

END-OF-LIFE COMMUNICATION IN NURSING HOMES: EXPERIENCES OF BEREAVED OF PEOPLE WITH DEMENTIA

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Abstract

Title: End-of-life communication in nursing homes: Experiences of bereaved of people with dementia

Background: Most people with dementia die in nursing homes or other long-term care facilities. End-of-life communication, which involves shared decision-making and Advance Care Planning (ACP), constitutes the basis for good care. Good communication has been identified as one of the most important aspects of end-of-life care that is correlated with the quality of dying. Therefore, end-of-life communication experiences might influence the quality of dying as experienced by the bereaved.

Aim: To explore the experiences of the bereaved of people with dementia with regard to end-of-life communication given by professional caregivers in nursing homes.

Method: In-depth, semi-structured interviews were conducted between February 2018 and April 2018 with a purposeful sample of twelve bereaved of people with dementia who had died in nursing homes within the last nine months. The interviews explored communications during the final three months of life regarding end-of-life wishes, informing and supporting loved ones and interactions with residents. Data were analyzed using thematic analysis methods.

Results: The results highlight the need for tailored end-of-life communication for people with dementia and their loved ones. Key themes include 1) Making contact, 2) Being sufficiently informed, 3) Supporting loved ones, 4) Challenges as proxy decision makers and 5) Starting the conversation about the end-of-life.

Conclusions: This study uncovers both positive and negative experiences with end-of-life communications of the bereaved of people with dementia. The bereaved articulated the need to be sufficiently informed and involved regarding care decisions, prognoses and palliative care.

Recommendations: Caregivers must start timely the conversation with residents and their loved ones about their wishes regarding care and the end-of-life. Further research should focus on the insufficient information about dementia and palliative care for residents' loved ones.

Keywords: Dementia, Palliative care, End-of-life communication, Nursing Home, Caregivers

Samenvatting

Titel: De communicatie rondom het levenseinde in verpleeghuizen: Ervaringen van nabestaanden van mensen met dementie

Achtergrond: De meeste mensen met dementie sterven in verpleeghuizen. Communicatie rondom het levenseinde vormt samen met gezamenlijke besluitvorming en vroegtijdige zorgplanning de basis voor goede zorg. Verbetering van communicatie is hierin cruciaal voor cliënten en hun naasten, want het is door hen geïdentificeerd als een van de belangrijkste aspecten van zorg aan het einde van het leven die leiden tot een goede kwaliteit van sterven.

Doel: Inzicht krijgen in de ervaringen van nabestaanden van mensen met dementie over de communicatie door zorgverleners rondom het levenseinde in verpleeghuizen.

Methode: Diepgaande semigestructureerde interviews zijn, tussen februari 2018 en april 2018, afgenomen bij een doelgerichte steekproef van twaalf nabestaanden van mensen met dementie die de afgelopen negen maanden zijn overleden in verpleeghuizen. Interviews gingen over de wensen rondom het levenseinde, het informeren en ondersteunen van naasten en de interactie met cliënten in laatste drie maanden van het leven. Gegevens werden geanalyseerd met behulp van thematische analysemethoden.

Resultaten: De resultaten benadrukken de behoefte aan communicatie op maat rondom het levenseinde voor mensen met dementie en hun naasten. De belangrijkste thema's zijn: 1) Bejegening 2) Voldoende geïnformeerd zijn 3) Het ondersteunen van naasten 4) Uitdagingen als gevolmachtigde 5) Het gesprek aangaan over het levenseinde.

Conclusie: Nabestaanden hebben zowel positieve als negatieve ervaringen over communicatie aan het einde van het leven van mensen met dementie. Ze hadden behoefte aan voldoende informatie rondom zorgbeslissingen, prognose en palliatieve zorg en om hierbij betrokken te worden.

Aanbevelingen: Zorgverleners zouden tijdig het gesprek met cliënten en hun naasten moeten aangaan over wensen ten aanzien van zorg en het levenseinde. Verder onderzoek moet zich richten op het geven van onvoldoende informatie over dementie en palliatieve zorg aan geliefden.

Kernwoorden: Dementie, Palliatieve zorg, Communicatie, Verpleeghuis, Zorgverleners

Introduction

In 2016, nearly 47 million people lived with dementia worldwide. As population ages, this number is expected to reach over 131 million by 2050.¹ In the Netherlands, approximately 270.000 people live with dementia of whom 70,000 reside in nursing home settings.² The majority of people with dementia (93%) eventually die in nursing homes or other long-term care facilities, indicating that these facilities play an important role in providing palliative care to individuals with dementia.^{3,4}

Palliative care involves the prevention and alleviation of suffering, through early signaling and the careful assessment and treatment of physical, psychological, social and spiritual problems.⁵ Improving quality of life and maximizing comfort are the main goals of palliative care.⁶ In practice, palliative care provision for people with dementia is often suboptimal due burdensome interventions such as tube feeding and laboratory tests, and distressing symptoms that may not be adequately managed.^{7,8} The goal of comfort positively affects families' satisfaction with care at the end of life.⁹ However, in a recent study, it was found that only half of the people with dementia in long term care facilities die peacefully according to their relatives.¹⁰ Research indicates that, for people with dementia, peaceful dying is positively correlated with adequate personal attention and sufficient availability of nurses within the facility as perceived by their families.¹¹ Loved ones of people with dementia are often closely involved in their care. Due to the cognitive deterioration associated with the disease, people with dementia may no longer be able to adequately communicate with professional caregivers. Hence, families of people with dementia have a particularly important role in safeguarding their wishes and making healthcare decisions in their best interest.¹²

Effective end-of-life communication between caregivers (i.e. nursing staff, physicians, spiritual caregivers and psychologists) and people with dementia and their loved ones that incorporates shared decision-making (SDM) and Advance Care Planning (ACP), constitutes the basis for high-quality end-of-life care, in which the patient and his or her loved ones should have a central role.⁵ SDM aims at involving people with dementia and their loved ones in healthcare decisions.^{6,13} Discussing the preferences, values, (information) needs and beliefs of the person with dementia and their loved ones with caregivers, may support proactive ACP.⁶ ACP is particularly important for people with dementia and their loved ones, as it involves an ongoing communication process that anticipates the fact that the person with dementia may lose the capacity to express their wishes and preferences.^{14,15}

Good communication is defined by people with dementia and their loved ones as involving trusted professional caregivers that provide information adapted to their individual' needs and level of understanding, inquire about end-of-life wishes and provide emotional and

spiritual support.^{6,16–18}

It is likely that a lack of caregiver–loved one communication contributes to loved ones' inability to envision and anticipate the dying trajectory of a relative with dementia. However, nurses and physicians consider communicating with the loved ones of people with dementia about death and dying to be difficult.^{19,20} Bereaved loved ones of someone with dementia often indicate to have been unprepared for the death of their relative, which might point to a lack of awareness amongst them that dementia is a life limiting disease.^{21,22}

Communication about desired end-of-life care must be improved to enable caregivers providing palliative care to people with dementia and their loved ones to timely assess their preferences.²¹ This is pivotal for residents and their loved ones, as they identify good communication as one of the most important aspects of end-of-life care.^{11,20,24} Often designated as proxy decision-makers, loved ones and their experiences with end-of-life communication might influence care processes and the quality of their relative's death.¹¹ Less satisfaction with care is associated with greater predeath grief.²⁵

An understanding of what the bereaved consider important in end-of-life communication is needed to empower caregivers providing palliative care to people with dementia and their loved ones in nursing homes in developing adequate end-of-life communication skills.

Therefore, the current study explores the experiences of the bereaved in this context, focusing on end-of-life communication. Investigating bereaved loved ones' unique experiences may contribute to improving end-of-life care for people with dementia residing in nursing homes.

Research Question

How did bereaved of people with dementia who deceased in nursing homes experience the end-of-life communication given by professional caregivers involved in palliative care?

Method

Design

A general qualitative design with individual, in-depth semi-structured interviews were conducted to investigate the unique in-depth experiences of bereaved of people with dementia regarding end-of-life communication. Additional quantitative questions were asked to clarify the context of bereaved loved ones' experiences. The study was conducted between February 2018 and July 2018, as a part of the overarching research project '*DEDICATED: Desired dementia care towards end of life*'. This project covers a period of four years and focuses on improving end-of-life communication, basic care competencies of

nursing staff and interdisciplinary collaboration between professional caregivers in home care and nursing home settings. Ethics approval was obtained from Zuyderland Hospital Human Participants Ethics Committee (Zuyderland, METCZ20180026).

Study population and setting

Participants were recruited from three nursing home organizations located in the southern regions of the Netherlands. The study population consisted of bereaved of people with dementia who had died in one of these facilities in the previous nine months. A purposive sampling method was used to recruit eligible participants and to select cases that would provide rich information related to the loved ones' experiences with end-of-life communication. Eligible participants (1) were able to comprehend and speak Dutch or a Dutch dialect, (2) were considered the closest to the person with dementia, (3) were a bereaved of a resident with dementia who was at least 65 years old, and (4) were a bereaved of a resident with dementia. This minimum age is maintained because 97% of the people in nursing homes were at least 65 years old.²⁶ A time frame from six weeks to nine months post-death was maintained for the interviews to reduce participant burden, and allow them to better recall the details of their relatives' final days.

Data collection

A semi-structured interview guide was developed, based on the relevant literature and plenary discussions with caregivers.^{6,16-18} The topics focused on the wishes and preferences for end-of-life care, and the information and support received from caregivers in the final three months of the relative's life. The interview guide consisted of four main questions with several sub-questions, all of which are included in Appendix I. The short questionnaire consisted of 1) the perception of the bereaved regarding their communication with the physician, as assessed with the Family Perception of Physician-Family caregiver Communication (FPPFC) questionnaire and 2) a single item from the Quality of Dying in Long-Term Care (QOD-LTC) inquiring about whether their relative died peacefully. The FPPFC comprises seven items that are scored on a four-point Likert scale (0 = strongly disagree, 1 = disagree, 2 = agree, 3 = strongly agree). Higher scores indicate a greater perceived quality of physician communication during the dying process (Cronbach's alpha = 0.96).¹⁷ The item concerning "dying peacefully" from the QOD-LTC questionnaire is scored on a five-point Likert scale; (1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, and 5 = completely). The total score may range from 1 to 5, with a higher score indicating a more peaceful death (Cronbach's alpha = 0.64).^{11,27} The socio-demographic variables included age, gender, time since bereavement, level of education and relationship to the resident.

Procedures

The collaborating nursing home organizations notified potential participants through a phone call from the caregiver in the organization known to the participants or a short information letter and flyer sent by post. The researchers only continued the procedure when these individuals gave oral or written consent to approach them further. The researchers called eligible participants and, upon agreement, sent them an information letter about the study by post, including an informed consent form. After sending the information letter, a timeframe of one week was maintained before calling back to inquire about their interest in participating. When individuals agreed to participate, an appointment was made. All participants gave their written informed consent on the day the interviews took place.

Before the interviews were conducted, the interviews were pilot tested for feasibility and face validity with patient representatives. At the beginning of the interviews, the participants were briefly informed about the purpose of the study and the content of the interview. Anonymity and the voluntary nature of participation were explained as was the ability to withdraw their participation and end the interview at any time. After, their socio-demographic details were requested before starting the official interview. Each interview was conducted by two of the three researchers (L.V., S.B., S.P.), one BSc and two MSc researchers, and took place in the participants' preferred location, often their home or the researchers' location. One researcher led the interview; the other researcher listened, observed and occasionally asked additional questions. Interviews lasted for approximately 90 minutes and were recorded with the participants' permission. The interviews were transcribed verbatim by a transcriptionist who had signed a confidentiality agreement. At the end of the interview, the participants were asked to fill out the FPPFC and QOD-LTC. For quality assurance, the researchers provided each other with feedback on their interviewing techniques after each interview.

Data analysis

The software Nvivo 11 (QSR international Pty Ltd, Australia) was used to assist with data management and the analysis of the interview transcripts.²⁸ Thematic analyses using Braun and Clarke's paradigm were used to investigate the participants' experiences.²⁹ Each interview was analyzed by "coding up" (inductive) and "coding down" (deductive) via researcher and analysis triangulation to improve rigor and trustworthiness. This combination is also referred to as "thick analysis."³⁰ Three researchers read the transcripts thoroughly to become familiar with the data. Subsequently, all three researchers independently clustered the data into meaningful fragments, and the emerging themes were labelled with codes. Three researchers independently conducted axial coding to cluster the codes into categories and reach a consensus about the code descriptions. Coding strategies were frequently compared to fine-tuned themes, and any instances of disagreement were discussed until

consensus was reached. Data saturation was reached when the definition of each category was sufficiently clear. The socio-demographic information and the data derived from the FPPFC questionnaire and the QOD-LTC item were entered into IBM SPSS Statistics version 23 (IBM, New York, United States) to descriptive analyze the quantitative data.

Results

Family member and resident characteristics

A total of twelve bereaved loved ones of people with dementia who had died were interviewed concerning their experiences with end-of-life communication in nursing homes (table 1). Most of the participants were the children of the residents. The mean age of the participants was 61.1 years, and nine participants were female (table 2). In eight cases, the length of residence was longer than one year. The causes of death for the residents were unknown in most cases (58.3%). The mean score on the FPPFC for relatives' perceived quality of communication with the physician is 19.25 (SD = 7.14; median = 20, range = 7–28), indicating a neutral to slightly positive overall perception of physician–family caregiver communication. The bereaved indicated that their relative died peacefully ('completely' or 'quite a bit' at peace in the last month of life) in 83% of cases.

[Insert table 1]

[Insert table 2]

Themes

The interview results demonstrate that loved ones report both positive and negative experiences with the end-of-life communication in nursing homes. Five main themes emerged, reflecting important experiences with end-of-life communication as perceived by loved ones. These themes are:

- 1) Making contact with residents
- 2) Being sufficiently informed
- 3) Supporting loved ones
- 4) The role as proxy decision maker
- 5) Starting the conversation about end-of-life wishes

1) Making contact with residents

Approaching residents during the provision of personal care is described as an important aspect of communicating with the person with dementia, fostering a feeling of safety in the resident. Often, a loving and warm approach towards the resident is described, tailored to the needs of each individual.

"Just to sit down with her for a minute and have a chat. Well, I mean, she could not talk, you know. But just a little communication, rubbing her hand for a bit—yes you could see her eyes light up when someone did that." (daughter, 62 years)

Although the majority of the participants are positive about the caregivers' approaches to the resident, four participants report a lack of adequate contact.

"My mother was almost blind and could scarcely hear. So, if you were suddenly getting caught and dressed and do not know what is happening, well I would find that very annoying. I think I would find that very annoying, and I also saw that my mother was always restless." (daughter, 61 years)

Interactions with residents:

The participants describe varying experiences with the interactions between caregivers and their relatives. Seven participants spoke positively and warmly about caregivers interacting with their relatives. This often contributed to friendly and empathic individual interaction with the resident. Participants mentioned that caregivers felt what a person with dementia needed. However, five participants reported that caregivers lacked sufficient competencies in communication. Caregivers did not enter into the interaction or did not understand what the residents meant.

"But there are also, well, they come in, you know, good morning. And they did not really start the interaction. And I found that quite difficult." (daughter, 62 years)

Participants mentioned less empathy and an incomprehension of the residents' cognitive problems, whereby the caregivers did not meet the residents' care needs, wants and wishes.

Emotional support to residents:

The bereaved report varied experiences with providing emotional support to the person with dementia. Seven participants report that the caregivers paid attention to the residents' emotions. This attention consisted of listening, being with the resident and taking the time to tend to the resident, was considered as sufficient support for the resident.

"Some of them sat down with her and asked, 'Are you sad? What are you sad about?' Well, she could not say anything, but the attention she got at that moment was enough for her." (daughter, 62 years)

Four participants did not have enough insight into providing emotional support. In one case, the caregivers informed the loved one about the residents' emotions, but did not take any action to provide support. This participant indicate that it would have been pleasant if the caregiver had also paid attention to it. Insufficient emotional support is often, according to loved ones, due the caregivers' high workload.

2) Being sufficiently informed

Five participants report that they received insufficient information regarding the expectations of palliative care. This lack of information about their loved one's healthcare status fostered feelings of distrust toward caregivers.

"But I did think that the communication about what we do now and whether we are going to sedate or not sedate happened too cautiously. I prefer it to the right, you do not have to take me into account, but that was too cautious. The nursing home doctor was not always clear about that." (daughter, 62 years)

"There was, however, somewhere else where communication was a problem, and that is what palliative care and palliative sedation actually are. And, when does palliative care actually begin?" (daughter, 62 years)

Caregivers were sometimes unable to answer the questions participants had about palliative care. According to the participants, the caregivers were not unanimous about when palliative care or sedation was to be initiated. Therefore, participants turned to other information sources, like family members or acquaintances, who also work in healthcare, to have their questions about expectations of palliative care answered.

Seven participants report that they were not always informed about changes in daily care, such as the application of restraints or changes in daily nutrition.

"When you come in and do not see a cup anywhere, [you ask], 'Has my mother drank anything today?' 'Oh, I do not know.'" (daughter, 62 years)

"Even in the beginning, I said, 'Well my mother always drinks black coffee, but she now has it with milk and sugar.' 'Yes, [her] tastes have changed' was the answer I got. Then I think, yes, I do not know much, I am not aware of dementia and how that process is going. It may well be that mother loves milk and sugar again, but that was not real. It was not obvious that they listened to the family." (daughter, 53 years)

Participants often took the initiative to learn about the situation and changes in care.

"I usually had to. We have four children and have contact with three of them. I was always the one who called about 'How is it now? What has happened? We see this with our mother, what now? What are you doing about it? What can we do about it?' So, the initiative must come from us very often." (daughter, 53 years)

The lack of information caregivers provided is, according to the participants, a consequence of being not aware of the residents' situation or difficulties talking about the end-of-life.

Participants report that the level of information provided depends on which caregivers were involved. The participants describe a need to be more adequately informed about the palliative phase, sedation and what to expect regarding the dying process.

3) Supporting loved ones

Nine participants felt that informal support from caregivers was sufficient to help them cope with their relatives' dying process and illness.

"And yes, I collapsed and started crying. Then, there were nurses right with me who took me into their arms, holding me and saying, 'Well, I get it. Let it go.'" (daughter, 59 years)

However, three participants did not feel that this was sufficient, because they did not need any support or the caregivers were less when the residents' loved ones were visiting. All of the participants regularly visited their relatives and the majority report positive relationships with the caregivers. This often contributed to being informed and receiving support. In particular support and attention to loved ones during and after warding is reported as pleasant.

"Well, and then two staff members came in when I was waking. They came and put an arm around me for a moment – just for a moment – and it did so well." (daughter, 61 years)

There was always a member of the nursing staff present for questions or to inform relatives about the care; however, the participants reported that they would have liked more frequent contact with the physicians during the last weeks of the resident's life. The participants indicated that they considered telling their story to the physician to be important. Moreover, positive notions regarding the frequency and quality of communication with physicians appeared to be an important contributor to families' satisfaction with care.

4) Challenges as proxy decision maker

All participants were proxy decision-makers for their relatives with dementia and saw their role as a challenge.

"The moment you feel like you have to go everywhere, you have to check and you are in the fight, that takes a lot of energy." (daughter, 61 years)

"I even think about, you know, things like antibiotics and the like. Yes, I think you should all think carefully about what you do." (daughter, 55 years)

One participant say it was strange to suddenly make decisions for their mother. Two participants indicated that it was sometimes difficult to break with the physicians' treatment plan.

Being involved in decisions:

Seven participants report being involved and supported in making decisions. Most decisions were made by the proxy decision-maker and caregivers. One participant reports that their relative had been involved in conversations about her treatment preferences and values regarding healthcare. The majority of participants report that their relative did not have the capacity for decision making as a consequence of cognitive decline. Some participants report that they found out that something had changed in their relative's treatment plan of which they were not aware.

"But I know that my mother reacted so badly. They had not told me that she was given Haldol, but I noticed it immediately. I said, 'She gets Haldol?' 'How do you know that?' she said. I said, 'I noticed that immediately. Would you please stop that? That is such a mess. There are other resources.' They immediately stopped it." (niece, 64 years)

Participants indicate the relevance of involving loved ones in SDM to meet the needs and wishes of the residents.

5) Starting the conversation about end-of-life wishes

This theme describes the wishes of residents and their loved ones about end-of-life care, if and how these wishes were discussed and if and how they were documented. The majority report positive experiences, but others report feelings of frustration.

ACP conversation:

Residents' wishes, that were known were discussed with their loved ones in multidisciplinary consultations. Residents were often unable to express their wishes, as a consequence of

cognitive decline. The minority of participants report that their relatives were not involved in such discussions while they were still able to do that. Participants would have appreciated it if their relatives had been more involved.

*"From the moment my mother was admitted, she was left out of everything. These conversations were about my mother, but she never joined them."
(daughter, 53 years)*

Do-not-hospitalize and do-not-resuscitate protocols have, in most cases, been discussed, although participants express concerns about the timing of this discussion.

*"And then I said, 'If she had something to say about it now, what would you do? I really do not want her to be sent to the hospital, because she is so bad that I just do not want her to go to the hospital, even with a break.' That sounds very loud, of course. And they said, 'Yes, you should talk with the doctor because we have to send someone in.' Because then, it went really well. You can say that, but I had something like that, so I find this complicated."
(daughter, 55 years)*

Participants indicate that the functional decline of the resident should have been discussed earlier, such as upon admission or when the resident was still able to make decisions. Participants reported that it is often not clear whether these wishes were actually documented. The majority of them assume that their wishes have been discussed and documented in the residents' dossier or in an electronic file.

Discussion

The findings of this study suggest that loved ones of people with dementia have both positive and negative experiences. Five important elements contribute to positive and negative experiences with end-of-life care: the caregivers' contact with residents, caregivers' efforts to inform loved ones in the final phase of their relative's life, caregivers' efforts to support loved ones, the challenges as proxy decision-maker and involving loved ones in end-of-life care decisions.

The positive experiences were most mentioned to the contact with the residents, considered as an important aspect of end-of-life communication, but insufficient information was reported as a negative experience in most cases. The results suggest that social interactions between caregivers and dementia residents are not always satisfactory but are viewed as fundamental to understanding the resident's needs. This finding is in line with Perrar et al.'s review, which argues that there is clear evidence for the urge to participate in social interactions and communications to explore residents' special needs.¹⁸ Just touching a

resident's hands is sufficient to meet the emotional support needs in our study. Moss et al. found that the caregivers viewed resident's needs for touch and holding hands (78%) as fundamental.³¹ Adequate personal attention is related to a peaceful death in most cases.¹¹ This corresponds with the finding in our study that 83% of the relatives died peacefully.

Loved ones of people with dementia feel that the provision of sufficient information by caregivers is lacking at times. The participants mentioned insufficient information about palliative care and described a need for a better understanding of palliative care. Moreover, Anderson et al. suggest that patients and families must understand what palliative care is,³² and Lawrence et al. indicate that knowledge about dementia is needed to identify and respond to physical care needs.³³ Future research should focus on estimating the relevance of caregivers' knowledge about dementia and palliative care.

Being informed about changes in residents' conditions was described as an important aspect of end-of-life communication. They also indicated that it often coheres with the staff's degree of continuity. In addition, Erel et al. found that a lack of communication with the family might inhibit the implementation of a palliative approach.⁷ Loved ones of people with dementia indicated a need for improved and more frequent contact with physicians. Previous studies have reported that loved ones want more complete information and communication regarding their relative's condition and were dismayed by the lack of contact.^{34,35} The mean FPPFC score, indicating a neutral to slightly positive ranking, corresponds to the loved ones' negative and positive experiences regarding physician communication in this study.

In this study, participants indicated that caregivers lacked ACP experience and found that the timing of ACP was crucial. Robinson et al. argue that the right time to initiate ACP is unclear to caregivers, meaning that opportunities for care planning are not provided while the resident still has the capacity to engage.³⁶

Strengths and Limitations

The rigor of the qualitative analysis was increased by using both inductive and deductive methods of analysis. Moreover, three researchers carried out the analysis independently followed by discussion for fine tuning and reaching a consensus on the themes, which contributed to the trustworthiness of the study.³⁰ This study has some limitations. The population under study was relatively small, but the sample size was adequate for qualitative analysis because data saturation was achieved.³⁷ Further research with a broader range of settings and more participants is needed to generalize the findings. The retrospective nature of this study increased the chance of recall bias; therefore, a length between six weeks and nine months between resident death and the interviews was chosen. This is in line with previous studies. DiBiasio et al. indicate that a data collection timeframe between three and nine months after resident death is recommended to reduce recall bias.³⁸ However, in the

current study, some participants could not remember everything due the time that had passed or their emotions during the final three months of their relatives' lives. In further research, a timeframe shorter than nine months will be chosen to improve recall.

Recommendations and implications

There is a need for tailored end-of-life communication for people with dementia and their loved ones that fits their circumstances and preferences. In practice, professional caregivers must start timely conversations with residents and their loved ones about their wishes regarding care and the end of life. Further research should focus on estimating the causes of insufficient information given to loved ones and whether this may connect with knowledge about dementia and palliative care.

Conclusion

This study covered bereaved loved ones' positive and negative experiences of end-of-life communication. Overall, they articulated the need to be sufficiently informed on and involved in care decisions, prognoses and palliative care. The caregivers' availability and knowledge in the final phase of life appears to be connected to positive experiences with end-of-life communication, which leads to good end-of-life care.

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Tables

Table 1:

Table 1. Family member characteristics (N=12)		
Loved ones characteristics		
Age in years (range, mean)	53-72 (61.1)	
Time since bereavement in months (range, mean)	2-8 (4,5)	
	Frequency	Frequency
Gender		
Male	3	25,0
Female	9	75,0
Age in years (range)	53-72	-
Level of education		
High school graduate	6	50,0
MBO*	2	16,7
HBO**	1	8,3
WO***	3	25,0
Relationship to resident		
Son or daughter	10	83,3
Spouse or Ex-spouse	1	8,3
Nephew or niece	1	8,3

* Equivalent to Intermediate vocational education

** Equivalent to Associate's Degree

*** Equivalent to Master's Degree

Table 2:

Table 2. Resident characteristics (N=12)		
Age in years (range, mean)	74 – 93 (86,25)	
	Frequency	Percent (%)
Gender		
Male	1	8,3
Female	11	91,7
Length of residence in nursing home setting before dying		
0 - 1 month	2	16,7
1 months - 6 months	1	8,3
6 months - 12 months	1	8,3
1 years - 2 years	5	41,7
2 years - 5 years	3	25,0
Cause of death		
Stopped eating / drinking	2	16,7
Infection	1	8,3
Complications after fall incident	1	8,3
Stroke	1	8,3
Unknown	7	58,3

Appendix I : Interview guide

1. Have the caregivers talked to you and your relative about desired (future) care?
 - a. How did you experience this conversation?
 - b. When was this first addressed? And by who?
 - c. Was it a good time to come into this or was it too early or too late?
 - d. Was your relative at that moment sufficiently able to think along and decide about it?
 - e. If not, did your relative have a (legal) representative? Who was this? Have you made these wishes known in his / her place?
 - f. If discussed, are the wishes of your relative documented as well?
 - g. Was there, in your opinion, sufficient handled to the wishes of your relative / yourself?
2. In general, how did you experience the communication with the caregivers in the last phase of your relative's life?
 - a. Were the caregivers in your eyes competent / competent in communicating with you or your relative?
 - b. Did you feel as if you were involved and listened to during the entire care process?
 - c. Did you feel emotionally supported, was there any attention for?
3. What was the cause of the death of your relative?
 - a. Did you feel sufficiently prepared for the death or was it unexpected for you? How do you think so?
 - b. Did you receive aftercare, and if so, how did you experience this aftercare after the death of your relative?
4. What would you like to have seen differently in the communication around the last phase of your relative's life? What would you like to recommend to the caregivers?