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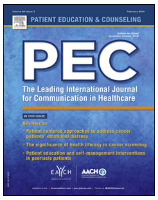

Recognizing decision needs: first step for collaborative deliberation in dementia care networks

Leontine Groen van de Ven, MSc, Ph.D candidate[a,*], Carolien Smits, Ph.D[a], Glyn Elwyn, MD, Ph.D[b], Marijke Span, LL.M., Ph.D[a], Jan Jukema, Ph.D[a], Jan Eefsting, Ph.D[c,e], Myrra Vernooij-Dassen, Ph.D[d]

[a] Research Group Innovating with Older Adults, Centre of Expertise in Health Care and Social Work, Windesheim University of Applied Sciences, Zwolle, The Netherlands
[b] Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, Hanover, USA
[c] Care Organization IJssel-Vecht, Zwolle, The Netherlands
[d] Scientific Institute for Quality of Healthcare (IQ healthcare) and Nijmegen Alzheimer Centre, Department of Primary Care, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands
[e] Department of Nursing Home Medicine and EMGO Institute for Health and Care Research, Free University Medical Centre Amsterdam, The Netherlands

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ABSTRACT

Objective: This study describes the process elements of decision-making for dementia, in order to enrich a model to facilitate shared decision-making for professionals working with people with dementia and their informal caregivers.

Methods: We performed a qualitative study based on secondary analysis of 117 interviews from 23 care networks consisting of people with dementia, their informal caregivers and professionals. Findings were compared to an existing model of collaborative deliberation.

Results: We made an enhancement to the existing collaborative deliberation model, to include: (1) constructive network engagement, (2) recognizing the need for a decision, (3) defining what to decide on, (4) developing alternatives, (5) constructing preferences through deliberation and trying out alternatives, (6) multiple preference integration, and (7) evaluating decision-making.

Conclusion: In describing the process elements of decision-making in dementia, this empirical study proposes a modification of the model of collaborative deliberation for the context of dementia care. The adaptation highlights the special attention needed to recognize and define what to decide on, try out alternatives, and handle conflicting interests and preferences.

Practice implications: Professionals should be attentive to mark the start of the decision-making process and work with participants towards a shared view on the pressing matters at hand.

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1. Introduction

Shared decision-making aims to reach decisions that reflect what is important in patients' lives [1,2]. Through this process, knowledge about health care options is exchanged and patients are facilitated to express their values and develop informed preferences. As shared decision-making models focus mainly on the patient – health professional dyad [2], they are less suitable in the context of decision-making for dementia, where decisions are made in care networks. Care networks are networks including a patient, and a mixture of often multiple informal caregivers and professionals who collaborate to care for this particular person [3]. Few publications address the nature of interactions among networks of clients, informal caregivers and health professionals when making decisions [4,5]. The evidence till now indicates that professionals tend to overlook the possible role of the informal caregivers in decision-making; their role is often not discussed by professionals and they are not facilitated to contribute their unique perspectives [6]. Shared decision-making involving multiple participants is not self-evident for dementia care professionals.

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[*] Corresponding author. Research Group Innovating with Older Adults, Centre of Expertise in Health Care and Social Work, Windesheim University of Applied Sciences, Campus 2-6, F119, P.O. Box 10090, 8000 GB Zwolle, The Netherlands, Tel.: +31 88 469 87 52.

E-mail address: lm.groen-vande.ven@windesheim.nl (L. Groen van de Ven).

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Reaching shared decision-making in the context of dementia is even more difficult because people with dementia experience increasing difficulties in making decisions due to cognitive decline [7]. They want to be involved in decisions about their lives as long as possible, but realize that over time they will increasingly have to rely on their Informal caregivers [7–9]. In addition, informal caregivers experience difficulties in deciding for their loved ones. This is partly because it involves balancing their own interests with those of the person with dementia [10,11], as decisions have implications for them both [12,13]. Decision-making in the context of dementia should thus be considered a relational process, in which the interdependency between people with dementia and their caregivers is evident [11]. Professionals who want to facilitate shared decision-making must address both the person with dementia and informal caregivers.

The theoretical model of collaborative deliberation may be helpful when facilitating shared decision-making with multiple participants [14]. This model describes deliberation and collaboration as the main processes for reaching decisions in accordance with the preferences of participants. Deliberation is the process whereby participants cooperate to consider and explicate alternatives and develop their personal and mutual preferences. Collaboration encompasses multiple participants working together to move towards a certain course of action. Rather than focussing on reaching consensus, collaboration emphasizes the process of working together in reaching decisions. This model may offer professionals a tool when practicing shared decision-making in dementia care networks. However, we do not know whether the model matches the empirical context of decision-making in dementia where cognitive deterioration hinders the decision-making.

Our research questions are:

- What are the process elements of decision-making in dementia care networks?
- How can the model of collaborative deliberation be enriched in order to facilitate shared decision-making in dementia care networks?

2. Methods

2.1. Design

This study involves a secondary analysis of data gathered for a large longitudinal study on decision-making in dementia care networks [15,16]. For this study we interviewed people with dementia, their informal caregivers, and the professionals involved. Data were analysed using content analysis. The resulting categories were compared to the model of collaborative deliberation [14].

2.2. Setting

This study followed the care networks of people with dementia in the Netherlands, both those living independently and those admitted to a nursing home. People with dementia and their informal caregivers were interviewed at their homes or in the nursing home. Professional caregivers were interviewed at their workplaces.

2.3. Participant selection

In the original study [15] we purposefully selected care networks of people with dementia, consisting of the person with dementia, two informal caregivers, and two professional caregivers. We sampled for maximum variation regarding the characteristics of the person with dementia (gender, socio-economic status and stage of dementia) and type of informal caregiver (spouses, children, other relatives or friends). We recruited care networks via: (1) health care organizations, (2) Alzheimer cafés, and (3) the website of the Dutch Alzheimer's Society. The inclusion criteria were: a diagnosis of any form of dementia, the ability to participate in an interview, and the availability of at least one informal caregiver.

We reached out to 30 care networks, of which 25 consented to participate. Refusals of care networks were due to the expected burden on caregivers or people with dementia. Two care networks were excluded because the person with dementia did not meet the inclusion criteria. The remaining 23 care networks included two care networks with only one informal caregiver who was willing to participate, resulting in 113 interviews in total. Table 1 lists the characteristics of the care networks.

2.4. Data collection

Overall, 11 interviewers conducted the semi structured interviews. The topics included the decisions made, participants in decision-making, and communication about decisions (Table 2). The interviewers included the researchers and eight bachelor students (Nursing or Applied Gerontology) whom two researchers (LG and MS) trained in interviewing people with dementia. The interviews lasted 1 hour on average and were audio-recorded and transcribed verbatim.

2.5. Data analysis

Our analysis consisted of three steps. First, we used content analysis to determine the process elements of decision-making in dementia care networks [17–19]. For this secondary analysis, we used codes that had been developed in an earlier part of our study on decision-making in dementia care networks. These codes were developed by two researchers independently using the method of open coding [20], and formed the empirical basis of this study [15]. Second, we clustered the codes into meaningful categories regarding the process elements of the decision-making. We did this by using the method of affinity diagramming. LG, CS, JJ, and MS worked together in a group session, using the predetermined steps of clustering, labelling, and defining categories [21,22]. Third, we aligned our categories with the elements of the model of collaborative deliberation [14] and defined the necessary adaptations.

2.6. Ethical considerations

This study was approved by the local ethics committee of the Isala Klinieken (number: 10.11113). All persons provided informed consent before participating. Participants received oral and written information before consenting to participate. The interviewers stopped the interview in response to any verbal or nonverbal signs that the person with dementia did not want to continue the interview [23].

3. Results

Through our analysis we found four process elements of decision-making in dementia care networks: (1) constructive network engagement, (2) recognizing the need for a decision, (3) defining what to decide about, and (4) collaborating in deliberation and trying out alternatives to reach a course of action. These elements, though presented here as separate and sequential, are in

Table 1
Characteristics of the participants with dementia and the caregivers interviewed.

Respondent characteristics		Care network numbers
Gender	8 Male	1, 4, 8, 10, 14, 17, 19, 23
	15 Female	2, 3, 5, 6, 7, 9, 11, 12, 13, 14, 15, 16, 18, 20, 21, 22
Age	80.4 Mean (6.6 SD)	
Dementia stage	5 Beginning	5, 8, 11, 19, 20
	16 Middle	1, 3, 6, 7, 9, 10, 12, 13, 14, 15, 16, 17, 18, 21, 22, 23
	1 Advanced	2
	1 Unknown	4
Marital status	13 Married	1, 4, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22, 23
	7 Widowed	2, 5, 8, 13, 15, 16, 19
	3 Single	3, 18, 20
Living arrangements	16 Community dwelling	5, 7, 8, 9, 10, 11, 12, 14, 14, 15, 16, 17, 19, 20, 21, 22
	5 Nursing home	2, 4, 6, 18, 23
	2 Home for the elderly	1, 3
Informal caregivers interviewed	11 Spouse	1, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22
	17 Daughter/son	1, 2, 4, 5, 6, 8, 9, 11, 14, 15, 17, 19, 21, 23
	5 Daughter-/son-in-law	4, 12, 13, 15, 16
	10 Other family	3, 13, 18, 20, 22, 23
	1 Friends	5
Professionals interviewed	18 Case manager/care coordinator	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 15, 16, 17, 18, 19, 20, 22
	8 Day-care employee	5, 7, 11, 12, 14, 17, 20, 22
	7 Home care nurse	8, 13, 14, 15, 16, 19, 21
	7 Principal attendant nursing home	1, 2, 3, 4, 6, 18, 23
	3 Team leader/head of the department	6, 13, 21
	1 Creative therapist	10
	1 Domestic help	9

Table 2
Interview topics for the different types of respondents.

Subject	**Topics and questions for PWD**	**Topics and questions for informal caregivers**	**Topics and questions for professional caregivers**
General information	Age Former profession Ethnicity Gender Living accommodation (community dwelling, home for the elderly, nursing home)	Gender Relationship with the PWD	Professional background Tasks related to the care of the PWD Type of organization where professional works Team composition Involved in care for the PWD since when? Diagnosis of the PWD (by whom and what type?) Professional assessment of the stage of dementia
Decisions	• How are you? • What has changed for you lately? • What choices have you had to make because of these changes? • What do you think about your decisions now?	• How do you feel the PWD is doing at the moment? • What has changed for the PWD lately? • What choices have you had to make because of these changes? • What do you think about your decisions now?	• What has changed for the PWD lately? • What choices have you had to make because of these changes? • What do you think about your decisions now?
Decision-making	• What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision?	• What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision?	• What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision?

practice blurred and partly overlapping. Participants may move forward and later revert to previous elements.

3.1. Constructive network engagement

This element is a precondition for decision-making and covers the whole process of working collaboratively towards choosing a course of action. It includes engaging with all relevant care network members to involve them in decision-making. The sub-elements are defining the participants, involving participants, and handling the nature of the interactions between participants.

3.1.1. Defining the participants

Case managers are identified as facilitators of the decision-making. Depending on the problem at stake and the participants of the care network, others such as informal caregivers, nurses or day-care employees may be involved. Care network members may be closely involved and present during consultations, or influence the decision-making alongside the formal consultations. Some couples choose not to involve their children in decision-making. In -laws are also sometimes excluded. As such, the decision-making participants may change depending on the care network and the particular decision at stake.

Box 3.1.1 Examples quotes for defining participants
<TS: Set as extract>
[Interviewer: Were all your children involved in the decision to start day-care?] No, well they may have talked about between themselves, but it was [name of daughter] who went with me to the doctor. That was when I was angry with my husband again. – Care network 11, woman living with dementia
The couple has good contact with their children, but they say: 'They have a life of their own. As long as we can manage ourselves, we will do that'. – Care network 9, case manager of a couple in which the woman is living with dementia.

</Extract>

3.1.2. Involving participants

Facilitating shared decision-making means involving people with dementia as well as their informal caregivers. To meaningfully involve people with dementia, they need support in overseeing what is relevant to their situation and to understand information about a number of alternatives. As their dementia progresses involvement will become too difficult or stressful for the person with dementia. This is carefully monitored by case managers, who will then support the informal caregivers by helping them to understand their new role and encouraging them to express their concerns and interests.

Box 3.1.2 Example quotes for involving participants
<TS: Set as extract>
I can't anticipate so well, and what will be possible, and he [spouse] can do it all so much better. [Interviewer: And how is that for you?] Well, pleasant. That's why I say, if he wouldn't be there, it would be a disaster. – Care network 9, woman living with dementia
[The spouse] kept trying to explain everything to her. While, I sometimes had the idea that . . . at a given moment, the time had come, that explaining hurt her more than just doing things for her. – Care network 7, case manager of a woman living with dementia

</Extract>

3.1.3. Handling the nature of the interactions between participants

Shared decision-making in the context of dementia means working together with couples or families, where individuals each have their own roles and where communication patterns have been developed over the years. Some families are used to discussing things openly, while in other families this is more difficult. Dementia complicates interactions in the network because role changes may become necessary. Professionals can operate strategically once they are aware of the interactions within the care network, and can thus navigate between the network members to find common grounds. For instance, they can function as a bridge between care network members who have difficulties in discussing their situation together.

Box 3.1.3 Example quotes for handling the nature of the interactions between participants
<TS: Set as extract>
There were quite a lot of relational issues. That is why we decided that I would see [her] alone first, and then her husband also alone. Before, we would be together. I had to explicitly promise her not to convey anything she told me to her husband. Well, that's how we did it. – Care network 11, case manager of a woman living with dementia
I find it difficult to take the initiative. Because you take things away from him, you know? You are going to decide and do this and that. You don't want to do more than just mediate. But it becomes more and more you taking the lead about what he can and cannot do, kind of an executive role. – Care network 19, son of a man living with dementia

</extract>

3.2. Recognizing the need for a decision

This is a necessary element because of the gradual emergence of problems stemming from progressive decline and other changes in the care network. The changes result in an emerging realization that the situation as it is can no longer be maintained. Participants may differ, however, in their level of recognition of problematic situations. The sub-elements are: decision-making triggers, raising a decision topic, and respecting the decision-making pace of participants.

3.2.1. Decision-making triggers

Decision-making triggers include the declining functioning of the person with dementia and other circumstances that generate the need to make decisions. Triggers may result from a particular event, such as the primary informal caregiver being hospitalized, or from a safety hazard regarding the person with dementia. However, a trigger can also mean a gradual change in views of the situation, which can sometimes make the start of decision-making blurred.

Box 3.2.1 Example quotes for decision-making triggers
<TS: Set as extract>
I went cycling with her once, and we may have cycled about 40 kilometres when she became tired and then everything went wrong. She began swinging and not riding on the right side of the road, and suddenly crossing the road. That's when I thought: 'Oh, this is going wrong'. Then I really saw it myself.– Care network 2, daughter of a woman living with dementia

I used to think: 'Till my last breath [I will care for her]'. But then you are confronted with the effect of that. You have no future for yourself. This only gets worse. More care, more monitoring . . . And, what if it takes another five years? Or eight? How old will I be then? What's left for me? – Care network 7, spouse of a woman living with dementia

</extract>

3.2.2. Raising a decision topic

When a trigger for decision-making is experienced, someone in the care network needs to act upon it and initiate decision-making. Topics are raised by case managers or another professional caregivers, but also by informal caregivers. Problems experienced in the here and now, as well as topics expected to become a problem in the future are relevant. Most people with dementia do not raise topics for decision-making themselves. Exceptions to this in our study were two single women who were used to living their own lives and arranging things for themselves.

Box 3.2.2 Example quotes for raising a decision topic
<TS: Set as extract>
About five weeks ago I had a small cerebral infarction. That was the reason for me to consult with the case manager again. I said: 'What shall we do?' Because what if something happens again and my wife is left home alone? – Care network 21, spouse of a woman with dementia
At a given moment she said 'I think you should put me on a list. That if you get ill, then I can go there [to a nursing home]'. Well, and then this woman came to talk to her, and she clearly stated to that woman: 'I cannot take care of myself anymore, so I should go and live in [name of nursing home]. – Care network 18, sister of a woman with dementia
</extract>

3.2.3. Respecting the decision-making pace of the participants

Case managers want to prepare the care networks for future decisions. However, in doing so they must attune to the decision-making pace of the participants. Pushing is not effective and professionals need to act carefully by slowly introducing topics and proceeding in accordance with the reaction of care network members. The difficulty here is that the pace may vary among the different care network members.

Box 3.2.3 Example quotes for respecting the decision-making pace of the participants
<TS: Set as extract>
I am not there to push them into all kinds of things that they may not want for the time being. No, you should wait for the right moment. – Care network 11, case manager of a couple in which the woman is living with dementia
They leave that to you, you know? Whether you think it's time for a nursing home admission. It's your choice. Not like they don't care. No, it's simply your choice. They leave you in peace. Then [the care coordinator from the nursing home] said to me: 'I'll call you up every month'. I said: 'That's fine'. You know, they are looking at me too, right? How am I doing? Am I still keeping up with it? – Care network 6, spouse of a woman living with dementia

</extract>

3.3. Defining what to decide on

This element includes participants defining problems that require decisions now, and defining what they want to achieve in the situation of the person with dementia. Sub-elements involve: defining the decision topic and goal setting.

3.3.1. Defining the decision topic

Care network members may have different views about what constitutes a problem in the situation of the person with dementia. Some care networks experience conflict because of these differing views. This is especially apparent when people with dementia or their informal caregivers have trouble accepting the decline caused by dementia. Multiple problems may also be relevant simultaneously. To avoid miscommunication during decision-making, case managers must help the care network to develop a shared view of which decision topic needs to be discussed.

Box 3.3.1 Example quotes for defining the decision topic
<TS: Set as extract>
I relied especially on what the daughter said. That her mother called her a lot, especially at night. And [the person with dementia] also stated that she had been outside alone at night and had lost her way. Particularly the daughter played an important role on the whole in getting a clear idea about what was going on. – Care network 5, case manager of a woman living with dementia
Well . . . actually she doesn't want any care, because she feels she can still do it herself. Acknowledging that she cannot do something is very hard for my mother. – Care network 9, daughter of a woman with dementia

</extract>

3.3.2. Goal setting

Goals relate to overarching values that care network members strive for when making decisions. Making decisions becomes easier when these overarching goals have been explicitly discussed. Professionals use goals that were set with the care network to focus their conversations about particular decisions. Goals include the person with dementia remaining independent for as long as possible, the well-being of the person with dementia and the informal caregiver, and the safety of the person with dementia living at home alone or living in the nursing home.

Box 3.3.2 Example quotes for goal setting
<TS: Set as extract>
A long-term care plan with long-term goals is important, because you can continually refer to that: 'We agreed all together that we would try for you to remain here in your own home as long as possible. That is what you want, right?' They will agree. Then you explain that some measures are necessary. – Care network 15, case manager of a woman with dementia
I would rather not move from this house. We have lived her for so long. Selling the house . . . I don't like the sound of it. But they have said in [the day-care organization] 'You don't have to do that. Don't worry, you can stay in your own home'. So that's what I want to try for as long as possible. – Care network 5, woman living with dementia
</extract>

3.4. Collaborating in deliberation and trying out alternatives to reach a course of action.

This element includes the process of developing alternatives, deliberating over them, and trying them out to reach a course of action that is suitable to the particular situation of the care network. Sub-elements include: developing alternatives, constructing preferences through deliberation and trying out alternatives, balancing conflicting preferences and interests, and evaluating the decision. As these sub-elements were seen both simultaneously and alternately in the interviews with the care networks, they have been combined into one element.

3.4.1. Developing alternatives

The problems that care networks experience are intertwined with their specific situation, and consequently no standard alternatives are readily available. Finding out what the alternatives are implies deliberation as well as trying-out alternatives through trial and error and observing what works well. Informal caregivers sometimes have difficulties to develop ideas about possible solutions and therefore rely on professional caregivers for information about the alternatives. Unfortunately, professionals themselves are not always aware of all the alternatives or are reluctant to provide information about alternatives that go beyond their own organization.

Box 3.4.1 Example quotes for developing alternatives
<TS: Set as extract>
It took us quite some time to figure out what to do with her. Now it's . . . no, she likes it a lot. She helps with cooking here at [name of the ward]. Preparing the food.. involving her in that, potatoes, vegetables, cleaning. She likes it all. She likes doing that a lot. – Care network 3, principle attendant of a woman with dementia living in a nursing home
If the alternative is outside your organization, that's a pity of course. Preferably you'd see her with your organization for the whole trajectory. But those are choices they make themselves. You provide options, but at some point the possibilities for your organization stop. – Care network 22, principal attendant of a woman living with dementia
</extract>

3.4.2. Constructing preferences through deliberation and trying out alternatives

Deliberation and weighing alternatives is quite difficult for people with dementia. What they say is not always congruent with their behaviour, which makes it difficult for others to attune to their preferences. For this reason, trying out alternatives and observing the reactions of the person with dementia is incorporated into the deliberation process in order to reach conclusions about the suitability of alternatives. In this way, emotions are relevant cues to interpret the preferences of the person with dementia. The process of deliberating upon considerations and developing preferences is full of emotion because of the confrontation with the declining functioning of the person with dementia. Informal caregivers may experience feelings of guilt about having to relinquish care to others, or fear for the safety of the person with dementia. It is important to acknowledge these emotions during the deliberations.

Box 3.4.2 Example quotes for constructing preferences through deliberation and trying-out alternatives
<TS: Set as extract>
Saying and doing is not quite alike with her. Like the issue of privacy. That's very important to her. So you would expect her to retire in her own room. But she is actually the person who is the most often in the joint living room. – Care network 3, principal attendant of a woman living with dementia in a nursing home
What happens is that other issues rise to the surface too: 'You want me out of the home'. On occasion we have talked about day-care or a care farm or something. Well, then I have to explain endlessly why this may not only be good for her, but also for me. To keep up. – Care network 9, spouse of a woman living with dementia
</extract>

3.4.3. Balancing conflicting preferences and interests

People with dementia and their informal caregivers sometimes have different considerations and preferences based on their different perspectives and interests. Primary informal caregivers tend to conform to the preferences of people with dementia, while secondary informal caregivers seem to have less difficulty in contesting their preferences. For professionals who want to facilitate shared decision-making in care networks, this means balancing the potentially conflicting preferences of people with dementia and their informal caregivers. Depending on the situation, professionals assert the preferences of the individual least heard. Making decisions takes time and it is sometimes difficult to reach consensus given the differences in perspectives and interests. When consensus is hard to reach, decisions are sometimes postponed or accepted as temporary, with the explicit understanding that they will be reviewed and may be reversed later.

Box 3.4.3 Example quotes for conflicting preferences and interests
<TS: Set as extract>
My brother comes over much more...almost daily . . . to check dad. Well, I have said . . . wouldn't it be better . . . if he moved to another setting? I would want to take action and settle for him to be somewhere else. But my brother is like . . . : 'Let him be. It's okay like this'. Care network 19, son of a man living with dementia
When he says no [to extending day-care by an extra day] it will become very difficult. Often it won't happen then. We will simply wait another while and try again later. – Care network 14, day-care employee of a man living with dementia
</extract>

3.4.4. Evaluating the decision-making

Evaluating decisions is seen by professionals as a way of continuing the consensus on courses of action, and if necessary making adjustments to these actions to align with the changing preferences of participants. Evaluations look at both the content and the timing of the decision. It is important to take into account that people with dementia may need some time to adjust to changes. This means that evaluations should not be planned too soon after the implementation of a decision. Evaluating decisions includes deliberating as well as observing the person with dementia, with respect to well-being, satisfaction and sense of ease. These observations provide more information for the evaluation of the decision than the verbal contributions of the person with dementia alone.

Box 3.4.4 Example quotes for evaluating the decision-making
<TS: Set as extract>
[The person with dementia] agreed to try and see how it went. If he or his wife didn't like it, we could reverse it. We agreed to try it out for six weeks. – Care network 1, principal attendant of a man living with dementia
When she was just living here, the family had the idea that she didn't find it to her liking with us [in the nursing home]. She kept saying she didn't like it here. Of course, that's bothersome. But, we saw her laughing, or enjoying activities. We thought we could gather that from what we saw. We observed that in some ways she is nevertheless enjoying herself. – Care network 6, Head of the department of a nursing home housing a woman living with dementia
</extract>

3.5. Enriching the model of collaborative deliberation to support professionals in facilitating shared decision-making in dementia care networks

The model of collaborative deliberation consists of five elements [14]: (1) constructive engagement, (2) recognizing alternatives, (3) comparative learning, (4) preferences construction and elicitation, and (5) preference integration. The model seems helpful in structuring the process of shared decision-making in dementia care networks. Nevertheless, some process elements are lacking.

Constructive engagement in the context of dementia means involving all relevant participants in the decision-making, thereby handling the interactions between them by aligning to longstanding spousal and family relationships. This implies that the professional builds constructive relationships with and within the network of the person with dementia. Before proceeding to the next element of recognizing alternatives, two elements are necessary in the context of dementia that are not described in the model of collaborative deliberation.

First, there is a need to mark the start of the decision-making, because of the progressive character of the dementia, which implies an ever changing situation. This implies an emergent realization that the situation as it is can no longer be maintained. As the multiple participants involved may differ in their level of recognition of the need for a decision, it is necessary to reach agreement within the network that decision-making is required. Second, the multiple participants involved may have various ideas about what constitutes a problem in the situation of the person with dementia and about what they want to achieve. This makes it necessary to explicitly define what to decide about, before moving on to deliberating about the alternatives.

Recognizing alternatives in the context of dementia implies a process of negotiating in order to develop the alternatives. Alternatives are often not readily available, but are intertwined with the particular situation of the care network. The next element of the model of collaborative deliberation is comparative learning,

Table 3
The enriched model of collaborative deliberation in dementia care networks compared to the original model of collaborative deliberation [14].

Elements in the model of collaborative deliberation [14]	The enriched model of collaborative deliberation in dementia care networks	The empirical basis for the adaptations to the model
Constructive engagement takes place when interactions between participants are characterized by curiosity, respect, and empathy.	*Constructive network engagement* includes involving the network of the person with dementia and aligning to the nature of the longstanding family or spousal relationships in the network.	*Constructive network engagement* • Defining decision-making participants • Involving participants • Handling the interactions between participants.
	Recognizing the need for a decision now is an additional element to the model. It includes negotiating with the network about emerging decision topics, arising from the differences between participants in terms of recognizing problems.	*Recognizing the need for a decision* • Decision-making triggers • Raising a decision topic • Respecting different decision-making paces.
	Defining what to decide on is an additional element to the model. It includes explicating decision topics and the related goals, and choosing which problem needs to be addressed now.	*Defining what to decide on* • Defining the decision topic • Goal setting.
Recognizing alternatives takes place when interactions between participants recognize the existence of relevant, alternative potential courses of action.	*Developing alternatives* includes developing alternatives together with the network, often by trial and error. Care networks usually perceive a lack of readily available alternatives. Alternatives therefore depend on the possibilities and knowledge of the care network.	*Collaborating in deliberation and trying out alternatives to reach a course of action.* • Developing alternatives.
Comparative learning takes place when interactions between participants compare alternative courses of action *Preference construction and elicitation* takes place when interactions between participants consider, construct, and elicit preferences in relation to alternatives courses of action	*Constructing preferences through deliberation and trying out alternatives* means combining and alternating deliberation and trying out alternatives to find what suits best. The emotions and behaviours of people with dementia may be used by informal caregivers and professionals to interpret their preferences.	• Constructing preferences through deliberation and trying out alternatives.
Preference integration takes place when interactions between participants integrate individual preferences in determining the subsequent courses of action	*Multiple preferences integration* means balancing the potentially conflicting interests and preferences of the person with dementia and the informal caregivers into a course of action.	• Balancing conflicting preferences and interests.
	Evaluating decision-making is about looking back at decisions made and modifying decisions if necessary. It is also important to evaluate the process of reaching decisions in order to learn for future decision-making situations.	• Evaluating decision-making.

which implies comparing the alternatives that are recognized in the earlier stage of the decision-making. For people with dementia it is often difficult to compare alternatives based on deliberation alone. Trying-out alternatives is an important way of finding out the pros and cons and to develop their preferences. The emotions and behaviours of people with dementia during these try-out periods may be used by informal caregivers and professionals to interpret their preferences. As such, comparative learning and preference construction are linked processes in the context of dementia, and both are supported by people with dementia trying-out alternatives. The last element in the model of collaborative deliberation, preference integration, is complicated in the context of dementia by the fact that people with dementia and their informal caregivers have different perspectives, preferences and interests. This means that preference integration includes balancing the potentially conflicting interests and preferences of the person with dementia and the informal caregivers into a course of action.

The model of collaborative deliberation does not include evaluation of the decision made. However, in the context of dementia evaluating seems to be relevant for adapting the course of action if necessary. Besides this, by looking back at the process of reaching decisions, care networks may learn for future decision-making situations.

Based on our empirical findings, we enrich the model of collaborative deliberation for the context of dementia care by highlighting the special attention needed to recognize and define what to decide on. Moreover, we address the roles of the multiple participants involved in the decision-making. Additionally, we clarify that alternatives need to be developed with the participants. Besides, we add trying-out as part of the work needed to construct preferences. Finally, we explain the need for evaluating the decision-making. The enriched model of collaborative deliberation consists of the following elements: 1) constructive network engagement; 2) recognizing the need for a decision; 3) defining the problem; 4) Developing alternatives; 5) constructing preferences through deliberation and trying out alternatives; 6) multiple preferences integration; 7) evaluating decision-making. Table 3 compares the existing model to the enriched model of collaborative deliberation in dementia care networks, that was based on the empirical elements of our study.

4. Discussion and conclusion

4.1. Discussion

Three elements are essential for collaborative deliberation in the context of dementia care networks. First, preparatory work is needed before care networks can actually start deliberating about possible alternatives to deal with a certain problem. This includes recognizing the need for decision-making and defining the decision at stake. Problems are often recognized at first by informal caregivers, but they may find it difficult to initiate discussions about them. Professionals could help informal caregivers to do this by making it a regular part of the consultation to discuss the concerns of all participants involved. Multiple views on what is experienced as a problem often exist, since care network members tend to focus on different aspects of the situation [24]. Wolfs, de Vugt, Verkaaik, Haufe, Verkade, Verhey and Stevens [25] described how decision-making in dementia starts by identifying the individual needs of people with dementia and their informal caregivers, based on experienced problems that are likely to differ. These different views of participants are a potential cause of miscommunication during decision-making and it is recommended to discuss them and reach agreement about which problem needs to be addressed now.

Second, deliberation includes rational discussion as well as trying out alternatives, expressing emotions and observing the behaviour of the person with dementia. This is important for two reasons. First, contributing to decision-making by observing emotions and trying out alternatives allows for an inclusive way of involving people with dementia throughout the course of their dementia. It recognizes the potential agency of people with dementia as a first step in supporting their decision-making role [26]. It helps to understand what people with dementia prefer in a certain situation, without always requiring them to be cognitively involved. Carefully monitoring the emotions of people with dementia and allowing them to experience certain alternatives supports their capabilities and provides them with the opportunity to engage in decision-making in a meaningful and less burdensome way [27,28]. Second, in the complex context of dementia care networks, the evidence about the pros and cons of different alternatives is often unclear and depends on the particular context of the person and his or her informal caregivers [24]. Through a process of trial and error new alternatives may become clear, which are then compared through processes of deliberation and trying out alternatives. Because the alternatives are not clear upfront, it is the participants who must decide together when enough alternatives have been considered, deliberated upon and tried out [29].

Third, collaborative deliberation in the context of dementia care networks inevitably includes conflict between care network members given their different perspectives on the situation and their different interests concerning the decision-making outcome. Quinn, Clare, McGuinness and Woods [5] have described how triads of people with dementia, their spouses and nurses must constantly negotiate the balance between their own needs and the views of the others involved. In this context, coalitions may be formed between participants to reach solutions for certain problems [4,5]. Professionals should be aware of these coalition strategies, because they may involve overruling the perspectives of either the person with dementia or the informal caregiver. As a result, collaborative deliberation in dementia care networks may often include some form of struggle in order to reach compromises, and in some cases consensus may not be reached.

4.2. Strengths and limitations

The strength of this study lies in its reliance on empirical data stemming from a rigorous approach leading to rich data from multiple perspectives [30]. This study nevertheless has several limitations. First, we used secondary analysis of interview data about decision-making. This means we did not gather data with the model of collaborative deliberation as a basis, which means that we could not ask on questions about elements of collaborative deliberation. Second, this study is based on interviews about decision-making processes, and not on observations of actual decision-making encounters. The reported behaviours of the professionals may be an overestimation. The fact that we gained information from multiple perspectives may have counterbalanced this limitation.

4.3. Conclusion

This empirical study has helped to validate and enrich the model of collaborative deliberation for dementia care networks. It is a useful model for structuring the often blurry decision-making process regarding dementia. Special attention is needed, however, for the preparatory steps of decision-making, for trying out alternatives, and for handling conflicting interests and preferences.

4.4. Practice implications

Professionals who want to facilitate collaborative deliberation in dementia care should be aware that they need to involve both the person with dementia and the informal caregivers. They should be attentive to the preparatory steps of decision-making and start by working with all participants towards achieving a shared view about the problem requiring decision-making. They can include people with dementia in the deliberation process by allowing them to try out alternatives instead of merely relying on rational discussions about alternatives. Behaviours and emotions of the person with dementia serve as indications of preferences during this process. Finally, they should be aware of the potentially conflicting perspectives of people with dementia and their informal caregivers when working towards a course of action, and stress the perspectives of those participants least heard.

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