

Planning for the future: decision-making in people with early stage dementia

A qualitative design

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SAMENVATTING

Titel Plannen voor de toekomst: het maken van beslissingen door mensen met beginnende dementie

Achtergrond Mensen met dementie en hun mantelzorgers komen voor verschillende beslissingen te staan. Het is belangrijk om mensen met dementie vroeg te betrekken in het besluitvormingsproces, omdat ze uiteindelijk het vermogen verliezen om betekenisvolle beslissingen te maken. Professionals kunnen hieraan bijdragen, maar vinden het vaak een uitdaging om mensen met dementie in dit proces te betrekken. Daarom hebben professionals kennis nodig over hoe mensen met dementie en hun mantelzorgers zich voorbereiden op de toekomst.

Doel Inzicht krijgen in hoe mensen met beginnende dementie en hun mantelzorgers zich voorbereiden op de verschillende beslissingen die zij tegenkomen gedurende het ziekteproces.

Methode Het onderzoek heeft een generiek kwalitatief design, met een thematische analyse. Halfgestructureerde interviews met personen met dementie en hun mantelzorger zijn uitgevoerd.

Resultaten Hoe mensen met dementie en hun mantelzorgers zich voorbereiden op beslissingen kan worden verdeeld in vijf fasen: 1) Beslissingen zijn nog niet aan de orde; 2) Nadenken over mogelijkheden voor beslissingen; 3) Mogelijkheden voor beslissingen besproken; 4) Wensen voor beslissingen besproken; 5) Beslissingen gemaakt voor de toekomst. Een belemmerende factor in het besluitvormingsproces is dat mensen met dementie aannemen dat mantelzorgers of professionals de beslissingen voor hen maken als het nodig is. Een bevorderende factor is dat professionals het initiatief nemen door het benoemen van belangrijke onderwerpen.

Conclusie en aanbevelingen De vijf fasen en beïnvloedende factoren geven inzicht in hoe mensen met dementie en hun mantelzorgers beslissingen maken voor de toekomst. Professionals hebben een belangrijke rol in het benoemen van belangrijke beslissingen. Verder onderzoek is nodig om inzicht te krijgen in hoe professionals mensen met dementie het best kunnen begeleiden bij het voorbereiden op de toekomst, door ze in een vroeg stadium van het ziekteproces te betrekken in het maken van hun eigen beslissingen.

Sleutelwoorden Beginnende dementie, Mantelzorgers, Gezamenlijke besluitvorming, Advanced Care Planning

ABSTRACT

Title Planning for the future: decision-making in people with early stage dementia

Background People with dementia and their informal caregivers have to make various decisions about difficulties they will encounter in living with dementia. It is important to engage people with dementia early on in the decision-making process, because they lose the capacity to make meaningful decisions. Professionals can contribute this, but find it often a challenge to involve people with dementia. Therefore, professionals need knowledge about how people with dementia and their informal caregiver prepare for decisions.

Aim To get insight into how people with early stage dementia and their informal caregivers prepare for various decisions they encounter over the course of the dementia trajectory.

Method The study has a generic qualitative descriptive design, using thematic analysis. Semi-structured interviews with people with dementia and their informal caregivers were conducted.

Results How people with dementia and their informal caregivers prepare for decisions can be divided into five phases: 1) Decisions have not been discussed; 2) Thinking about possibilities for decisions; 3) Discussed possibilities for decisions; 4) Discussed wishes for decisions; 5) Decisions arranged for the future. A barrier for preparation is that people with dementia assume that informal caregivers or professionals will make decisions for them when necessary. A facilitator for preparation is that the professional takes initiative by bringing up important decision categories.

Conclusions and recommendations The five phases and influencing factors provide more insight in how people with dementia and their informal caregivers make decisions about the future. Professionals have an important role in bringing up important decisions. Further research is necessary to show how professionals can support people with dementia to prepare for the future in an early stage of the dementia trajectory, so people with dementia have the opportunity to be involved in the decision-making process.

Key words Early stage dementia, Informal Caregivers, Shared decision-making, Advanced Care Planning

BACKGROUND

Dementia is a general term for mental decline caused by damage in the brains as a result of a disease(1). The most common causes of dementia are Alzheimer's disease, vascular dementia, dementia with Lewey bodies and Frontotemporal dementia(2). All causes have a progressive nature, symptoms will gradually get worse(1). In general, the course of the dementia trajectory is divided into early, middle and late stage(3). In the early stage, people experience decreased memory of recent events(3). People in the middle stage have major memory problems and need some assistance to complete daily activities(3). In the late stage, people have no ability to communicate and need assistance with most activities(3).

In 2016 there were more than 260 000 people with dementia (PWD) and more than 300 000 informal caregivers (IC's) for PWD in the Netherlands(4). An IC can be defined as '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).

PWD and their IC's have to make various decisions over the course of the dementia trajectory(6). Groen et al.(6) described categories PWD and their IC's make decisions about, these categories are: Self-care, i.e. activities of daily living; Structuring the day, i.e. day care, daily rhythm; Mobility, i.e. driving a car, going out alone; Handling finances, i.e. handling money, shopping; Arranging professional care, i.e. case management, home care; Living arrangements, i.e. house adjustments to care-needs, being admitted to a nursing home; Representing the person with dementia, i.e. involving care network members in decision-making; Decisions at the end of life, i.e. living will, arrangements for the funeral.

PWD are rarely asked about their preferences about future decisions(7), although they are often willing and able to state their values and preferences(8)(9). A study of Mitoku(10) showed that around one-third of PWD were able to participate in their care decisions. Generally, IC's want to respect the autonomy of PWD as long as possible(11). They are often aware that thinking ahead about decisions allows PWD a voice in these matters and that this approach respects their autonomy(12). However, it seems to be a challenge to involve PWD in a way that suits their capabilities(12). IC's often indicate that it is a challenge to discuss future issues, because it can be an emotional task(12). Furthermore, if discussions about preferences are postponed, families may have to make critical decisions in emergency situations without having the possibility to receive input from PWD(13). In sum, because PWD progressively lose the capacity to make decisions, it is important to engage them early on in the decision-making process(14).

Shared Decision-Making and Advanced Care Planning, guided by a professional(15), can contribute to this early involvement of PWD(16). Shared Decision-Making gives PWD a voice by expressing their needs and preferences, it can lead to increased feelings of well-

being and autonomy(17). Advanced Care Planning is a process of enabling PWD to express their wishes regarding the future in consultation with an IC and a professional(14). Although Shared Decision-Making and Advanced Care Planning can contribute to the involvement of PWD in the decision-making process, it seems to be a particular challenge for professionals and IC's to involve PWD in a way that corresponds with their capabilities(12).

A recent study described three major themes of how PWD prepare for the future(18). The first theme was 'the future is now', where PWD indicated that there was no need for planning. In the second theme 'considering the future', PWD tend to focus on the desires they still have for the future. Third, in 'anticipating the future', PWD see the value of planning. To our knowledge, no research has yet described how PWD and their IC's prepare for various decisions about decision-making categories they encounter over the course of the dementia trajectory. Furthermore, it is important to know what factors influence the decision-making process. When professionals know how PWD and their IC's prepare for decisions and what the influencing factors are, it allows them to guide PWD and their IC in an improved manner. Therefore, the aim of the current study is to provide insight into how PWD and their IC's prepare for various decisions.

AIM

To gain insight into how people with early stage dementia and their informal caregivers prepare for various decisions they encounter over the course of the dementia trajectory.

METHOD

Study design

The current study used a generic qualitative descriptive design involving semi-structured interviews. Qualitative research was conducted to gain in-depth information(19) on how people with dementia (PWD) and their informal caregivers (IC's) prepare for decisions over the course of the dementia trajectory.

Setting and subjects

The current study included PWD and their IC's. People with early stage dementia were included because they were still mentally competent. PWD and their IC's were recruited by dementia case managers' network and district nurses of an organization in the North of the Netherlands, they judged if PWD and their IC's were eligible to participate in the research. PWD were eligible when they were able to participate in a conversation and understand the Dutch or Frisian language, were diagnosed with early stage dementia and lived at home. IC's were eligible when they were the most important caregiver with respect to the involvement in decision-making of the person with dementia. PWD were excluded if they had behavioural problems, symptoms of a psychiatric disorder or symptoms of multimorbidity that were more prominent than the symptoms of dementia. IC's were excluded if they were an assigned caregiver with no other connections to PWD.

Data collection

Data was collected between February 2017 and May 2017. Interviews had a duration of 30 to 100 minutes. Before the start of the interviews, demographic information was collected about age, education level, time since diagnosis, type of dementia, relationship between PWD and their IC's and living situation of PWD.

During the interviews, cards were used with images about decision-making categories PWD and their IC's make decisions about. Groen et al.(6) described these categories: self-care, structuring the day, mobility, handling finances, arranging professional care, living arrangements, representing the person with dementia and decisions at the end of life. An interview guide (figure 1) with possible questions for the categories of each card was used to make sure similar questions were asked throughout the interviews.

Place here: Figure 1 Interview guide

To test whether the right questions were asked and if the questions were relevant, the cards and interview guide were pilot tested by conducting two test interviews. If necessary, questions were adjusted. To optimize interview techniques, the transcript of the pilot interviews was discussed with an independent researcher (LG). Consequently, feedback was given and applied in the following interviews.

PWD and their IC's were interviewed separately, so they both could feel free to talk about the situation from their own perspective. In one case, the IC was present at the interview with the person with dementia, because it made the person feel more confident. The interviews were conducted at the homes of the participants. In all cases, the IC was interviewed first so they could give a preliminary overview of the facts. Because of this setup, it was possible to ask deeper questions during the interview with PWD.

Data analysis

The inductive thematic analysis as described by Braun & Clarke(20) was used for the data analysis. This is a flexible and useful approach which provides a thick description of data(20). The principles of open coding and axial coding were used for a detailed and step-by-step code process(21).

Analysis started with a process of becoming familiar with the data by transcribing verbatim and reading the interviews repeatedly(19). Consequently, the collected data was divided into fragments. Fragments dealing with the same subjects were labelled with the same code(21). So called 'open codes' were given without any interpretation(21). After three interviews, the codes were rearranged and clustered thereafter the researcher (DB) searched for themes(21). Hereafter, themes were reviewed, discussed and checked in relation to the entire data set(19). Definitions and names were generated(19). The last step was to establish how the themes related to each other(19). Moreover, codes were added and changed during the whole data analysis, making it an iterative process(19).

Rigor

The interviews were performed by one researcher (DB), which served to improve the reliability(19), because all interviews are conducted in the same manner. Interviews were recorded and transcribed verbatim to increase trustworthiness and transferability(19). To increase credibility and to test whether the researcher understood the participants correctly, given answers were summarized and submitted to the participants during the interview(19). The interviews of one couple were coded independently by a second researcher (AN). NVIVO 11 (QSR International, Melbourne, Australia) was used to provide transparency during the coding process. To increase trustworthiness(19), defined themes and relations between themes were discussed with an independent researcher (LG). Furthermore, Bijlsma, D. Planning for the future: decision-making in people with early stage dementia. June 28, 2017

following the phases of thematic analysis increases reliability, because it shows the process of the data analysis(19). Finally, it must be noted that all interviews were conducted in Frisian and translated into Dutch. To increase the reliability of the translations, this was done in collaboration with an employee (NA) of The Department Frisian Language and Culture of the University of Groningen.

Ethical approval

Approval for the study was provided by the local research ethics committee (number: 170116). Prior to the interviews, participants were asked to sign the informed consent.

All data was handled anonymously. Transcripts of the interviews will be kept for fifteen years in a secured database of the research group.

RESULTS

Participants

Fourteen semi-structured interviews with seven couples, consisting of a person with dementia and their IC, were conducted. In two cases (couple 1 and couple 4), two IC's were interviewed for one person with dementia. These two IC's were considered to be one IC in the data analysis, and the data was merged accordingly. Variation was achieved on all aspects. Ages of PWD ranged from 64 to 89, ages of IC ranged from 45 to 84. The time since being diagnosed with dementia varied from six months to eight years. See table 1 for a detailed overview of the participant characteristics.

Place here: Table 1. Participant characteristics

Preparing for decisions

The different decision-making categories that PWD and their IC's encounter over the course of the dementia trajectory were discussed in the interviews. These categories were: self-care, structuring the day, mobility, handling finances, arranging professional care, living arrangements, representing the person with dementia and decisions at the end of life. From now on, these will be referred to as 'categories'. In each category, various decisions are possible. In the current study, this will be referred to as 'decisions'. The data reveals five phases in how PWD and their IC prepare for these decisions: 1) Decisions have not been discussed yet discussed; 2) Thinking about possibilities for decisions; 3) Discussed possibilities for decisions; 4) Discussed wishes for decisions; 5) Decisions arranged for the future. Decisions about one category are not fundamentally located in only one of these phases, this is why categories can be described in several phases. In which phase a

decision is located, depends on influencing factors: barriers and facilitator. See figure 2 for an overview of the relations between the phases, barriers and facilitators.

Place here: Figure 2. Relations between phases, barriers and facilitators

Phase 1: Decisions have not been discussed yet

All PWD and IC's (except IC2 and PWD2 who had Parkinson's disease) indicated that making decisions have not been discussed for the following categories: self-care, structuring the day, mobility, handling finances, arranging professional care, living arrangements, representing the person with dementia and decisions at the end of life. PWD and IC's indicated that decisions have not been discussed because they presently were not an issue: PWD could still do everything themselves.

"It is actually not an issue at all, I am still as healthy as a fish" (PWD1)

"No, it will take a long time before it becomes an issue [domestic help] and our mother also thinks that it's [the house] not too dirty at all, so it's not necessary at all" (IC5)

Box.1

Phase 2: Thinking about possibilities for decisions

Some PWD and IC's have thought about possibilities for decisions, but did not discuss them with someone else. They indicated this for: self-care, mobility, arranging professional care, living arrangements, representing the person with dementia and decisions at the end of life. For example, they were thinking about possibilities to receive more help for self-care in the future and about admission to a nursing home.

"I think that if it all gets worse, well, I would choose, if it is possible, that she gets a place in an nursing home ..." (IC4)

Box.2

Phase 3: Discussed possibilities for decisions

PWD and IC's indicated that they discussed possibilities for decisions with someone else, which could be PWD, IC or professionals. This applies for: self-care, structuring the day, handling finances, arranging professional care, living arrangements, representing the person with dementia and decisions at the end of life. For example, possibilities for increasing care at home were discussed with a professional. Furthermore, possibilities for day care were discussed with a case manager. Finally, PWD and IC discussed the power of attorney and enrolment for a nursing home.

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"I did say that when my husband is no longer here then they can bring me to a nursing home. I discussed this with my husband and children" (PWD3)

Box.3

Phase 4: Discussed wish for decisions

PWD discussed concrete wishes for decisions with their IC's or professional. Wishes were discussed for: living arrangements and decisions at end of life. Discussed wishes were, for example, about preferences for a particular nursing home, and the wish to not be resuscitated.

"I do not want to be resuscitated, the children know that too" (PWD1)

Box.4

Phase 5: Decisions for the future are made

PWD and IC's indicate that they have made decisions, with each other or with a professional, about: self-care, structuring the day, mobility, handling finances, arranging professional care, living arrangements and decisions at the end of life. Decisions that have been made are, for example: IC's arranged that home care will increasingly assist PWD with washing, they arranged a power of attorney and adjustments to the house to meet future care needs.

"And I also, oh, I have to say that, it's about finance, a power of attorney. That if my husband cannot do it anymore, I can also regulate his finances in all cases. " (IC2)

Box.5

Influencing factors: Barriers to prepare for the future

PWD and IC's assume that *if a decision is necessary it will be made for them*. Generally, they assume that if PWD cannot make decisions anymore decisions will be made by someone else. This applies for: self-care, structuring the day, mobility, handling finances, arranging professional care, living arrangements and decisions at the end of life. It is assumed that if PWD need help, it will be provided: if PWD cannot live at home any longer, they will be admitted to a nursing home, and when the time comes their funeral will be arranged. Therefore, there is no need to think about making these decisions yet.

"If living at home is no longer possible, then there will be a solution" (PWD5)

Box.6

All PWD think that *when a decision is necessary in the future their IC's will make it*. This applies for: handling finances, living arrangements, representing the person with dementia and decisions at the end of life. Generally, they say that their IC's will make sure that the situation is satisfactory.

"If I cannot do it [in general] anymore, yes, the children will do it" (PWD4)

"My brother in law will take care of it [if PWD cannot take care of herself anymore], at least I think he will" (PWD6)

Box.7

IC's indicated that *maintaining the self-governance of PWD* is important regarding: self-care, mobility, handling finances and representing the person with dementia. For example, IC's find it important that PWD can wash and dress themselves, go out alone, handle the finances alone for as long as possible.

"...that is a lot of independence for them [to have pocket money]. And I want to keep it that way, so ..." (IC2)

"... but it was not yet an issue [power of attorney] but, yes, that is what she said, I want to keep my self-governance of my own life. So we moved that forward" (IC6)

Box.8

IC's indicated that they try to maintain the self-governance of PWD, but may have doubts about the situation. Instead of arranging things, they supervise PWD behind-the-scenes to let PWD maintain self-governance as long as possible. This applies for: self-care, mobility and handling finances. For example, IC's have doubts about eating and taking medication.

"She thinks she can do it herself and she thinks it is nonsense that those women will help her because she can do it herself very well, although I think that she does not always wash herself in the morning" (IC5)

Box.9

PWD and IC's indicated that *professionals will take care of making decisions, when necessary*. They assume that when the situation of PWD declines, a professional can be informed and will take care of the situation. This applies for: self-care, arranging professional care and decisions at the end of life. For example, they assume that home care will arrange more help with self-care if it is necessary.

"It is not yet an issue. If you see more deterioration, we will contact the case manager. If you think dad declines" (IC1)

Box.10

Another barrier that PWD and IC's indicated, is the *uncertainty of the future*. Generally, PWD and IC's said that as long as it goes well, you should not look too far ahead, because they do not know what the future will bring. This applies for: living arrangements and decisions at the end of life.

"The future is always different, the reality is often different from what you think. Tomorrow she cannot be here anymore, and so do I" (IC6)

Box.11

Influencing factors: Facilitators to prepare for the future

PWD and IC's indicated that *professionals take initiative by bringing up categories*, causing them to think about decisions. This was indicated for: self-care, structuring the day, mobility, arranging professional care, living arrangements and representing the person with dementia. For example, case managers brought up meals on wheels, and admission to a nursing home.

*"And day care has been discussed with the case manager" (IC7)
"I have been to a nursing home with the case manager" (PWD7)*

Box.12

PWD and IC's indicated that some *decisions were made because of the safety of PWD*. This applies for: self-care, structuring the day, mobility, handling finances, living arrangements. For example, one person with dementia had a GPS system and IC's have taken over finances because it is safer.

"Yes, then you have a bit of a safe feeling with such a thing [GPS], then my wife knows exactly where I walk" (PWD2)

Box.13

PWD and IC's indicated that the *situation of PWD can change quickly*. Generally, they said that today there is nothing going on, but tomorrow may be different. Therefore, it is better to look forward and think or talk about decisions for the future in case the situation changes. This applies for: self-care and decisions at the end of life. For example, an admission into a nursing home might be necessary in the future, therefore it is wise to talk about it.

"Well, when I see others, I always think that can happen suddenly to me too. That I need medication or so" (PWD4)

Box.14

PWD and IC's indicated that some *decisions are made for the independence of PWD*. This is indicated for: self-care, structuring the day and mobility. For example, PWD have an alarm for the medication to take the medicines themselves.

"He would like to maintain his independence, I want to maintain his independence and know where he is through the GPS" (IC2)

Box.15

During the interview, some PWD and IC's *experienced moments of self-reflection*. They indicated that they should talk to someone about their wishes regarding: living arrangements and decisions at the end of life. During the interview they realized that others would not know what their preferences were, for example their preferences for a particular nursing home.

"But it is a point to mention, because if it's that far, I would rather go there [particular nursing home]" (PWD1)

Box.16

DISCUSSION

Summary of main findings

The current study provided new insights in the way PWD and their IC's prepare for various decisions they encounter over the course of the dementia trajectory. The data revealed five phases in how they prepare for decisions: 1) Decisions have not been discussed yet; 2) Thinking about possibilities for decisions; 3) Discussed possibilities for decisions; 4) Discussed wishes for decisions; 5) Decisions for the future are made. The data revealed that there are influencing factors, barriers and facilitators, for the way PWD and their IC's prepare.

Comparison with other studies

All PWD and IC's, except PWD2 and IC2, stated for all categories that some *decisions have not been discussed yet*. An influencing factor they indicate was that the *future is uncertain*. This is also shown in previous research, the unpredictable course of dementia leads to uncertainty about the future for PWD and their IC's(22). This uncertainty makes them feel unable to prepare for the future(23). Professionals can reduce this uncertainty by bringing up the categories that PWD and IC will encounter over the course of the dementia, in an early stage.

A barrier to prepare for the future is that PWD and their IC's assume that when *necessary, their IC's or professionals will take care of making decisions*. This is also shown in other studies: preparing was not considered necessary because PWD assume that family knows what to do(24). In a study in which nurses take care of elderly people, it was found that patients heavily rely on family members or a professional to make decisions on what is best for them(25). Professionals and IC's can prevent that they have to make decisions for PWD, by bringing up the categories PWD and IC will encounter in an early stage.

The current study showed that a facilitator for preparing for the future is that *professionals take the initiative by bringing up the categories*. Therewith, *the moments of self-reflection PWD and IC's experienced during the interview* seem to indicate that PWD and their IC did not realize that preparation was already necessary. Previous research confirms that they did not recognize the importance of advance planning until the cognitive impairment in PWD was so advanced that it was too late to have discussions(26). This shows that PWD and their IC can use support from a professional who can facilitate this by bringing up decision-making categories earlier on, so that PWD and their IC start to think and talk about these categories with each other.

During the recruitment of PWD and IC's, it appeared that they experienced difficulties in talking about their future with dementia. Four eligible PWD indicated that they did not want to participate because of this. This also seems to be apparent from the interviewed participants, because most of them expressed that they were not preparing for their future. Thus, while we would expect that the willingness of PWD and IC's to participate in a study about planning the future with dementia would mean that they would have an easier time talking about these categories, this was still a difficult topic for them to talk about. Previous research showed that IC's often indicate that it is a challenge to discuss future issues, because it can be an emotional task(12). Professionals need knowledge about how to take into account that talking about dementia is a difficult topic for PWD and their IC's.

Strengths and limitations

One person with dementia had Parkinson's disease, and during the interview it turned out the Parkinson's disease was probably more on the foreground than early stage dementia. Nevertheless, data of the interview with this person and IC were useful for the current study, because it generally matched the other data. There was a difference with the other participants though, because every participant in the research stated for decisions on all categories that it was not discussed, except this couple. Probably Parkinson's disease already forced them to make decisions.

PWD and IC's were able to talk in their native language, Frisian. Caldwell-Harris(27) showed that persons can express their feelings and emotions better in their native language. This was important, because dementia is a difficult subject to talk about. To increase the reliability of the translations, all interviews were translated into Dutch in collaboration with an employee (NA) of The Department Frisian Language and Culture of the University of Groningen.

Conclusion and recommendations

Description of the five phases provides more insight into how PWD and their IC's prepare for decisions about categories they encounter over the course of the dementia trajectory. An important barrier to prepare is that PWD and IC's assume that if decisions are necessary, IC's or professionals will arrange them. An important facilitator is that professionals takes initiative by bringing up important categories.

Professionals have an important role in bringing up important decisions about categories for the future. When they do, PWD and IC's will start to think about these decisions and PWD get the chance to determine their own future for as long as possible. Further research is necessary to show how professionals can support PWD and their IC's to prepare for the future in an early stage of the dementia trajectory, taking into account that talking about dementia is a difficult topic for PWD and their IC's.

DECLARATION OF CONFLICTING INTERESTS

The author declares that there are no conflicts of interest.

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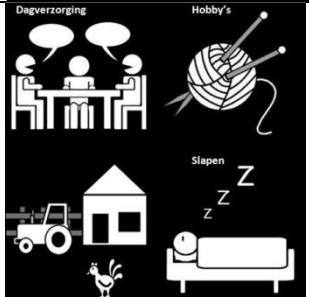



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Figure 1. Interview guide

Categories	Possible questions	Card
<i>Self-care</i>	<p>For example decisions about activities of daily living, taking medication, cooking, housekeeping</p> <p>Do you know how this will be arranged in the future?</p>	
<i>Structuring the day</i>	<p>For example decisions about day care, daily rhythm</p> <p>Do you know how this will be arranged in the future?</p>	
<i>Mobility</i>	<p>For example decisions about driving a car, cycling, going out alone, mobility tools</p> <p>Do you know how this will be arranged in the future?</p>	
<i>Handling finances</i>	<p>For example decisions about Handling finances, i.e. handling money, shopping and small purchases</p> <p>Do you know how this will be arranged in the future?</p>	
<i>Arranging professional care</i>	<p>For example decisions about case management, home care, domestic help</p> <p>Do you know how this will be arranged in the future?</p>	

<p><i>Living arrangements</i></p>	<p>For example decisions about house adjustments to care-needs, registering or being admitted to a care home or nursing home</p> <p>Do you know how this will be arranged in the future?</p>	<p>Wonen</p> 
<p><i>Representing the person with dementia</i></p>	<p>For example decisions about involving care network members in decision-making, power of attorney</p> <p>Do you know how this will be arranged in the future?</p>	<p>Rolverdeling beslissingen</p> 
<p><i>Decisions at end of life</i></p>	<p>For example decisions about living will, nonresuscitation statement, arrangements for the funeral</p> <p>Do you know how this will be arranged in the future?</p>	

Then the cards with categories were divided into three groups.

Groups	Possible questions	Card
<p>Group 1: I have made arrangements for the future</p>	<p>Can you tell me more about these categories?</p> <ul style="list-style-type: none"> - Where did you make arrangements about? - What did you arrange? - Who did you make the arrangements with? - What made it relevant to make these arrangements? - What were your wishes regarding these categories? - How did making arrangements take place? 	 <p>Groep 1: Heb ik afspraken over gemaakt voor de toekomst</p>
<p>Group 2: I discussed with others</p>	<p>Can you tell me more about these categories?</p> <ul style="list-style-type: none"> - What was it about? - What did you discuss? - With who did you discuss this? - Who first started about it? - What made it relevant to talking about it? - What would you like? - Why did not you make any arrangements about this earlier? 	 <p>Groep 2: Heb ik met anderen over gesproken</p>


	- Is that something you would like to do?	
Group 3: Did I think about	<p>Can you tell me more about these categories?</p> <ul style="list-style-type: none"> - Where did you think about? - Why did you think about these categories? - What would you like? - Why did not you talk about it with others? - Do you think about discussing it with others? 	

Table 1. Participants characteristics

Participant ¹	Sex ²	Age	Education ³	Time since diagnosis	Type of dementia	Relation between IC and PWD	Living situation PWD
PWD1	M	82	High	4 years	Alzheimer's disease		Living alone
IC1a	M	47	Middle			Son	
IC1b	F	45	Middle			Daughter in law	
PWD2	M	64	Middle	5 years	Parkinson's disease dementia		Living with spouse
IC2	F	61	Middle			Spouse	
PWD3	F	86	Low	3 years	Alzheimer's disease		Living with spouse
IC3	M	84	Low			Spouse	
PWD4	F	88	Low	2 years	Alzheimer's disease		Living alone
IC4a	F	64	Low			Daughter	
IC4b	F	57	Middle			Daughter	
PWD5	F	89	Low	6 months	Vasculair dementia		Living alone
IC5	F	49	Middle			Daughter	
PWD6	F	84	Low	1 year	Alzheimer's disease		Living alone
IC6	M	71	Middle			Brother in law	
PWD7	F	78	Middle	8 years	Alzheimer's disease		Living alone
IC7	F	50	Middle			Daughter	

¹PWD = person with dementia, IC = informal caregiver

²M = male; F = female

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

Figure 2. Relation between phases, barriers and facilitators

Phases of how PWD and their IC prepare for the future

Decisions have not been discussed yet

Thinking about possibilities for decisions

Discussed possibilities for decisions

Discussed wish for decisions

Decisions arranged for the future

Barriers to prepare for the future

- If decisions are necessary it will be arranged
- If necessary, IC will arrange decisions
- If necessary, professional will arrange decisions
- Maintaining self-governance PWD
- Future is uncertain

Facilitators to prepare for the future

- Initiative professional by bringing up categories
- Decisions arranged for safety PWD
- Situation of PWD can change quickly
- Decisions arranged for independence PWD
- During the interview PWD and IC's experienced self-reflection

