

MASTER THESIS

Planning for a future life with dementia

A qualitative study

Name/ Student number: Janine Roenhorst, 4072871
University: Utrecht University
Education: Master Study Clinical Health Sciences, Nursing Science,
University Medical Center Utrecht
Course: Research Internship 2: Master Thesis
Version/Date: Final version, 27-06-2016
Supervisor: Leontine Groen – van de Ven / Carolien Smits
Lecturer: Harmieke van Os – Medendorp
Internship: Windesheim University of Applied Science, Zwolle
Journal for publication: Journal of Advanced Nursing
Criteria for publication: max. 5000 words, Harvard reference style
Criteria for reporting: SRQR, COREQ
Reference style: Vancouver
Words: 3800
Words Dutch summary: 299
Words Abstract: 298

SAMENVATTING

Achtergrond: Advance Care Planning (ACP) biedt de mogelijkheid om de normen en waarden van de patiënt aan de basis van beslissingen aangaande hun toekomst te houden. Het wordt echter nog weinig toegepast in de dementiezorg, omdat mensen met dementie en hun mantelzorgers er de waarde niet van inzien, of niet weten hoe ze dergelijke toekomstplannen moeten maken. Om de toepassing van ACP te vergroten, dient er in een vroeg stadium van de dementie mee worden gestart. Om mensen met beginnende dementie en hun mantelzorgers hier beter in te begeleiden, moet voor gezondheidszorgprofessionals duidelijk zijn hoe deze doelgroep momenteel vorm geeft aan dit proces en hoe dat wordt ervaren.

Doel: Inzicht verkrijgen in de manieren waarop mensen met beginnende dementie en hun mantelzorgers vormgeven aan het proces van plannen voor een toekomst met dementie en hoe dat wordt ervaren.

Methoden: Een kwalitatieve, exploratieve studie werd uitgevoerd. Zes mensen met beginnende dementie en hun mantelzorgers namen deel aan de studie. Alle twaalf participanten werden individueel geïnterviewd tussen februari en juni 2016, in Nederland. Binnen deze studie werden elementen van de Grounded Theory-benadering toegepast.

Resultaten: Drie grote thema's werden geïdentificeerd, welke het dynamische proces beschrijven hoe participanten plannen voor hun toekomst. Met de tijd kunnen zij bewegen tussen alle drie thema's: 1) Vandaag is de toekomst; 2) De toekomst overwegen en 3) Anticiperen op de toekomst.

Conclusie en implicaties van de bevindingen: Een grote nadruk ligt op praktische plannen, of plannen anticiperend op fysieke achteruitgang. Moeilijke gesprekken worden doorgaans vermeden. Als persoonlijke normen en waarden aan de basis van beslissingen aangaande de toekomst moeten liggen, zal meer rekening gehouden moeten worden met cognitieve achteruitgang en het verlies van beslissingsbekwaamheid. Gezondheidszorgprofessionals moeten deze onderwerpen tactvol bespreekbaar maken en hun patiënten begeleiden in het onderzoeken van hun wensen.

Sleutelwoorden: Beginnende dementie, ACP, toekomst

ABSTRACT

Background: Advance Care Planning (ACP) offers great advantages for keeping patients' personal values and beliefs at the core of decisions regarding their future. Uptake in dementia care is low however, because persons with dementia (PWD) and their informal caregivers (IC's) do not understand the value of or know how to proceed such plans. To increase uptake, it should start earlier in the disease process. In order for health care professionals to provide better guidance to persons with Early Stage Dementia (ESD) and their IC's during this process of ACP, it should be clear how they currently give shape to this process and how it is experienced.

Aim: To gain better understanding of the ways that persons with ESD and their IC's give shape, and experience the process of planning for a future life with dementia.

Methods: A qualitative, exploratory research design was used. Six persons with ESD and their IC's participated in the study. Interviews with all twelve participants took place individually between February and June of 2016 in the Netherlands. Within this study, elements of the Grounded Theory approach were used.

Results: Three major themes were identified describing the dynamic process on how participants plan for their future. They may switch back and forth between these themes through time: 1) The future is now; 2) Considering the future and 3) Anticipating the future.

Conclusion and implications of key findings: A great focus lies on practical plans, or plans anticipating physical decline, avoiding difficult conversations. If we want personal values and beliefs to lie at the core of future decisions, then cognitive decline and the loss of decisional capacity should be considered more profoundly. Healthcare professionals should address these issues with delicacy and guide their patients in exploring their wishes.

Keywords: Dementia, early stage dementia, ACP, future

BACKGROUND

Persons with dementia (PWD) and their informal caregivers (IC's) face many decisions that need to be made while living their everyday life (1). Decisions regarding living circumstances, treatment options, finances and safety need to be made as a result of deterioration of cognitive functions affecting memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (2).

As time progresses, cognitive deterioration may affect decisional capacity of the PWD (3). A systematic review undertaken in 2014 showed that in most cases the IC takes over decision-making without – or in a limited way – involving the PWD (4). An IC is usually a spouse, family member or friend, who aids and supervises the day to day activities of a person unable to complete all tasks of daily living (5). Research shows that family members usually have a good sense of what preferences regarding these matters are important to the PWD. However, they often have difficulties in distinguishing their own values from those of the PWD (6,7). Uncertainty regarding the wishes of the PWD, not knowing which alternative is most beneficial and differing opinions or preferences amongst family members about decisions, increase the difficulty and stress associated with proxy decision making (8). From the perspective of the PWD, Fetherstonhaugh *et al.* (2013) described how being ignored in decision making made the PWD feel insignificant, as though their identity as a person was under threat (9).

Keeping the patients' values and preferences at the core of decisions and providing guidance for IC's in proxy decision making, can be realized by performing Advance Care Planning (ACP). ACP is described as a process that "involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about those preferences, often by putting them into an *advance directive*". An advance directive is a legal document that goes into effect when the patient is incapacitated and unable to speak for himself (10).

Medical- and nursing literature emphasize the need to realize a continuous communicational process of ACP, involving the patient, family members and healthcare professionals throughout the complete illness trajectory (11-15). Menne and Whitlatch (2007) found that individuals with fewer months since their diagnosis report more decision-making involvement (16). Medical decision-making capacity however, declines rapidly after mild cognitive impairment converses into dementia. These findings emphasize that ACP should start early in the disease process. Persons with early stage dementia (ESD) may experience having memory lapses, increasing trouble with planning or organizing, and having difficulties

performing tasks in social- or work settings (17), but they generally still have decisional capacity (17,18).

A recent systematic review (n=113) carried out in 2014 showed that ACP in general decreases life-sustaining treatment, increases the use of hospice and palliative care and prevents burdensome hospitalisation. Complex ACP-interventions seem to increase compliance with patients' end-of-life wishes (14). Despite these advantages, uptake of ACP within dementia care is low (19). Dickinson (2013) found that barriers of initiating ACP in dementia comprise a lack of knowledge and awareness, difficulty in finding the right time, a preference for informal plans over written documentation and a lack of support to make choices about future healthcare (20). Furthermore, although most general practitioners think that early discussions would facilitate decision making during advanced dementia, they are divided whether to initiate ACP at the time of diagnosis (21).

It is known through research that IC's tend to own a pro-active, reactive or inactive decision style when it comes to making decisions about the future (22). This may indicate that persons with ESD and their IC's also give shape to the process of planning for their future in different ways. Research also indicated that guidance by a professional contributes to the PWD and their IC's in making decisions regarding their future (23). However, in order for healthcare professionals to provide guidance in planning for their future that is tailored to the individual needs of their patients, more insight is needed in the different ways in which they currently shape this process, and how it is experienced. This knowledge is now lacking.

AIM

The aim of this study is to gain a deeper understanding of the ways that persons with ESD and their IC's give shape to and experience the process of planning for a future life with dementia. With this knowledge, factors that play a role regarding why people plan for a future life with dementia in a particular way may be identified.

METHODS

Design

In order to gain in-depth information on how people with ESD and their IC's give shape and experience the process of planning for a future life with dementia, a research design was needed that uses flexible methods and enables contact with the participants (24). This study therefore used a qualitative exploratory research design with elements of the Grounded Theory (GT) approach, enabling an iterative process of data collection and analysis (25).

Participants

This study focussed on persons with ESD (from this point onwards: PWD) and their IC's. Although including PWD in research may pose challenges, the views of persons with dementia are essential in trying to construct the reality of living with this disease (26). Six couples, all comprising of one PWD and one IC, were selected through purposeful sampling, via a case managers' network and a physician of an outpatient memory clinic in (the area of) Zwolle, the Netherlands. Variation was sought in the relationship of the IC with the PWD, age and sex of the PWD and the IC, level of education, and the amount of time that has passed since the diagnosis was received.

The PWD was eligible for participation if there was a diagnosis of ESD, if he/she had an understanding of the Dutch language and the ability to participate in a conversation. The IC was considered eligible for participation if he/she was primarily involved in the care for the PWD.

A PWD was excluded from participation if there were severe behavioural problems (i.e. verbal or physical aggression) or symptoms of a psychiatric disorder (e.g. delirium or depression) prominently present, for this may have interfered with data collection and result in bias.

Eligible participants received an informational letter and informed consent forms, through their case manager or memory clinic physician. They were asked for their consent to be approached by the researcher. If consent was given, the researcher contacted them by telephone, asking them if they had read the informational letter and if they had decided on participating. This also gave participants and the researcher the opportunity to ask additional questions and set interview appointments.

Data collection

Twelve semi-structured interviews were conducted between March and May 2016, lasting between 20 and 90 minutes. Prior to the interviews, demographical information on age, educational level, time since diagnosis and kinship was obtained. An pilot tested interview guide (see Box 1) with possible questions was used to make sure that similar topics are

discussed throughout the study (27). It was slightly changed after six interviews, providing more focus from the start of the interviews.

The interviews took place at the interviewees homes in all cases but one, and were held separately so that participants felt safe to talk freely. In two cases, a PWD was interviewed in the presence of the IC, because it made them feel more secure. In all cases but one, the IC was interviewed first so that facts could be gathered before interviewing the PWD, as factual questions are often the most difficult for a PWD (28).

For the researcher to be able to establish rapport, approximately one and a half hour was reserved for every interview so that there was time to set the interviewee at ease, gain trust and take a pause if needed (29). Field notes were made during and right after the interviews.

Place here: Box 1 Interview guide

Data analysis

Analysis was guided by the Qualitative Analysis Guide of Leuven (QUAGOL) method (30), which uses GT-principles such as constant comparison and open- axial- and selective coding (25). Analysis started right after the first steps in data collection were made. Interviews were audio-taped and transcribed verbatim to ensure trustworthiness and transferability of the results (27). Emerging ideas from data analysis further guided data collection, creating an iterative process.

Analysis consisted of two alternating phases. First, the researcher performed a thorough preparation by reading and re-reading the interview transcripts and writing narrative interview reports. This helped to familiarize with the data.

Second, the actual coding process took place by highlighting meaningful segments in the transcripts and adding a code that does not include any interpretation yet. This resulted in a list of 'open codes'. During the complete coding process, writing memos ensured that decisions and thoughts regarding this process were properly documented. After the formation of the initial code set, open codes were rearranged and clustered, together forming a shorter list of concepts and their meaning, dimensions and characteristics.

The last step in the coding process comprised of integrating the concepts into a meaningful conceptual framework in response to the research question.

To provide transparency during the coding process, NVIVO 11 was used.

Rigour

To obtain rigour, the transcript of the first interview was presented for feedback on interviewing techniques to an experienced researcher (LG), after which interviewing techniques were optimized. The first three interviews were coded independently by a second

researcher (ED) experienced in working with PWD. The final results of the coding process were discussed with both researchers (LG, ED) and further optimized, adding to the trustworthiness of the research (27).

Ethical considerations

Permission to conduct this study was provided by the local research ethics committee. Prior to the interviews, informed consent was given by all participants. For the PWD, consent was also provided by the IC.

RESULTS

The sample consisted of six PWD, males and females, and their IC's. Variation was achieved on all aspects except kinship, because all but one IC were spouses. Ages ranged from 53 to 86 years. Educational levels varied from primary school to university. The time since being diagnosed varied from three months to four years. For further details on participant characteristics, see table 1.

Three major themes emerged from the collected data: 1) The future is now; 2) Considering the future and 3) Anticipating the future. In the corresponding tables 2-4, quotes of the major themes and their subthemes are provided. Although three major themes are identified, participants do not necessarily engage in only one of these themes. They may switch back and forth through time, making it a dynamic process.

Place here: Table 1 Demographical characteristics

The future is now

Participants gave many reasons why they focus on the present. Three subthemes were identified: 'No need for planning', 'uncertainties about planning' and 'consciously not planning'.

Participants that experience *no need for planning*, describe how they live day by day as a result of the fickleness of their situation. They deal with the future by owning a 'time will tell'-attitude. They feel that it is not necessary to plan ahead because everything is fine at this moment. Therefore, they are not aware of possible plans to make. Both PWD and IC's tend to put focus on the tasks that the PWD is still able to carry out and they try to hold on to the things that are familiar to them. If an important decision should be made in the future, they seem to rely on an authority – e.g. children, doctor, nurse – as if they do not need to have a say in the matter. One couple stated that they resign on their faith and lay their future in the hands of God; a way of dealing with uncertainties that seems to be their way of life.

Participants experiencing *uncertainties about planning* describe how they see the future as unsure and unpredictable, keeping them from planning ahead. Some are not aware that there are plans to make preparing for the future, others are aware but do not know which plans to make or how to make them. One IC explains that she is not good in judging nursing homes and therefore suspects not to be of value in this matter. One PWD explains feeling unsure about making plans, because he is afraid that he cannot change his mind in the future when he no longer has decisional capacity. He also feels that dementia and the future are two opposites which he does not know how to combine.

Participants that *consciously decide not to plan* gave several reasons: Some feel that it is not worthwhile making plans because everything can change. They prefer to hold on to the things they have right now. IC's expect planning for the future to be too burdensome and are afraid to upset the PWD. They try to avoid confrontation by not talking about the subject. For this reason, one IC thinks that it is better to wait with certain decisions until the PWD cannot understand their meaning anymore. Another IC does not make plans regarding future treatment-decisions because he finds it only natural for the doctor to treat conditions without limitations.

Place here: Table 2 The future is now

Considering the future

Two subthemes describe how participants consider the future: 'Expectations of the future' and 'considering planning'.

When participants talk about their *expectations of the future*, they describe how they expect not knowing anything anymore. One PWD called it 'disappearing'. They fear that they forget who their family is, being submitted to a closed ward and losing their freedom. These expectations seem to be negatively influenced by experiences with dementia they have through acquaintances. Although in general participants have these negative expectations of the future, they perceive their own future as 'unclear'.

Participants also *consider making plans* that allow them to prepare for the expectations they have of their future. These plans generally focus on complicated subjects such as representation for the PWD, how far to go in treatment and home-care, possible nursing homes, wishes regarding end-of-life care or the funeral or drawing up a life testament. These plans however, are mostly considered by the IC's. PWD tend to focus on the desires they still have for the future, such as going on holidays, seeing their grandchildren grow older and staying a pleasant person. One PWD mentions how she wants to make sure that her partner stays behind taking care for. An important factor that seems to keep the participants

from actually bringing the intentions to put plans into practice, is awaiting the right time.

Place here: Table 3 Considering the future

Anticipating the future

Five subthemes describe how participants anticipate the future: 'Value of planning', 'open communication', 'process of planning', 'plans made for the future' and 'experiences with planning'.

Participants who see the *value of planning*, find it important to 'handle their affairs well'. They do not want to burden others, especially their children, with difficult decisions. They also see it as a way of staying in control of one's own life.

Those who are open to planning for the future, *communicate* about it openly. IC's mention how they introduce a certain subject as soon as they see an occasion to do so, for example a step backwards in the functioning of the PWD. Deterioration of physical functioning also seems to be common reason for participants to start a conversation about planning, possibly because it is more acceptable or understandable than cognitive decline.

They sometimes try to enlighten the conversation by talking about it while undertaking activities. IC's try to start the conversation by addressing the subject casually. Their goal is to discuss and make plans together.

While discussing the *process of planning*, one couple stressed the importance to set things in motion on time, because of the possibility of discussing things together. Others were urged by their practitioner to make plans. IC's and PWD feel that 'the right time' for planning usually occurs when something changes for the worse in the situation of the PWD. However, they cannot foresee when this will happen. Sometimes, friends or family are asked for advice, and one PWD mentions that he 'relies on his gut feeling'. However, he would like to have tools for planning.

Plans made for the future are mainly of practical nature, requiring little thought on personal values or opinions. Practical plans were arranging power of attorney, drawing up a will, deciding on where to move if necessary, putting in writing their wishes regarding the funeral, adjusting the interior of the house to care-needs, cleaning up the attic, handing over finances, and testing and monitoring driving-skills. Not all plans were made anticipating cognitive deterioration, but also because one was getting older. Some care-related plans were made as well, including putting in writing their wishes regarding treatment and care, but also deciding not to receive life-prolonging treatments such as resuscitation. Often, these plans were made anticipating physical- rather than cognitive deterioration.

Experiences with planning vary among participants and was seemingly influenced by interaction. One participant feels taken by surprise by his doctors decision not to resuscitate and states that it came too early. This impacted him greatly as he did not make the decision himself. His partner however feels relieved that she did not have to bring up the subject. One couple started making plans on their own initiative. They mention that it feels good to talk about their wishes together.

Place here: Table 4 Anticipating the future

DISCUSSION

This study provides new insights in the ways that PWD and their IC's make plans for a future with dementia. One way is (more or less) consciously choosing not to plan, preferring not to think about problems that haven't occurred yet. Another way is considering making plans, although the right time has not been identified yet. A third way is actually making plans attempting to anticipate future decisions. The plans that are made are often of practical nature, sometimes made anticipating cognitive deterioration, but also because of old age. Care-related plans were more often made anticipating physical deterioration.

Several factors influencing the initiation of ACP found in this study, were also found in other populations. First, this study shows how participants prefer to live day by day. This focus on the present is also described in a population of housebound, chronically ill elderly people who were asked how they perceive their future (31). This preference of focussing on the present is in contrast with the principle that ACP is based on: considering decisions ahead of time. Second, the reliance on an 'authority' to make care-decisions for the PWD and their IC's is why participants in this study don't perceive necessity to plan ahead. Similar statements were made in a study involving community nurses caring for elderly people, who indicate that their patients rely on family members or a trusted health professional to make decisions in their 'best interest' (32). These findings may indicate that old age influences the degree in which persons want to keep control over the care that they receive in the future. Another explanation may be the fact that the current generation of elders is accustomed to living in a 'welfare state' (33). This might cause them to adopt a more awaiting attitude towards the future and their needs.

Third, identifying the right time appeared to be a decisive factor of engaging in ACP. Participants have difficulties identifying *when* it is considered the right time for making such plans, because they perceive their future as unpredictable. Two other studies describe that doctors and community nurses have the same struggle of identifying the right time (20,34). This may cause missing out on opportunities in involving the PWD in decisions

regarding the future.

Some participants in this study somehow did find the right time, as they already made plans preparing for their future. It is noticeable however that these plans are mostly of a practical nature, or they are placed in a context of physical deterioration. The consequences of dementia for the cognitive functioning, the ability to express values and opinions, and the capacity to make care decisions, did not seem to be a subject of debate. This may be founded in the taboo or stigma that lies on dementia (35), or in the way that people cope with having an illness (36). Although it is understandable that they want to avoid distress by not talking about problems that might occur, it prevents them from truly considering how their values and beliefs can be at the core of future decisions.

To appreciate the findings of this study, some aspects require further consideration. First, although including co-morbidities made the sample reflect the actual population in a better way, maximum variation could not be achieved on kinship. Therefore, data saturation could only partially be achieved. Second, after analyzing the data, no member check was undertaken. This might have disadvantaged the credibility of the findings (27). Finally, the scope of this study was restricted with twelve interviews, limiting the possibility of verifying the results and obtaining data saturation.

By contrast, this study possesses several strong aspects. First, participants were candid and sincere, and they showed a strong voice while sharing their experiences. Second, by discussing the results of the data-analysis several times with two independent researchers (ED, LG) valuable insights were obtained. With these valuable insights, this study adds to the body of knowledge of the ways in which PWD and their IC's make plans for a future life with dementia and how they experience this process. Additionally, this knowledge can be used as a first step in developing a typology (37). A typology on planning for a future life with dementia may help healthcare professionals identify what guidance their patients need.

Conclusion & Recommendations

The description of the three major themes provide more insight in the ways that PWD and their IC's make plans for their future and how this is experienced. It was found that a great focus lies on practical arrangements and most care-related plans are made anticipating physical – and not cognitive – deterioration. Interaction between the PWD and the IC seems to influence the way of planning extensively. If we want personal values and beliefs to lie at the core of future decisions, cognitive decline and the loss of decisional capacity should be considered in a more profound way. The reluctance communicating about the future and the lack of awareness regarding ACP, hinders this process. This is where healthcare professionals can be of value; by addressing these issues with delicacy, and guiding their patients in exploring their wishes. Healthcare professionals should be trained in guiding this

process, especially in identifying 'the right time'. Factors such as age, coping strategies, feelings of stigma and identifying the right time seem to play a role regarding why people plan in a certain way. When developing a typology on planning for the future, these factors should be further explored.

DECLARATION OF CONFLICTING INTERESTS

The author declares that there are no conflicts of interest.

ACKNOWLEDGEMENTS

The author thanks the participants for welcoming the author into their homes and for their openness during the interviews.

REFERENCES

- (1) Alzheimer's Society. **Making decisions and managing difficult situations** 2014; Available at: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2298. Accessed November 15th, 2015.
- (2) World Health Organisation. Factsheet Dementia. March, 2015; Available at: <http://www.who.int/mediacentre/factsheets/fs362/en/>. Accessed October 6th, 2015.
- (3) Mitoku K, Shimanouchi S. The decision-making and communication capacities of older adults with dementia: a population-based study. *Open Nurs J* 2014 Jun 13;8:17-24.
- (4) Taghizadeh Larsson A, Osterholm JH. How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings. *Int Psychogeriatr* 2014 Nov;26(11):1849-1862.
- (5) Savage S, Bailey S. The impact of caring on caregivers' mental health: a review of the literature. *Aust Health Rev* 2004;27(1):111-117.
- (6) Hirschman KB, Kapo JM, Karlawish JH. Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person? *Am J Geriatr Psychiatry* 2006 Aug;14(8):659-667.
- (7) Ayalon L, Bachner YG, Dwolatzky T, Heinik J. Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses. *Int Psychogeriatr* 2012 Nov;24(11):1798-1804.
- (8) Samsi K, Manthorpe J. Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatr* 2013 Jun;25(6):949-961.
- (9) Fetherstonhaugh D, Tarzia L, Nay R. Being central to decision making means I am still here!: the essence of decision making for people with dementia. *J Aging Stud* 2013 Apr;27(2):143-150.
- (10) National Institute on Aging. *Advance Care Planning*. 2012; Available at: <https://www.nia.nih.gov/health/publication/advance-care-planning>. Accessed October 8th, 2015.
- (11) Gillick MR. Adapting advance medical planning for the nursing home. *J Palliat Med* 2004 Apr;7(2):357-361.
- (12) Teno JM. *Advance care planning for frail, older persons*. Geriatric Palliative Care New York: Oxford University Press, Inc.; 2003. p. 307-313.
- (13) Karel MJ, Moye J, Bank A, Azar AR. Three methods of assessing values for advance care planning: comparing persons with and without dementia. *J Aging Health* 2007 Feb;19(1):123-151.
- (14) Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014 Sep;28(8):1000-1025.
- (15) Lovell A, Yates P. Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012. *Palliat Med* 2014 Sep;28(8):1026-1035.
- (16) Menne HL, Whitlatch CJ. Decision-making involvement of individuals with dementia. *Gerontologist* 2007 Dec;47(6):810-819.

- (17) Alzheimer's Association. Stages of Alzheimer's. 2016; Available at: http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp#mild. Accessed April 28th, 2016.
- (18) Mitoku K, Shimanouchi S. The decision-making and communication capacities of older adults with dementia: a population-based study. *Open Nurs J* 2014 Jun 13;8:17-24.
- (19) Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliëns L. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *Int Psychogeriatr* 2012 Jul;24(7):1133-1143.
- (20) Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr* 2013 Dec;25(12):2011-2021.
- (21) Brazil K, Carter G, Galway K, Watson M, van der Steen JT. General practitioners perceptions on advance care planning for patients living with dementia. *BMC Palliat Care* 2015 Apr 23;14:14-015-0019-x.
- (22) Wackerbarth SB. The Alzheimer's Family Caregiver as Decision Maker: A Typology of Decision Styles. *Journal of Applied Gerontology* 2002;21(3):314-315-332.
- (23) van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliëns L, de Boer ME, et al. Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis* 2014;40(3):743-757.
- (24) Boeije H. Introduction to qualitative research. Analysis in qualitative research. 1st ed. London: SAGE Publications Ltd; 2010. p. 13.
- (25) Creswell JW. Five Qualitative Approaches to Inquiry. *Qualitative Inquiry and Research Design, Choosing Among Five Approaches*. 3rd ed. Thousand Oaks, California: SAGE Publications, Inc; 2013. p. 83-84-89.
- (26) Cotrell V, Schulz R. The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research. *Gerontologist* 1993 Apr;33(2):205-211.
- (27) Holloway I, Wheeler S. *Qualitative Research in Nursing and Healthcare*. Third ed. Chichester: Blackwell Publishing Ltd; 2010.
- (28) Hubbard G, Downs MG, Tester S. Including older people with dementia in research: challenges and strategies. *Aging Ment Health* 2003 Sep;7(5):351-362.
- (29) Polit DF, Beck CT. *Data Collection in Qualitative Research. Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 9th ed. Philadelphia: Wolters Kluwer Health | Lippincott Williams & Wilkins; 2012. p. 542-543.
- (30) Dierckx de Casterle B, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud* 2012 Mar;49(3):360-371.
- (31) Carrese JA, Mullaney JL, Faden RR, Finucane TE. Planning for death but not serious future illness: qualitative study of housebound elderly patients. *BMJ* 2002 Jul 20;325(7356):125.
- (32) Seymour J, Almack K, Kennedy S. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliat Care* 2010 Apr 8;9:4-684X-9-4.
- (33) Smits CH, van den Beld HK, Aartsen MJ, Schroots JJ. Aging in the Netherlands: state of the art and science. *Gerontologist* 2014 Jun;54(3):335-343.

(34) Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliat Med* 2013 May;27(5):401-408.

(35) Burgener SC, Buckwalter K, Perkhounkova Y, Liu MF, Riley R, Einhorn CJ, et al. Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia (London)* 2015 Sep;14(5):589-608.

(36) Ferguson E, Cox T. The Functional Dimensions of Coping scale: Theory, reliability and validity. *British Journal of Health Psychology* 1997;2(2):109-129.

(37) Jansen H. Typologieconstructie: tussen euforie en empirie. 2016; Available at: https://www.tijdschriftkwalon.nl/inhoud/tijdschrift_artikel/KW-16-3-6/Typologieconstructie-tussen-euforie-en-empirie. Accessed May, 28th, 2016.

Box 1. Interview guide

Topic	Possible Questions
Expectations of the future	<ul style="list-style-type: none"> Hoe ziet u de toekomst? Hoe verwacht u dat deze zal verlopen?
Possible decisions or plans	<ul style="list-style-type: none"> Hebt u wel eens nagedacht over welke belangrijke beslissingen/plannen er t.a.v. een toekomst met dementie genomen moeten worden? Waar denkt u dan aan, welke zijn dat dan volgens u? (bv verpleeghuis, behandelbeleid, financiën, autorijden)
Needs and wishes	<ul style="list-style-type: none"> Zou u (als) PWD betrekken (betrokken willen worden) in beslissingen aangaande de toekomst? Waarom wel/niet? Wat zijn dingen die u nog graag geregeld wilt hebben voor de toekomst, voor als PWD daarover niet meer kan beslissen? Kunt u voorbeelden geven? Wat denkt u nodig te hebben, wat vindt u belangrijk, om de toekomst met vertrouwen tegemoet te gaan? Wat is volgens u het juiste moment om dingen te gaan regelen?
Plans made	<ul style="list-style-type: none"> Bereidt u zich al voor op deze belangrijke beslissingen? Hoe dan? (Afhankelijk van voorgaande): Welke plannen heeft u al gemaakt? Wat is er afgesproken of vastgelegd? Denkt u wel eens na over de grenzen van behandeling; tot hoever gaan we? (bv palliatief of symptomatisch beleid, niet reanimeren). Is dat besproken met partner?
Proces	<ul style="list-style-type: none"> Was er een aanleiding of een moment in de tijd waarop u besloot plannen te maken? Hoe is dat verlopen? Wie deed wat, hoe was rolverdeling? Hoe was betrokkenheid Welke beslissingen hebt u daarvoor moeten maken? Hoe deed u dat, wat was uw rol? En hoe ervaaarde u dat? Bij geen betrokkenheid PWD → Op welk moment, kunt u dat aanwijzen, betrok u uw partner niet meer bij belangrijke beslissingen?

Table 1. Participant characteristics

Participant ¹	Sex ²	Age (years)	Education ³	Time since diagnosis	Kinship IC	Caregiving situation
PWD1	M	53	High	4 years		Living in NH
IC1	F	?	High		Spouse	Living with children
PWD2	F	84	Low	6 months		Living with spouse
IC2	M	86	Middle		Spouse	
PWD3	F	77	Low	6 months		Living with spouse
IC3	M	77	Low		Spouse	
PWD4	M	76	High	4 years		Living with spouse
IC4	F	75	High		Spouse	
PWD5	F	84	Low	2,5 years		Living alone
IC5	F	64	Low		Daughter	
PWD6	F	61	Low	3 months		Living with spouse
IC6	M	70	Low		Spouse	

¹ PWD = person with dementia, IC = informal caregiver

² M = male; F = female

³ Low: primary school, lower secondary general, lower vocational. Middle: higher secondary general education, intermediate vocational education. High: higher vocational education, University.

Table 2. The future is now

Subtheme	Data
No need for planning	<p>JR: Are there particular plans that you made, for the future in case your wife's dementia further declines? IC2: No, no, no... because it depends on the circumstances. I'm sure there are rules for how that goes. You'll be admitted to a nursing home, on some kind of ward. I cannot influence that.</p> <p>JR: Hearing about the diagnosis of dementia... Did that make you think about the future more? PWD2: The future, well... no I don't think so. I'll wait and see. We don't know. Fortunately, we can lay or faith in the hands of God, ask him to provide guidance, for me to stay with it a bit longer.</p> <p>JR: And are there more situations about the future that you might discuss with your mother? IC5: No, not so many situations actually, no... there aren't so many things to discuss because well, everything goes smoothly really!</p> <p>IC6: Nothing much has changed really, at first you just go with the flow, like you did. You still don't notice much about her, so then you don't start doing... other things.</p>
Uncertainties about planning	<p>IC4: It's hard, the idea, you don't know, it could last a year, or five years, you don't know, it's a process that worsens step-by-step but you don't know if the steps are long or short and so I think, let's just try and enjoy our time together because it will end one day.</p> <p>PWD1: What I wonder is... whether to ask the question... so I'm curious about what you're going to find out because I can't... I can't imagine how to map out that route... [of making plans]</p> <p>JR: If things won't work out at home anymore, and she needs to be submitted in a nursing home, how would you decide on a nursing home? IC5: I'm not a good judge of that, so I won't say "mother is suitable for this or that nursing home"... So, I don't know yet.</p> <p>PWD6: No, I think I should discuss it with him some time, but frankly I don't actually know what to discuss. Everything is in order, kind of. So for me it's just waiting really, for something to change in my head, you see, and then it's a different situation.</p>
Consciously not planning	<p>PWD1: It makes you, in a way, because it makes your future so difficult... difficult to shape... it makes you avoid further detailing it.</p> <p>IC5: I think it's very admirable that she wants that [living independently] and she tries her best to realize it. Because she does her housekeeping, and when I visit her, she says "look at me! I cleaned this and that, and I even cleaned the skirting-boards!" No, there can't be dust on the skirting-boards. And then she says "I did it all by myself, even if I have to drop on my knees! I will maintain it you know!" You know... because she's afraid that she... she doesn't want to be placed into care...</p> <p>JR: Does that experience [with relatives] make you prefer not to think about what the future might bring? IC2: You can't live anymore, if you think about that. You won't be able to live a day longer. You will collapse I think. Right? You have to.... No, that's no way to live.</p> <p>JR: Have you ever talked with your daughter, or the family practitioner about the future, whether certain things need to be put in writing, in case your wife can't express her wishes anymore? IC3: No, no... actually I'm afraid to already... Like I said, I think it would do no good talking about it already or whatever, because I think that she wouldn't want to... I'm afraid to... No, I don't think so.</p> <p>IC6: I don't know how she would react to those conversations, I haven't gone down that road yet. To be honest, I kind of fear talking to her about it already, I'm afraid I'll talk her down.</p>

*Abbreviations: PWD = Person With Dementia IC = Informal Caregiver JR = Executive investigator

Table 3. Considering the future

Subtheme	Data
Expectations of the future	<p>PWD3: I expect not knowing much anymore... that's what I see in mind really, that I'd be really... how should I put it... I see everything passing by me without noticing... That I don't understand much of what they're saying anymore... yes, something like that, I don't know...</p> <p>IC1: The bizarre thing is... my mother has Alzheimers... my father took care of her for a long time, so in a way we walked that road at the same time because my mother deteriorated at the same time my husband got sick. And so a really saw my father go downhill and he would give up everything for my mother, but I am younger. When my husband got the diagnosis [dementia], I thought hard about, well... how far to go. Because I know that that isn't possible [giving up everything]...</p>
Considering planning	<p>IC1: For years I've been trying to find out, what do you want? How far will you let – at the time he didn't have dementia – the physical deterioration go and.. he's in much pain, so, what can you take? What's your boundary? Because there is one, only he's reluctant to put it in writing because he's afraid to give up control. I'm just saying, if it's necessary, and If you want to, than I have to be able to put it into practice so you need to write it down. Especially now, you need to write it down, because later on you won't be taken seriously anymore, and then I have a problem...</p> <p>IC4: Of course what you also think about is how you want to.. this might seem odd... but of course it isn't, but how would you want your funeral or cremation to take place? My husband wanted to be buried for a long time, but now he knows he wants to be cremated. And those are good things to know about each other.</p> <p>PWD4: We have a testament. The other person gets authorities when you pass away. But a life testament is for the period before that. So that means that your decisional capacity... you need to go to the notary to decide how do we deal with that...Because your partner will take things over.</p>

*Abbreviations: PWD = Person With Dementia IC = Informal Caregiver JR = Executive investigator

Table 4. Anticipating the future

Subtheme	Data
Value of planning	PWD4: When you get dementia, you try to hold on to the steering wheel for as long as possible. I don't want to be taken away drifting, like a piece of drifting wood, not knowing where you end up. I want to know.
Open communication	IC4: One friend is being cared for here, another there, well and then my husband says "definitely not here, or there", and he might end up somewhere else but we do discuss it. But not that were discussing it at night on the couch, like "what do you think, should I give notice?" No, we don't do that. Situations grow. They need time to be discussible. JR: How was it for you to talk about your wishes regarding treatment? PWD4: Well, acceptable. See, life comes and life goes and you try to visualize that for yourself, but also for your partner. So yes, it feels good.
Proces of planning	PWD4: You shouldn't let it take you by surprise. So 'time will tell' doesn't mean that you should wait until you drop, and then you move, you need to stay on it and keep monitoring carefully. IC1: Well, yes being able to give consent... you need to think about that, it is important to think about such things in a relatively calm period, and not to wait until it is inevitable because then you're in a different situation and you probably can't think things through well enough, so in that case it's good to deal with such things. PWD6: If I start noticing things, if this is not good or that is not good, then you start thinking ok, now it all starts [planning ahead].
Plans made for the future	IC2: I've talked about it with my son [inheritance]. I've showed him how it should be done, how we want it to be divided. Well there is not much to divide, but certain things, it's about sentimental things of course. PWD1: We agreed that I won't be resuscitated on medical grounds. If they would help that hart, with the dementia, it's chanceless. You won't recognize anyone anymore and be, well... out of control...
Experiences with planning	PWD1: The funny thing is... I didn't have tears then... That night, it all came out, but at that moment, it didn't. All I thought was, you won't do this to me. I need to stick to my gun. JR: I understand that you said to the practitioner that you don't want all the bells and whistles anymore. How did you feel about that? PWD5: I felt relieved.

*Abbreviations: PWD = Person With Dementia IC = Informal Caregiver JR = Executive investigator

Appendix 1 Code Tree

Subtheme	The Future is Now	
Uncertainties about planning	Lack of understanding	
	Lack of Know-How	Future vs. Dementia – opposite poles Not knowing what to expect No knowledge about nursing homes
No need for planning	Trusting on the support of the children	
	Seize the day	
	Laying future decisions in the hands of an authority	
	Old age influences thinking about the future	
	Time will tell	
	No added value as a result of fickleness	
	Not much to plan	
	Resigning in one's faith	
	Everything's ok now	
Accepting attitude, trying to make the best of it		
Consciously not planning	Waiting with planning until the PWD doesn't understand anymore	
	Planning is no good	
	Talking about NH is to burdensome	
	Thinking about problems in the future is doom-mongering	
	Thinking or talking about the future is avoided	
	Holding on to what's in the present	
	Wanting to be treated	
	Affraid of confrontation	

Subtheme	Considering the Future
Expectations of the Future	<ul style="list-style-type: none"> The future is decided The future is unclear Fearing the future Experiences with acquaintances influence expectations
Considering planning	<ul style="list-style-type: none"> Wishes regarding the end of life Thinking about a future NH Thinking about wishes regarding the funeral Thinking about representation / agency Thinking about a life testament Thinking about the boundaries of caring Thinking about the boundaries of treatment Future Desires (PWD)
Subtheme	Anticipating the Future
Value of planning	<ul style="list-style-type: none"> Staying in control Not burdening another with difficult decisions Important to handle affairs well
Open communication	<ul style="list-style-type: none"> Changing roles Mutual agreement Talking together, deciding together Talking about the future occurs casually Turningpoint in the relationship regarding equality To be well prepared Discussing euthanasia Planting seeds (on a subject)
Proces of planning	<ul style="list-style-type: none"> Exchanging thoughts about planning with family/friends Setting something in motion on time Planning initiated by another

