagine you have someone you don’t get along with and he/she always comes in; so it switches.” Participant 29

Finally, the communication lines between HCPs can influence the information exchange. The HC participants did not provide evident examples of short communication lines, but the communication lines overall seemed to be short between the nurses and the doctor. Short communication lines were only experienced by one NH participant. Some NH participants would initiate direct contact with the addressed HCP, when they felt that a long time period passed for the HCPs to communicate with each other. One participant stated the following:

> “You noticed the structure; you pass it on to us and we will pass it on to them. We partly went along with that. On the other side I would say that we still hadn’t heard anything. I said I’m going to inform myself and I would make sure that when mom would have therapy, I’d be there so I could discuss things with him. Some time would pass due to several reasons, either because they had a few days off or because, I don’t know what kind of pattern they have in relaying…When I would think, this is taking too long, I would take the initiative.” Participant 9

3.2 Relationship between inter-professional collaboration and peaceful dying

Quantitave analyses show that NH participants most frequently (41.7%) indicated that they agree completely with the statement that the person with dementia had died peacefully (Table 2). HC participants most frequently (62.5%) indicated that they agree quite a bit with this statement. A Chi-Square Test has been performed (Table 2) to assess whether there was an association between the type of care setting and the level of agreement on the dying peacefully item from the QOD-LTC. The p-value[2] (0.375) indicates that these variables are not dependent of each other and there is no statistically significant association between the type of care setting and loved ones' agreement with the persons with dementia having died peacefully.

Table 2. Dying peacefully of persons with dementia according to loved ones

	Nursing home care [2]		Home care [2]		Total	
	Count (n)	Percentage (%)	Count (n)	Percentage (%)	Count (n)	Percentage (%)
Dying peacefully[1,2]						
Completely	10	41.7	2	25.0	12	37.5
Quite a bit	9	37.5	5	62.5	14	43.8
A moderate amount	0	0.0	0	0.0	0	0.0
A little	3	12.5	0	0.0	3	9.4
Not at all	2	8.3	1	12.5	3	9.4
Total	24	100.0	8	100.0	32	100.0

1. Missing = 0%
2. Non-significant (p=0.375) association between type of care setting and level of agreement on dying peacefully item

3.2.1 Qualitative exploration of the relationship between inter-professional collaboration and peaceful dying

In the following section, identified patterns in loved ones' experiences in both settings regarding the themes are discussed in relation to a negative (not at all and a little bit) or positive (quite a bit and completely) category of agreement to the statement that the person with dementia has died peacefully. Clear patterns seem to be missing in the experiences of HC participants.

Negative categories of agreement

NH participants within the negative categories of agreement had negative experiences with being informed. One participant stated the following:

> "...I heard it afterwards and thought 'guys, you never told me anything about that'. Once, I came in and she was moody; 'Oh yes, she had a little seizure this morning. I said: Why didn't I know that? Why didn't you call me about that? 'Oh yes we forgot.' I had to hear that a lot of times." Participant 5

This participant suggested using a client file, like in home care, as a communication tool to be kept up-to-date with personal information, but this was not considered. One participant from the “little bit” category and both participants from the “not at all” category overall had negative experiences with HCPs’ passive attitude in involving them in the care of their loved ones. The HCPs did not provide the participants access to the patient files, nor engage the willing participants in medical decision making:

> “I hadn’t gotten her vaccinated against the flu for the past three years and they gave her one there. I said: You should have asked me, because she wouldn’t have gotten one.” Participant 5

Besides not being asked anything, one participant stated that everything they said, was being contradicted by the HCPs, which bothered them.

Moreover, the participants from the “not at all” category experienced that the HCPs did not listen to them, mainly regarding food or care indications. This type of information thus often had to be repeated. When having monitored that their loved one was being restless and indicated to administer more morphine, one participant did not feel heard:

> “I said to put her on morphine; she is 93, then she should not be lying there like that. At a certain moment it happened, but with a light dosage they had to keep injecting. I said: You are going to give more or I’m going to make sure she gets more. I said I’d give it to her myself. I have morphine at home.” Participant 5

This participant had provided the HCPs with feedback on the care, which they did not take it into account, making the participant not feel heard and taking a more passive role in indicating information. The many negative experiences with not being heard, led to negative effects on the participant’s health status. The participant indicated to not have been able to let go of the situation, due to not being sure whether the loved one was taken good care of. The person with dementia was not being involved by the HCPs as she was deaf and blind, which required a lot of effort in communicating, which according to the participant, not everyone had patience for. Moreover, the participants overall did not seem to have actively relayed information between HCPs, even though one participant had indicated that the HCPs did not seem to communicate properly with each other. However, the participants felt that the HCPs were competent to provide care for their loved one. The participants also indicated positive experiences with the first responsible HCP. In two cases the participants found it unpleasant that the first responsible HCP had resigned. In one case it took five weeks for a new HCP to be assigned, which made the participant feel forgotten about. Two participants from the “little bit” category, of which one participant did not have a first responsible HCP, indicated to have contacted whoever was available. Finally, the participants overall did not indicate to have engaged in coordinating the care of their loved one or to have felt as being part of the team.

Positive categories of agreement

Most NH participants from the “quite a bit” category had negative experiences with being informed and a passive attitude of HCPs in involving them, while some were well informed. In negative experiences, participants indicated to have initiated contact to acquire information:

> “I was always the one reaching out: ‘What happened? We see this in our mother, what now? What are you doing about and what can we do?’ So we initiated very often” Participant 2

Participants in the “completely” category overall had positive experiences with a proactive attitude of HCPs, with regards to involving loved ones in medical decision making, asking for opinions and providing information. One participant stated the following:

> “We got information on all hands, and we were asked how we thought she was emotionally and physically and if we had questions or remarks, things we didn’t like or did like. They really listened to me.” Participant 17

These participants furthermore initiated contact with the HCPs to acquire information. The participants overall had more positive experiences with being listened to by the HCPs. However, four participants had indicated that being listened to was HCP-dependent. Not being listened to led to more active engagement in the care, as shown in the following statement:

> “They did say it, but it did not always happen, so I helped her myself every time. At a certain point, you just have to get over it.” Participant 10

Four participants from the “quite a bit” category indicated that the staff was competent, but had too little time. Others and the participants from the “completely” category overall had indicated some form of incompetency. One participant stated that the HCPs did not possess knowledge on the specific type of dementia their loved one had. Participants mainly regarded the substitutes or interns as less competent, leading to an active monitoring role of the participants. One participant stated the following:

> “The last half year my mother was there, there was a high sick leave. Many self-employed persons came in. One would be really good and the other you would have to lead and tell him what to do.” Participant 15

Overall, participants were in need of more clear and direct HCP communication regarding their loved ones’ health status. The experiences with regards to a first responsible HCP were overall positive. Some participants indicated that this HCP was not always available, or there had been a switch, and in one case there was none. This did not disturb most participants as they would contact other HCPs. One participant stated the following:

> “We all knew it had to do with skills and assertiveness; that you dare and talk to

> people. And it wasn't only me, but my brothers and sisters as well; if we wanted something we would make it discussable." Participant 9

Participants were overall not in need of repeating information. Two participants from the "quite a bit" category and four participants from the "completely" category indicated to have actively relayed information between HCPs, which was linked to poor communication among HCPs. One participant stated the following:

> "...Maybe they gathered around too little and listened to each other. I had to be the one gathering all the information...I was the linking part every time...I had to send emails every week. That was so exhausting." Participant 4

Four participants from the "quite a bit" category and three participants from the "completely" category indicated to have engaged in coordinating care. One participant stated the following regarding engaging a psychologist and recruiting volunteers:

> "...the grief for her husband and leaving her home played a role too. I called in a psychologist myself, through the family doctor, which actually should have been done by them."
>
> "I put a large message on Facebook for an interested younger volunteer to help the elderly with lunch, because I see them light up when they see a younger face...Some asked: 'Did you put something on Facebook about this?' I said: yes, because you do have enough volunteers but they were hard to reach, I took over the task and thought let's try it like this. Two people applied." Participant 32

Participants contacted the HCP directly when they felt it took a long time before arrangements between HCPs were made, indicating their need of short communication lines. Furthermore, one participant from the "quite a bit" category and one participant from the "completely" category indicated to have tried to collaborate with HCPs:

> "At one point we had a conversation with the manager and doctor and psychologist to find out how we can work together. What can we, as kids, do for the department and support them?" Participant 2

Finally, three NH participants and three HC participants from the "quite a bit" category and five NH participants from the "completely" category were familiar with the healthcare sector, which according to them affected their view on care, involvement and skills. One NH participant stated the following:

> "And I'm lucky to work in the healthcare, so I dare to talk to doctors because I do that a lot; I learnt that and that's my advantage." Participant 9

One HC participant stated the following answer to the question whether she had a case manager:

> "I don't know what he would be doing here. I was capable enough to see and manage everything. I taught in dementia myself, so I don't need a case manager. If I had been a lay in nursing, they would have had the control." Participant 22

4. Discussion

4.1 Main findings

The aim of this study was to explore loved ones' needs and challenges regarding the inter-professional collaboration in end-of-life dementia care in home care and nursing home settings, and explore the relationship between these experiences and how loved ones perceived peaceful dying of the persons with dementia. Regarding loved ones' involvement in the collaboration with HCPs, loved ones in both settings wanted to be actively and continuously informed about the current health status, changes in care provision, medical decisions and the course of dementia and process of dying. Loved ones in the home care setting were closely linked in the care process and actively engaged by HCPs, with which they indicated to have had a teamwork with. The client file as a communication channel contributed to good collaboration between them and HCPs. In nursing home settings, loved ones' engagement in medical decision making, the extent to which they were informed, and the need to repeat information was influenced by HCPs' attitude in involving them and listening to them. First responsible HCPs, as a link between loved ones and HCPs, were often not available or frequently replaced. The extent to which this bothered loved ones, was related to their assertiveness in approaching other HCPs. Loved ones overall found it important to have a regular, permanent group of HCPs, they have a connection with. These HCPs are considered to be more competent and familiar with personal information, contributing to more person-centered care and leading to less repetition of information and additional monitoring of HCPs by loved ones. Regarding loved ones' perceptions of the collaboration among HCPs, loved ones in both settings overall had little insight in the structural collaboration between different HCPs, with regards to meetings, collaboration agreements and a task division. Most loved ones, however, were aware of an information exchange between mainly doctors and nurses. In home care settings, the communication lines seemed to be shorter, with the client file as main communication tool between HCPs as well. Most loved ones in nursing home settings had negative experiences with the consistency of executing care tasks and with regards to HCPs reading the patient record, which was due to substitutes or HCPs' lack of time.

The interplay between HCPs' inputs in the inter-professional collaboration and involving loved ones and the role loved ones took upon themselves seems to be related to how loved ones perceive peaceful dying of the person with dementia. HCPs seem to contribute positively to a peaceful death, by having a good communication among HCPs, being available and competent, and by actively involving loved ones and listening to them. Loved ones contribute positively to a peaceful death by compensating for HCPs' negative input or being involved regardless of HCPs' input, through active engagement in: relaying information between HCPs, initiating contact with whichever HCP is available to acquire information, executing care tasks themselves when not being listened to, or coordinating care, which seemed to be associated with being familiar with the healthcare sector. In loved ones' experiences in home care settings no clear patterns, related to how loved ones perceive peaceful dying of the person with dementia, were found. All loved ones in this setting indicated a positive input of HCPs and to be actively engaged on their own initiative. Furthermore, only one loved one indicated that the person with dementia had not died peacefully, regardless of positive experiences with the inter-professional collaboration. Not having experienced the death as peaceful could have been caused by other factors, such as physical and psychological distress in the person with dementia (de Roo et al., 2015).

Loved ones' limited understanding of the natural progression of dementia and process of dying (Gessert, Forbes, Bern-Klug, 2001), and their need for being informed, having continuity in the group of HCPs responsible for the care (Bolt et al., 2019, van der Steen et al., 2017), good communication among HCPs, and being involved in decision making, is in line with previous studies (Caron, Griffith & Arcand, 2005; Elliot, Gessert & Peden-McAlpine, 2007; Forbes, Bern-Klug & Gessert 2000; Majerovitz, Mollot & Rudder, 2009). A literature study of Hennings et al. (2010) showed that loved ones of persons with dementia use a range of values to underpin the decision-making process, including the preservation of dignity, the provision of comfort, the personal history of the person with dementia, honoring previously expressed wishes and quality of life. By not involving loved ones in decision making processes, decisions are not necessarily based on these values, which could have contributed to loved ones not considering the death of the person with dementia as peaceful. Authors on ethics (Fisk et al., 1998; Hertogh & Ribbe, 1996) furthermore promote decision making by consensus between HCPs and loved ones of cognitively impaired persons and thus encouraging HCPs to involve loved ones.
Loved ones indicating a more peaceful death were more assertive in approaching HCPs. However, taking the first step and contacting HCPs is emphasized as being difficult by informal caregivers (Stephan et al., 2015). Continuous contact with a single contact person is an important facilitator of a good collaboration among HCPs and loved ones (Stephan et al., 2015) and could be especially of importance in case of less assertive loved ones, who found the replacement of the first responsible HCP unpleasant.

Next to an optimistic resident's attitude and a moderate perceived influence of religious affiliation on end-of-life decision making policies, de Roo et al. (2014) found an association between loved ones' experience enough nurses being available and dying peacefully of the person with dementia. This does not seem to be in line with the findings of this study as all participants experienced understaffing. However, this also could have been a factor which loved ones compensated for, by active engagement.

4.2 Strengths and limitations

To the author’s knowledge, this is the first study to investigate loved ones’ specific experiences with inter-professional collaboration in relation to how they perceived the peaceful dying of the person with dementia. Furthermore, having used interview data rather than questionnaire data regarding loved ones’ experiences has provided in depth information, which might have stayed hidden otherwise (Hargie, 2010). The qualitative analysis was conducted by two individuals and discussed with a team of researchers, which has contributed to the trustworthiness of this study.

However, this study has some limitations. The data was limited to loved ones’ experiences from one single area in the Netherlands, with a limited amount of participants, especially from the home care setting. This had an effect identifying a clear pattern in loved ones’ experiences from this setting with regards to how they perceived peaceful dying of the person with dementia. Furthermore, the patterns in experiences and relationships between the experiences and peaceful dying were only analyzed descriptively, providing no quantitative significance levels.

4.3 Implications and recommendations

The findings of this study indicate an overall need for education for HCPs in nursing home settings and loved ones. HCPs need education on achieving a better collaboration and communication amongst each other, in order to be consistent in reading personal records and in executing care tasks. A personal and trusting relationship with other HCPs is an important facilitator for good collaboration amongst HCPs (Stephan et al., 2015), which is promoted in inter-professional education (Petri, 2010). Educational programs could be a successful tool for improving communication among HCPs. Training could furthermore address communication skills such as active listening and allowing residents and their loved ones to be active participants in the communication process. Loved ones’ education should inform them about the course of dementia and the process of dying and discuss ways to approach HCPs and communicate with them. Furthermore, aving consistency in the group of HCPs proving the care, could enhance a better communication and collaboration between loved ones and HCPs, and lead to more person-centered care. A permanent first responsible HCP, as contact person between loved ones and HCPs, can facilitate communication in case of passive HCPs’ attitudes or less assertive loved ones. Moreover, the personal file, as used in home care settings, could facilitate better communication between loved ones and HCPs, and among HCPs, in nursing home settings. Besides, a partnership agreement between HCPs and loved ones could benefit both parties as they would both clarify their expectations regarding their own and the other party’s role in the inter-professional collaboration. These expectations could be adjusted by both parties clarifying what they can and/or want to offer. This could affect not only loved ones' satisfaction with the collaboration, but also of HCPs, as satisfaction is the extent to which expectations are met (Kupfer & Bond, 2012).

Future research should include more loved ones from home care settings in order to assess the specific relationship between their experiences and the peaceful dying of the person with dementia, as there was no clear relationship in this study due to the small number of participants and only one participant having indicated a non-peaceful death. Furthermore, the experiences of persons with dementia and of the HCPs regarding inter-professional collaboration should be included and related to dying peacefully. The combination of these experiences could then lead to the establishment of comprehensive inter-professional collaborative strategies, enhancing the quality of palliative dementia care, which could in return contribute to dying peacefully. Finally, as inter-professional collaboration is only one aspect in the end-of-life care for persons with dementia, more qualitative and quantitative research is needed to gain insight in other aspects, which could contribute to a peaceful death.

Conclusion

Loved ones' active engagement in the care for the person with dementia in nursing homes settings, either as a compensation for HCPs' passive attitude in involving them, by being involved by HCPs, or regardless of HCPs' attitude, is related to a loved ones perceiving the death of the person with dementia as peaceful. Interventions should be aimed at educating both HCPs and loved ones, and establishing partner agreements between both parties. Evaluating loved ones' experiences with end-of-life care is valuable, as their perspectives inform unique requirements for palliative care that may contribute to dying peacefully.

References

Aaltonen, M., Raitanen, J., Forma, L., Pulkki, J., Rissanen, P., & Jylha, M. (2014). Burdensome transitions at the end of life among long-term care residents with dementia. Journal of the American Medical Directors Association, 15(9), 643-648.

Alzheimer Association. (2018). What is dementia? Retrieved January 10, 2019, from https://www.alz.org/what-is-dementia.asp

Alzheimer Nederland. (2015). Dementie in beeld. Jaarverslag 2015. Retrieved January 10, 2019, from https://www.alzheimer-nederland.nl/nieuws/jaarverslag-2015-staat-online-dementie-beeld

Arruda, E. H., & Paun, O. (2017). Dementia caregiver grief and bereavement: an integrative review. Western journal of nursing research, 39(6), 825-851.

Boeije, H. R. (2005). Analyseren in kwalitatief onderzoek: denken en doen. Boom Koninklijke Uitgevers.

Bökberg, C., Ahlström, G., Leino-Kilpi, H., Soto-Martin, M. E., Cabrera, E., Verbeek, H.,... Karlsson, S. (2015). Care and service at home for persons with dementia in Europe. Journal of Nursing Scholarship, 47(5), 407-416.

Bolt, S. R., Verbeek, L., Meijers, J. M., & van der Steen, J. T. (2019). Families' Experiences With End-of-Life Care in Nursing Homes and Associations With Dying Peacefully With Dementia. Journal of the American Medical Directors Association, 20(3), 268-272.

Campbell, S. M., Braspenning, J., Hutchinson, A., & Marshall, M. (2002). Research methods used in developing and applying quality indicators in primary care. Qual Saf Health Care, 11(4), 358-364.

Campbell, S. M., Roland, M. O., & Buetow, S. A. (2000). Defining quality of care. Social science & medicine, 51(11), 1611-1625.

Caron, C. D., Griffith, J., & Arcand, M. (2005). End-of-life decision making in dementia: The perspective of family caregivers. Dementia, 4(1), 113-136.

Claessen, S. J., Francke, A. L., Belarbi, H. E., Pasman, H. R. W., van der Putten, M. J., & Deliens, L. (2011). A new set of quality indicators for palliative care: process and results of the development trajectory. Journal of pain and symptom management, 42(2), 169-182.

Creswell, J. W., & Clark, V. P. (2007). Designing and conducting mixed methods research.

Dahlke, S., Steil, K., Freund-Heritage, R., Colborne, M., Labonte, S., & Wagg, A. (2018). Older people and their families' perceptions about their experiences with interprofessional teams. Nursing open, 5(2), 158-166.

Danermark, B., Ekstrom, M., & Jakobsen, L. (2005). Explaining society: An introduction to critical realism in the social sciences. Routledge.

Davies, N., Maio, L., Vedavanam, K., Manthorpe, J., Vernooij-Dassen, M., & Iliffe, S. (2014). Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences. Health Soc Care Community, 22(4), 386-394.

Deltaplan Dementie. (n.d.). Dementiezorg. Retrieved January 10, 2019, from https://www.deltaplandementie.nl/nl/dementiezorg

De Roo, M. L., Albers, G., Deliens, L., De Vet, H. C., Francke, A. L., Van Den Noortgate, N.,... & Cohen, J. (2015). Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities. Journal of pain and symptom management, 50(1), 1-8.

De Roo, M. L., Leemans, K., Claessen, S. J., Cohen, J., Pasman, H. R. W., Deliens, L., ... & IMPACT, E. (2013). Quality indicators for palliative care: update of a systematic review. Journal of pain and symptom management, 46(4), 556-572.

De Roo, M. L., van der Steen, J. T., Galindo Garre, F., Van Den Noortgate, N., Onwuteaka-Philipsen, B. D., Deliens, L., ... & EURO IMPACT. (2014). When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings. Palliative medicine, 28(3), 210-219.

Donabedian, A. (1988). The quality of care: how can it be assessed?. Jama, 260(12), 1743-1748.

Eisenmann, Y., Schmidt, H., Voltz, R., & Perrar, K. M. (2016). Expression and Perception of Needs in Severe Dementia. Journal of Hospice and Palliative Nursing, 18(3), 268-272.

Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2007). Decision making by families of older adults with advanced cognitive impairment: spirituality and meaning. Journal of gerontological nursing, 33(8), 49-55.

Erel, M., Marcus, E. L., & Dekeyser-Ganz, F. (2017). Barriers to palliative care for advanced dementia: a scoping review. Ann Palliat Med, 6(4), 365-379.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. International Journal of Social Research Methodology, 20(2), 181-194.

Fisk, J. D., Sadovnick, A. D., Cohen, C. A., Gauthier, S., Dossetor, J., Eberhart, A., & LeDuc, L. (1998). Ethical guidelines of the Alzheimer Society of Canada. Canadian journal of neurological sciences, 25(3), 242-248.

Flick, U. (2018). An introduction to qualitative research. Sage Publications Limited.

Forbes, S., Bern-Klug, M., & Gessert, C. (2000). End-of-life decision making for nursing home residents with dementia. Journal of Nursing Scholarship, 32(3), 251-258.

Gessert, C. E., Forbes, S., & Bern-Klug, M. (2001). Planning end-of-life care for patients with dementia: roles of families and health professionals. OMEGA-Journal of Death and Dying, 42(4), 273-291.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse education today, 24(2), 105-112.

Hargie, O. (2016). Skilled interpersonal communication: Research, theory and practice. Routledge.

Hebert, R. S., & Schulz, R. (2006). Caregiving at the end of life. Journal of palliative medicine, 9(5), 1174-1187.

Hennings, J., Froggatt, K., & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: the accounts of family carers. Reviews in Clinical Gerontology, 20(2), 114-127.

Hertogh, C. M., & Ribbe, M. W. (1996). Ethical aspects of medical decision-making in demented patients: a report from the Netherlands. Alzheimer disease and associated disorders, 10(1), 11-19.

IKNL, P. (2017). Kwaliteitskader palliatieve zorg Nederland. Retrieved January 9, 2019, from https://www.iknl.nl/palliatieve-zorg/kwaliteitskader-palliatieve-zorg

Kiely, D. K., Prigerson, H., & Mitchell, S. L. (2008). Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. The American Journal of Geriatric Psychiatry, 16(8), 664-673.

Kupfer, J. M., & Bond, E. U. (2012). Patient satisfaction and patient-centered care: necessary but not equal. Jama, 308(2), 139-140.

Lee, M., & Chodosh, J. (2009). Dementia and life expectancy: what do we know?. Journal of the American Medical Directors Association, 10(7), 466-471.

Lloyd-Williams, M., Abba, K., & Crowther, J. (2014). Supportive and palliative care for patients with chronic mental illness including dementia. Curr Opin Support Palliat Care, 8(3), 303-307.

Maas, M. L., Reed, D., Park, M., Specht, J. P., Schutte, D., Kelley, L. S., ... & Buckwalte, K. C. (2004). Outcomes of family involvement in care intervention for caregivers of individuals with dementia. Nursing research, 53(2), 76-86.

Majerovitz, S. D., Mollott, R. J., & Rudder, C. (2009). We're on the same side: Improving communication between nursing home and family. Health communication, 24(1), 12-20.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., ... & Hamel, M. B. (2009). The clinical course of advanced dementia. New England Journal of Medicine, 361(16), 1529-1538.

Munn, J. C., Zimmerman, S., Hanson, L. C., Williams, C. S., Sloane, P. D., Clipp, E. C., ... & Steinhauser, K. E. (2007). Measuring the quality of dying in long-term care. Journal of the American Geriatrics Society, 55(9), 1371-1379.

NZa. (2018). Samenwerken in de palliatieve zorg: zorg rondom de patiënt. Retrieved January 11, 2019, from https://puc.overheid.nl/nza/doc/PUC_254795_22/1/

Perrar, K. M., Schmidt, H., Eisenmann, Y., Cremer, B., & Voltz, R. (2015). Needs of people with severe dementia at the end-of-life: a systematic review. Journal of Alzheimer's Disease, 43(2), 397-413.

Petri, L. (2010). Concept analysis of interdisciplinary collaboration. Nursing forum (Vol. 45, No. 2, pp. 73-82). Malden, USA: Blackwell Publishing Inc.

Poos, M. J. J. C., Meijer, S., & Willemse. B. (2015). Trend in aantal mensen met dementie. Retrieved January 29, 2019, from https://www.volksgezondheidenzorg.info/onderwerp/dementie/cijfers-context/trends#node-trend-aantal-mensen-met-dementie

Rijksinstituut voor Volksgezondheid en Milieu. (2018). Volksgezondheid toekomstverkenning 2018: Trendscenario. Retrieved January 9, 2019, from https://www.vtv2018.nl/trendscenario

Saldaña, J. (2015). The coding manual for qualitative researchers. Sage.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. International psychogeriatrics, 25(6), 949-961.

Shanley, C., Fetherstonhaugh, D., McAuliffe, L., Bauer, M., & Beattie, E. (2017). Providing support to surrogate decision-makers for people living with dementia: Healthcare professional, organisational and community responsibilities. Health & social care in the community, 25(5), 1563-1570.

Smith, S. J. (1998). Providing palliative care for the terminal Alzheimer patient. Hospice Care for Patients With Advanced Progressive Dementia. New York, NY: Springer Publishing Co Inc, 247-256.

Stephan, A., Möhler, R., Renom-Guiteras, A., & Meyer, G. (2015). Successful collaboration in dementia care from the perspectives of healthcare professionals and informal carers in Germany: results from a focus group study. BMC health services research, 15(1), 208.

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. Jama, 291(1), 88-93.

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. American journal of evaluation, 27(2), 237-246.

Thompson, G. N., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. Palliative & supportive care, 12(3), 223-231.

Vanderleyden, L. (2015). Vergrijzing: een stand van zaken. Geron, 17(4), 7-13.

van der Steen, J. T. (2010). Dying with dementia: what we know after more than a decade of research. Journal of Alzheimer's Disease, 22(1), 37-55.

van der Steen, J. T., Dekker, N. L., Gijsberts, M. J. H., Vermeulen, L. H., & Mahler, M. M. (2017). Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. BMC palliative care, 16(1), 28.

van der Steen, J. T., Radbruch, L., Hertogh, C. M. P. M., de Boer, M. E., Hughes, J. C., Larkin, P., ... & Volicer, L. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliative Medicine, 28(3), 197-209.

van Soest-Poortvliet, M. C., Van Der Steen, J. T., Zimmerman, S., Cohen, L. W., Munn, J.,Achterberg, W. P., ... & De Vet, H. C. (2011). Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. Journal of pain and symptom management, 42(6), 852-863.

Volksgezondheidenzorg. (2015). Trends in aantal mensen met dementie. Retrieved January 9, 2019, from https://www.volksgezondheidenzorg.info/onderwerp/dementie/cijfers-context/huidige-situatie#!node-aantal-mensen-met-dementie

Appendix

Appendix 1. Inter-professional collaboration interview questions

1. Welke soorten zorgverleners/disciplines waren betrokken bij de zorg voor uw naaste in de laatste maanden? (gebruik lijst uit demographic data…)
    a. Hoe heeft u dat ervaren, al die zorgverleners om uw naasten heen?
2. Hoe werd u zelf en uw naaste betrokken door die verschillende zorgverleners, in het zorgproces?
    a. Had u het idee dat uw naaste of u zelf de regie had over de zorg? Waarom wel/niet?
    b. Voelde u zich erkend als mantelzorger?
    c. Bent u bevraagd naar uw eigen ervaringen in de zorg voor uw naaste, als mantelzorger?
    d. Werd er rekening gehouden met uw tips of signalen voor betere zorg? Hoe merkte u dit?
3. Werd de zorg gecoördineerd door één persoon? Was het voor u duidelijk wie uw aanspreekpunt was? Functioneerde deze persoon ook goed als aanspreekpunt voor u?
    a. Hoe verliep de samenwerking volgens u wanneer er veranderingen in de situatie van uw naaste was? Hoe kwam deze informatie bij de verschillende zorgverleners terecht (via het aanspreekpunt of op een andere manier)?
    b. Moest u hetzelfde verhaal vaak opnieuw vertellen?
4. Wat was uw algemene indruk over de samenwerking tussen de verschillende zorgverleners?
    a. Hoe kwam die samenwerking naar voren, hoe werd die zichtbaar voor u, of juist niet?
    b. Had u de indruk dat de zorgverleners wisten wie welke taak had in de zorg voor uw naaste? Oftewel, werkten ze samen, of werkten ze langs elkaar heen? Hoe vond u dit gaan? Waarin zag u dit terug?
    c. Werd er volgens u goed gecommuniceerd tussen de verschillende zorgverleners die betrokken waren? En op welke manier?
    d. Weet u of er samenwerkingsafspraken gemaakt werden over de zorg? Waar werden ze gemaakt en waar werden ze vastgelegd? (bijv. via overleg/MDO/dossier)
    e. Werden de afspraken over zorg door alle zorgverleners op dezelfde manier uitgevoerd?
5. Wat had u graag anders gezien in de samenwerking tussen de verschillende zorgverleners, of wat zou u zorgverleners mee willen geven?