

Master Thesis

**Participants involved in decision-making in the care network
of a person with dementia: a longitudinal multi-perspective
qualitative study**

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Introduction

Dementia is a chronic disease characterized by memory disorders and cognitive disturbances (2). Worldwide about 35.6 million people suffered from dementia in 2010 and this number is expected to double to 65.7 million people in 2030. Each year 7.7 million new cases of dementia occur (3). The average life expectancy of eight till ten years can rise up to a maximum of 20 years of the Person With Dementia (PWD), which results in a long term illness trajectory (4).

In this long term illness trajectory, the PWD and the informal caregiver are confronted with many decisions to be taken. Several studies researched specific decisions to be taken or decision areas in dementia (5-8). Decisions to be taken often start with prompting access to clinical assessments, obtaining a diagnosis and deliberating treatment options (5, 6). Other decisions are arranging home care (5), admission to a care or nursing home (5, 7), making legal arrangement around finances (5) and making risk assessments around driving or personal safety (5, 8). Decisions are made based on practical considerations, personal preferences or values (9, 10) and preferences and values of informal caregivers or healthcare workers (9).

Decisions tools can be used to help healthcare workers and patients in making informed, values-based decisions, also called Shared Decision Making (SDM) (11). SDM can be defined as *'an approach in which clinicians and patients share the best available evidence and patients are supported to consider options, to achieve informed preferences'* (12). SDM draws on the principles of Patient Centered Care (13), leads to higher patient satisfaction and improves clinical care results (14, 15). The approach of SDM assumes a dyadic process between the patient and healthcare worker, but forgets the role of the informal caregiver and other healthcare workers in decision-making in dementia (16, 17).

As the dementia progresses, there may be a transition from supported decision-making, where the PWD and the informal caregiver made decisions together, to substituted decision making, where informal caregivers take over much decisions as the result of the decline in cognition of the PWD (18). The increasing role and responsibility of the informal caregiver in separating the preferences and values of the PWD from their own and those of family members, is challenging and stressful (19). Besides that, the informal caregiver experiences consistently difficulties with the responsibility of making a decision for another adult, denial and resistance by the PWD and barriers to accessing services (5). Previous results of the larger study of which this study is part of, show that primary informal caregivers experience a high feeling of being responsible and feel alone in making the decision to choose for day care. Because other informal caregivers tend to participate less in this decision, an uneven distribution in the involvement of participants is created (20).

To complete the approach of SDM and make it useful in decision making for people with dementia, insight is needed in the participants involved in decisions. A total of ten categories of decisions were identified in a previous part of the larger study: 'memory problems and medical treatment', 'healthcare workers around the PWD', 'daily activities', 'self care', 'mobility', 'social network of the PWD', 'living at home or in an institution', 'informal caregiver and support', 'finances' and 'representation towards the future of the PWD'. Each category of decisions exists of a number of decisions taken emerged out of the interviews; these decisions taken were the starting point of this study (21).

Problem statement

The increase number of people with dementia asks for an appropriate support of informal caregivers. The primary informal caregiver experience a high feeling of being responsible and feel alone in making decisions. Therefore it is necessary to get insight in and consider the role of the primary informal caregiver and other participants in decisions making. An overview of the participants involved in decision-making is missed. This overview could be useful in making healthcare workers aware of and let them optimal use participants involved of the care network of the PWD, to reduce the negative feelings experienced by the informal caregiver.

Aim and research question

The aim of the study was to identify which participants are involved in the decisions taken in the care network of people with dementia. Involvement of these participants is studied by identifying patterns of participants involved related to decisions. Given the aim, the following main and sub question was formulated:

- Which participants are involved in decisions taken within the care network of people with dementia?
 - Which patterns can be recognized in categories of participants involved related to categories of decisions taken within the care network of people with dementia?

Methods

Design

The study was part of a larger longitudinal multi-perspective study on decision-making in people with dementia of the research group 'Innovation in elderly care' at the Windesheim University of

Applied Sciences Zwolle. In order to answer the research questions, an existing database of 316 in-depth interviews belonging to 25 care networks of people with dementia was used.

The method of a generic qualitative research was used for this part of the study as it is suitable to describe and understand the social phenomenon of participants involved in decision-making (22). In addition, the method is consistent with the nature of the research question and the purpose to describe patterns in categories of participants involved related to type of decisions.

Settings and entrance to the field

The decision-making was viewed from five different perspectives: the PWD, two informal caregivers and two healthcare workers. An informal caregiver and healthcare worker closely and remotely involved were recruited. The five perspectives together formed a so-called 'care network'. Purposive sampling was used to recruit 25 care networks in the region Zwolle and Rotterdam through contact persons of health care organizations for people with dementia (nursing homes, home care organizations, day-care centers), through a notice at a local meeting for informal caregivers and people with dementia (Alzheimer café) and through the website of the national Alzheimer's Society. When the PWD and the primary informal caregiver agreed to participate in the study, the other informal caregiver and healthcare workers were recruited via them.

For the aim of the current study purposive sampling was used to select ten care networks out of the total of 25 care networks based on gender, whether or not having a partner and stage of dementia (23, 24). The selection based on these three characteristics was done because of the expected differences in data based on literature and the experience and insight of the researchers (18). Given the richness of the data, ten care networks were seen by the researchers as sufficient to make some statements about the phenomenon and the interaction between participants.

Data collection

Data of the larger study were collected between September '10 and December '12. All five participants of each care network were interviewed three times, with an interval of six months. For each PWD gender, age, type of dementia, marital status and living situation were identified at the start of interview one. For the informal caregiver the relation towards the PWD was identified as well as the function of the healthcare worker for the professional (see table 1).

Insert table 1

An interview protocol was developed with questions and topics formulated from general to specific, with the aim to fit in with the open character of semi-structured interviewing (25). This kind of interviewing was chosen to leave space for content, formulation, sequence and answers of participants (26). Topics focused were the reason for the decision, purpose or desire behind the decision, participants involved, influence of participants involved, alternatives, considerations, mutual communication, desired information and evaluation of the decision. A two-day training in using the topic list and communicating with a PWD was given by the leading researchers to ensure the quality of the interviews.

The one-hour interviews took place at the residence of the PWD or informal caregiver or in case of healthcare workers, at their work place or at the institute of the research group of the Windesheim University of Applied Sciences Zwolle. Most interviews with the PWD were taken without the presence of others, so the PWD could share perspectives on decision-making without being influenced by others. In three cases, the PWD was only willing to participate if the informal caregiver was present.

Each individual participant received verbal and written information about the research, gave permission to participate and signed for informant consent. All participants were free to stop their participation at any time. All interviews were audio-taped and transcribed verbatim for analysis by students of the Windesheim University of Applied Sciences Zwolle. Names and places in the transcripts were made anonymous and all traceable information was replaced in general terms.

Participants were called three months after the first and second interview to maintain contact and prevent drop-outs (26). Fifty-nine of the 375 interviews did not take place, the reasons were (caregiver) burden, the PWD was not willing to participate or not being able to find a second informal caregiver or healthcare worker (see figure 1).

Insert figure 1

Data analysis

Categories of decisions and decisions taken, which had been identified in the larger study, were the starting point of the data-analysis (see table 4). Transcripts of the interviews were consistently analyzed by two researchers, independent of each other (26, 27). The

qualitative data analysis software program NVIVO is used, to assist the researchers in coding and retrieval along thematic lines as well as in making memos (28). Open coding and the technique of constant comparison was used to develop a list of codes (24). Participants were labeled as involved, if they were mentioned by one of the interviewees in relation to the specific decision. This did not have to mean that the participants had a considerable share in the decision. The following four steps were taken in data-analysis:

1. The participants involved belonging to the decisions taken were identified from the transcripts and were labeled with codes;
2. The participants involved were related to specific decisions and categories of decisions;
3. The labels of codes were categorized in meaningful clusters of the participants involved, which were called categories of participants;
4. Finally, the categories of decisions taken and specific decisions taken were related to the categories of participants involved;

Codes that emerged from the interviews were constantly discussed between the two researchers to reach consensus about the codes. Making memos was used to capture changes in codes, but also to reflect on the role of the researcher and be aware of the experiences, opinions, feelings and ideas of the researchers, and to be able to overcome any possible bias (26). During the whole research process, peer review was used of peer-researchers who had a fresh perspective on the analysis procedure and were able to see things the researcher may have overlooked (26). In addition, the meetings of the research group were used to monitor the progress of the analysis and to discuss the codes.

Ethical considerations

The larger longitudinal research is conducted according to the Declaration of Helsinki (29). The research is covered by the Medical Research Involving Human Subjects Act. In some cases, the interviewed PWD was mentally incompetent. A certificate of no-objection was attained by the Medical Review Ethics Committee of the ISALA clinic at Zwolle (reference number: 10.11113).

Results

Many different participants are involved in decision-making (mean 18, range 14-21) (see table 2). A few care networks have considerably less participants involved for one of the categories. In most of the care networks the PWD had a spouse who also performed the role of the primary informal caregiver. Others who performed this role were a daughter or in one case the niece of the PWD.

Insert table 2

The involvement of participants in decisions taken can be explained by two dimensions; being informal or formal involved and being directly or indirectly involved. These dimensions together form the four categories 'informal directly involved', 'formal directly involved', 'informal indirectly involved' and 'formal indirectly involved'. The categories describe the relationship and the amount of contact with the PWD. In all categories a number of participants can be placed (see table 2).

The category 'informal directly involved' include the PWD, spouse and immediate family or acquaintances who are regularly and closely involved with the PWD. In the care networks where the PWD has a spouse, decisions are taken together with the PWD and children are (in the beginning stage of dementia) hardly involved (see quote 1 & 2, table 3). In care networks where the role of the informal caregiver(s) was performed by others than the spouse, son or daughter it is notable that the informal caregiver(s) easier take a step back in the care and decision making for the PWD (see quote 3, table 3).

The category 'formal directly involved' consist of the participants regularly and closely involved with the PWD and working for an organization or institution. This group of healthcare workers often built up a relationship of trust with the PWD and informal caregiver(s), which may be useful in removing resistance of the PWD and making it easier for the informal caregiver(s) to accept decisions (see quote 4 and 5, table 3).

The category 'informal indirectly involved' include family or acquaintances that are involved on a distance. This does not mean that the participants do not influence decisions. Precisely this group of participants can have a decisive role in making a final decision (see quote 6, table 3). This category also includes healthcare worker(s) out of the informal network, because of the involvement as an acquaintance in only one or a few decision(s).

The category 'formal indirectly involved' include participants incidental involved with the PWD from an organization or institution. This group of participants can have a decisive role in making a final decision, because they create the conditions for making certain decisions (see quote 7, table 3). The quotes 4 and 7 show that resistance of the PWD against decisions can be removed by the involvement of participants formal directly and formal indirectly involved.

Insert table 3

Patterns

The number of networks in which the decision was taken for each (sub)category and total of networks in which the decision was taken are presented in table 4. Decisions taken that were mentioned in four or more care networks were included in the results. The category 'informal directly involved' is split up to three subcategories: the PWD, the spouse and Other Informal Caregivers (OIC).

The table demonstrates that particular participants out of the informal directly, formal directly and formal indirectly categories were involved in decisions. The informal indirectly involved participants were not involved in half or more of networks in which the decisions was taken. The informal directly involved participants are involved in all decisions spread over the three subcategories. The PWD was not involved in the decisions 'contacting fellow patients', 'starting/stopping/changing dementia related medication', 'otherwise or less involve the PWD in decisions' and 'capturing mentorship'. There are both decisions taken together with the involvement of the spouse and other informal caregivers, as only by the spouse or only by the other informal caregivers. Decisions taken without the involvement of the spouse, also in the care networks where a spouse was present, were 'getting a diagnosis', 'doing a memory test or psychological research', 'going outside or walking (alone)', '(stop) driving, renew license or disposing the vehicle', 'utilizing recourses with regard to mobility and safety', 'stimulating exercise', 'supporting or taking over cooking or arranging meal service', 'registration to waiting list care or nursing home', 'furnishing the room or disposing stuff', 'extending or reducing informal care' and 'taking over administration'.

The two formal involved categories were involved in a lot of decisions, except for 'visiting the general practitioner', 'contacting fellow patients', 'going outside or walking alone', 'being alone at home', 'furnishing the room or disposing of stuff', 'involving children in decisions', 'extending or reducing informal care' and 'making a visitor scheme'. These decisions are taken by informal directly involved participants.

Decisions that were taken with participants out of all (sub)categories except for the category 'informal indirectly involved' were 'utilizing recourses with regard to forgetfulness', 'being admitted to a care or nursing home', 'making use of day care' and 'changing daily activities'.

Insert table 4

Discussion

The findings of the study give an overview of the participants involved in decisions and show that in particular participants out of the informal direct, formal direct and formal indirect care network of the PWD are involved in decisions taken. The informal indirectly involved participants seem to have a limited role in the decision-making.

Earlier research regarding SDM described a dyadic process between doctor and patient, or just mentioned that at least these two parties are involved in decision-making (16, 17). Légaré et al. (2011) developed the Inter Professional SDM (IP-SDM) model, which describes the steps to be followed in making decisions and distinguishes the influence of the first contact person, decisions coach, family member(s) and healthcare professional(s). The model describes the participants involved in general terms and does not address the impact of the relationship with the patient in making decisions. The results of the current study complement the model by mentioning the specific participants involved in specific decisions and search for patterns in this involvement. In dementia, it is certainly not just a question of a dyadic process, but also many other participants play a role in and influencing the decision-making. Besides that, the results show the importance of making use of the right participants to overcome resistance of the PWD against decisions. Livingston et al. (2010) also described this as one of the strategies for healthcare workers to overcome resistance; another strategy is to introduce changes slowly and one at a time (5). Different than would be expected, there are some crucial decisions taken within the informal directly involved participants without support of healthcare workers. In particular, the decisions 'going outside or walking alone', 'being alone at home' and 'involving children in decisions' should be expected to be shared with formal involved participants. No previous literature can be found about this finding. The decisions 'making use of day care' and 'being admitted to a care or nursing home' can be seen as key decisions to be taken only once and thus have many participants involved. 'Utilizing resources with regard to forgetfulness' and 'changing daily activities' are smaller decisions that often take place over time and thus have many different participants involved.

One of the strengths of the study was that the existing data was rich of information due to the choice of a network approach and the longitudinal nature of the study. In addition, interviews were double coded, which contributes to the reliability of the findings and the quality of the research.

The study had several limitations. The first limitation is the involvement of people with dementia, which makes it possible that participants involved were not remembered by the PWD. Another limitation was that the findings were based on interview data that entail verbalized experiences and not observations of decision-making in action. Finally, participants are labeled

as involved as they were mentioned by one of the interviewees in relation to the decision. No attention was paid to the extent in which participants have a role in decisions taken, so it is possible that participants were involved, but shifted the final responsibility to another participant.

The findings of the study could inform healthcare workers in creating together with the PWD and/or informal caregiver for a balanced distribution of involvement in decisions. This may lead to a feeling of shared responsibility rather than a feeling of being alone responsible experienced by the informal caregiver. Crucial decisions now only taken with the informal directly involved participants are fine, as long as those decisions not lead to negative feelings experienced by the informal caregiver. Healthcare workers should be aware of these feelings and, if necessary, offer support. In addition, an optimal use of participants involved can prevent or reduce resistance of the PWD.

Conclusion

In conclusion, the PWD and informal caregiver(s) are involved in almost all decisions, whether or not supported by others from the informal directly involved, formal directly involved and formal indirectly involved participants. Informal indirectly involved participants seem to be not involved in any of the decisions.

Recommendations

The findings of the study are useful to healthcare workers to create together with the PWD and informal caregiver a balanced distribution in the involvement in decisions and overcome negative feelings of the informal caregiver in making decisions. To complete the overview of the participants involved in decisions and the model of SDM, further research is needed to get insight in the extent to which different participants play a role in decision-making.

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Table 1 – Characteristics of the included PWD's and their network

CN	Gender	Age	Marital status	Stage of dementia ¹	Living situation (T=0)	Type of informal caregivers interviewed	Type of healthcare workers interviewed
1	M	70	Married	Mo	IL	Spouse Son	Employee day-care centre Principal nurse home care
2	F	87	Married	Mo	IL	Spouse Daughter	Principal nurse home care Team leader nurses
3	F	82	Widowed	A	NH	Daughter Daughter	Principal attendant Case manager Nursing Home
4	F	83	Single	Mo	HE	Niece Niece	Principal attendant Case manager Nursing home
5	F	83	Widowed	B	IL	Daughter Friend of daughter	Employee day-care-centre Case manager Mental Health Organisation
6	F	62	Married	Mo	NH	Spouse Daughter	Principal attendant Head of department
7	M	80	Widowed	B	IL	Daughter Son	Home care nurse Case manager Home Care Organisation
8	F	74	Married	Mo	IL	Spouse Daughter	Domestic help Case manager Mental Health Organisation
9	M	?	Married	Mo	IL	Spouse -	Home care nurse Creative therapist
10	F	79	Married	B	IL	Spouse Daughter	Employee of day-care centre Case manager

¹Judgement by professional interviewee

CN= Care Network

M= Male

A= Advanced Dementia

T0= Interview one

IL= Independent Living

HE= Home for Elderly

F= Female

B= Beginning Disease

Mo= Moderate Dementia

T=2 Interview three

NH= Nursing Home

Figure 1 – Total of interviews and drop-outs

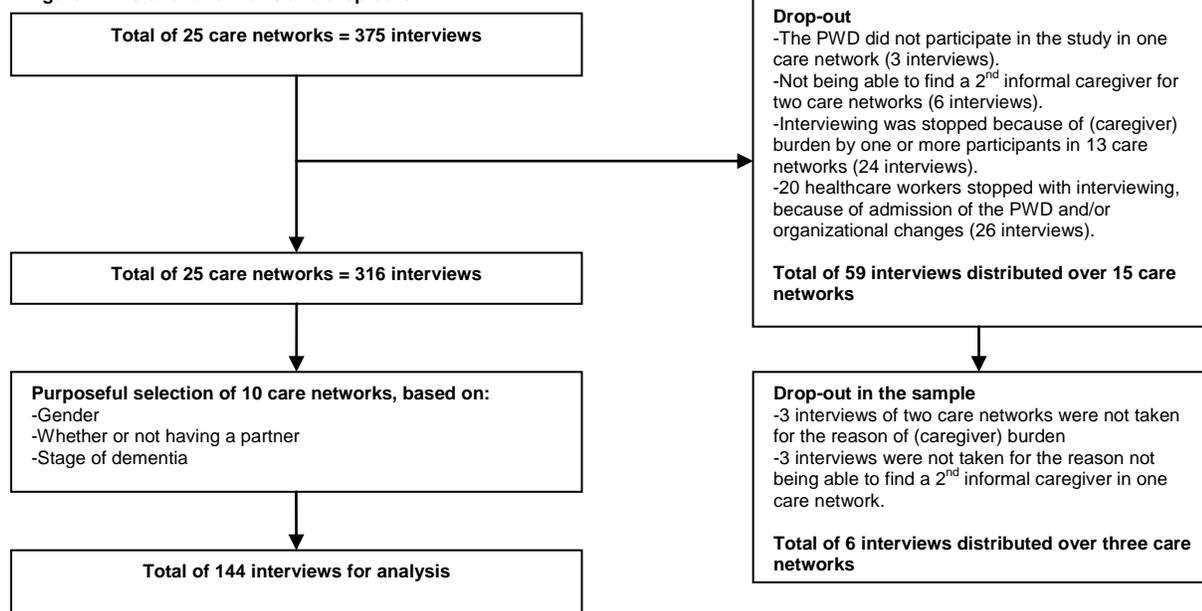


Table 2 – Categories of involvement related to participants involved named by the interviewees

Categories	Codes	Network in which the participants are involved										Mean ¹ (range)
		CN1	CN2	CN3	CN4	CN5	CN6	CN7	CN8	CN9	CN10	
1. Informal directly involved	PWD	X	X	X	X	X	X	X	X	X	X	0
	Daughter 1 ²	X	X	<u>X</u>		<u>X</u>	X	<u>X</u> ³	X		X	
	Son	X	X	X		X	X	X		X		
	Children	X	X	X			X	X	X	X	X	
	Daughter 2		X	X		X	X	X	X		X	
	Spouse	<u>X</u>	<u>X</u>				<u>X</u>		<u>X</u>	<u>X</u>	<u>X</u>	
	Son or daughter-in-law		X	X				X				
	OIC				<u>X</u>	X						
Total involved participants category 1		5	7	6	2	5	6	6	5	4	5	5 (2-7)
2. Formal directly involved	General practitioner	X	X	X	X	X	X	X	X	X	X	
	Case or care manager / Social Psychiatric Nurse		X	X	X	X	X	X	X	X	X	
	DC: First Responsible Nurse	X	X			X		X	X	X	X	
	CH/NH: First Responsible Nurse	X		X	X		X					
	Domestic worker		X					X	X	X		
	HC: Employee of homecare		X			X		X	X		X	
	HC: First Responsible Nurse						X	X		X		
	CH/NH: Team of the department			X	X		X					
	Volunteer								X	X		
	Communion of church or vicar						X	X				
	DC: Activity coordinator					X	X					
	Pedicure				X							
	Peer support								X			
	Music therapist									X		
	HC: Team of homecare							X				
CH/NH: Activity coordinator			X									
Multidisciplinary team						X						
Total involved participants category 2		3	5	5	5	5	8	8	7	7	4	6 (3-8)
3. Informal indirectly involved	Family ⁴				X		X	X			X	
	Grandchild(ren)		X			X		X				
	Sister 1 ³			X					X			
	Healthcare worker of informal network ⁵		X	X								
	Sister 2								X			
	Neighbor					X						
	Friends of PWD					X						
Total involved participants category 3		0	2	2	1	3	1	2	2	0	1	1 (0-3)

Min= Minimum

CN= Care Network

OIC= Other Informal Caregivers

HC= Home Care

NH= Nursing Home

Max= Maximum

PWD= Person With Dementia

DC= Daycare

CH= Care Home

¹The mean is rounded to a whole number. ²The participant who performs the role of the primary informal caregiver is underlined and bold. ³In case of care networks with more than one involved daughter/sister, the closest involved daughter/sister will be labeled with daughter/sister 1 and the other daughter/sister(s) will be labeled as daughter/sister 2.

⁴General code or label for when the family was mentioned as involved by one of the interviewees. ⁵Code for an involved healthcare worker that the PWD or informal caregiver knows out of the informal care network.

Categories	Codes	Network in which the participants are involved										Mean* (min-max)			
		CN	CN	CN	CN	CN	CN	CN	CN	CN	CN1				
		1	2	3	4	5	6	7	8	9	0				
4. Formal indirectly involved	Social worker	X		X	X		X		X						
	Indication Commission	X	X			X	X	X							
	Care- or Nursing Home	X		X	X		X			X					
	Memory clinic or other department of hospital	X			X		X	X					X		
	Geriatrician or other specialist of memory clinic (treating physician of)	X				X		X	X				X	X	
	Health Care Institution		X	X			X			X			X	X	
	Home Care		X			X		X			X				
	CH/NH: Director		X	X		X					X				
	CH/NH: Department head		X	X	X		X								
	Psychologist or psychiatrist			X	X	X								X	
	Daycare	X				X				X				X	
	CH/NH: Nursing or Care	X		X			X								
	Home physician														
	Transfer Nurse				X						X				
	Municipality						X				X				
	HC: Manager		X												
	HC: Team leader		X												
	Assistant of general practitioner		X												
	Physiotherapist		X												
	Foreign physician			X											
Total involved participants category 4		7	9	8	6	6	8	4	3	6	5	6 (3-9)			
Total involved participants		15	19	21	14	19	21	20	17	17	15	18 (14-21)			

Min= Minimum

CN= Care Network

OIC= Other Informal Caregivers

HC= Home Care

NH= Nursing Home

Max= Maximum

PWD= Person With Dementia

DC= Daycare

CH= Care Home

¹The mean is rounded to a whole number. ²The person who performs the role of the primary informal caregiver is underlined and bold. ³In case of care networks with more than one involved daughter/sister, the closest involved daughter/sister will be labeled with daughter/sister 1 and the other daughter/sister(s) will be labeled as daughter/sister 2.

⁴General code or label for when the family was mentioned as involved by one of the interviewees. ⁵Code for an involved healthcare worker that the PWD or informal caregiver knows out of the informal care network.

Table 3– Categories of involvement and typical quotes

Categories of involvement	Quote
Informal directly involved	<p>1. Spouse (IC1) of PWD about the involvement of their children: <i>'We do have children who are allowed to give their advice, they may even criticize, not too much, but that should, but the decision is mine. That's between [name PWD] and me. When I take a decision, I tell the kids what I've decided.'</i></p> <p>2. Case manager (HW2) about the involvement of the children: <i>'I've always talked with the two of them. Sometimes asked if the children wanted to be involved, but they actually held them off a bit.'</i></p> <p>3. Niece (IC1) after the PWD asked her to take over administration: <i>'Well, on the one hand, I liked that, she specifically asked for me. On the other hand, I also said to the care personnel of the [name care home]: 'Is there no one else who would like to help that is closer to her?' 'No, she specifically asked for you'. But that turn out that she break with [name niece 2] at that moment.'</i></p>
Formal directly involved	<p>4. Daughter (IC1) about domestic worker and the decision to support the PWD in Activities of Daily Living: <i>'As well as personal care, he showered no longer. That was quite annoying. The pedicure didn't want to help him because of that. Well...[name domestic worker] has persuaded him that he does his feed in to a bath and I think he takes a shower again. [Name domestic worker] gets more done than others.'</i></p> <p>5. Daughter (IC1) about staff of living room project in making the decision to ad miss the PWD to a nursing home: <i>'When [name of living room project] said: 'She's not in her place right now, she should actually go to a nursing home that would be much better for her. We're going to put her on a waiting list and you may say which waiting list.' Than that happens and you think: it will be so...'</i></p>
Informal indirectly involved	<p>6. Daughter (IC2) and case manager (HW2) after PWD has stayed with her sisters to relieve the spouse: <i>'Actually she didn't want to go to the care farm and she does not want it. But...because she had that distance and her sisters have spoken with her, more strange people. Or strange people, well...further away, she would not mind at that moment.'</i> <i>'When she comes back, and that's just the icing on the cake that she herself says: 'I've talked with [name sister] about it and I decided by myself that I go once a week to the care farm.'</i></p>
Formal indirectly involved	<p>7. Daughter (IC1) about stop driving of the PWD: <i>'I thought that goes wrong once those roundabouts, hey, but that's hard! So at one point he got that approval of that license. Then said [name son] also: 'Let's do it the official way, than it's easier for him to except'.'</i></p>

IC= Informal Caregiver, HW=Healthcare Worker, 1/2= First or second informal caregiver that have been interviewed, DC= Day Care, CM= Case Manager

Table 4 –Decisions taken related to categories of involvement

Categories of decisions	Decisions taken	Categories of involvement					
		Informal directly involved		Formal directly involved	Informal indirectly involved	Formal indirectly involved	
Subcategory of involvement		PWD	Spouse ¹	OIC ²			
Memory problems and medical treatment (7)	1. Getting a diagnosis	7/9 ³		4/9 ⁴	7/9		9/9
	2. Visiting general practitioner because of memory problems	8/8	4/8	6/8			
	3. Doing a memory test or psychological research	4/7		3/7	4/7		4/7
	4. Contacting fellow patients		5/6	3/6			
	5. Utilizing recourses with regard to forgetfulness	4/5	2/5	2/5	3/5		2/5
	6. Chancing method of approach with regard to behavior	2/5	2/5	2/5	2/5		
	7. Starting/stopping/changing dementia related medication		3/4	2/4			4/4
Mobility (6)	1. Going outside or walking (alone)	9/9		4/9			
	2. (Stop) driving, renew license or disposing the vehicle	6/6		4/6	3/6		3/6
	3. Utilizing recourses with regard to mobility and safety	5/6			5/6		4/6
	4. (Arranging) transport	4/5	2/5				3/5
	5. (Stop) cycling	4/4	2/4	2/4	2/4		
	6. Stimulating exercise	4/4			2/4		2/4
Healthcare workers around the PWD (5)	1. Utilizing case manager (or similar function)	4/8	5/8		6/8		
	2. Utilizing home care	6/6	4/6	3/6	5/6		
	3. Utilizing domestic help	4/4	3/4		3/4		
	4. Utilizing psychologist or therapist	3/4	2/4		2/4		3/4
	5. Extending or reducing moments of home care	2/4	3/4		3/4		2/4
Self-care (5)	1. Supporting or taking over Activities of Daily Living	7/7	3/7		6/7		5/7
	2. Supporting or taking over take or arrange medication	5/7	4/7		4/7		5/7
	3. Supporting or taking over household tasks	5/6	4/6		3/6		
	4. Being alone (at home)	4/6	5/6				
	5. Supporting or taking over cooking or arranging meal service	5/5		2/5	2/5		
Living at home or in an institution (3)	1. Being admitted to care or nursing home	7/7	3/7	6/7	7/7		5/7
	2. Registration waiting list care or nursing home	4/5		3/5	5/5		4/5
	3. Furnishing the room or disposing of stuff	2/4		4/4			

¹The maximum number of spouses involved is six, because there were only six networks in which the PWD had a spouse. ²OIC= Other Informal Caregivers. ³... / ...= Number of networks in which the decision is named for that category / total of networks in which the decision is named. The numbers are only called when the half or more of the number of networks in which the decision is named for that category. ⁴In case of an uneven number of total networks in which the decision is named, the minimal number of networks will be rounded down to be included in the table.

Categories of decisions	Decisions taken	Categories of involvement			
		Informal directly involved	Formal directly involved	Informal indirectly involved	Formal indirectly involved
Subcategory of involvement		PWD	Spouse	OIC*	
Representation towards the future (3)	1. Otherwise or less involve the PWD in decisions		6/9	5/9	7/9
	2. Involving children in decisions	4/4	4/4	3/4	
	3. Capturing mentorship		2/4	4/4	2/4
Daily activities (2)	1. Making use of daycare	7/8	6/8	6/8	6/8
	2. Changing daily activities	4/4	2/4	3/4	4/4
Support of the informal caregiver (2)	1. Utilizing volunteer to relieve the informal caregiver	2/5	2/5	3/5	5/5
	2. Extending or reducing informal care	2/4		4/4	
Social network of the PWD (1)	1. Making visitor scheme (quantity, frequency and timing of visits)	2/5	2/5	5/5	
Finances (1)	1. Taking over administration	4/4		4/4	2/4

¹The maximum number of spouses involved is six, because there were only six networks in which the PWD had a spouse. ²OIC= Other Informal Caregivers. ³... / ...= Number of networks in which the decision is named for that category / total of networks in which the decision is named. The numbers are only called when the half or more of the number of networks in which the decision is named for that category. ⁴In case of an uneven number of total networks in which the decision is named, the minimal number of networks will be rounded down to be included in the table.