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Involvement of people with dementia in making decisions about their lives: a qualitative study that appraises shared decision-making concerning daycare

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Competing interest declaration

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

Data sharing statement

Extra data is available by emailing Leontine Groen – van de Ven: lm.groen-vande.ven@windesheim.nl

Abstract

Objective To explore how people with dementia, their informal caregivers, and their professionals participate in decision-making about daycare and to develop a typology of participation trajectories.

Design A qualitative study with a prospective, multi-perspective design, based on 244 semi-structured interviews, conducted during three interview rounds over the course of a year. Analysis by means of content analysis and typology construction.

Setting Community settings and nursing homes in the Netherlands

Participants Nineteen people with dementia, 36 of their informal caregivers, and 38 of their professionals (including nurses, daycare employees, and case managers).

Results The participants' responses related to three critical points in the decision-making trajectory about daycare: (1) the initial positive or negative expectations of daycare; (2) negotiation about trying out daycare by promoting, resisting, or attuning to others; and (3) trying daycare, which resulted in positive or negative reactions from people with dementia, and led to a decision. The ways in which care networks proceeded through these three critical points resulted in a typology of participation trajectories, including: (1) working together positively towards daycare, (2) bringing conflicting perspectives together towards trying daycare, and (3) not reaching commitment to try daycare.

Conclusion

Shared decision-making with people with dementia is challenging, but possible. Our results show that initial preferences based on information alone may change when people with dementia experience daycare. It is important to have a trial period so that people with dementia can experience daycare without having to decide whether to continue it. Whereas shared decision-making in general aims at moving from initial preferences to informed preferences, professionals should focus more on moving from initial preferences to experienced preferences for people with dementia. Professionals can play a crucial role in facilitating the possibilities for a trial period.

ARTICLE SUMMARY**Strengths and limitations of this study**

- This study is based on rich interview data collected in three rounds from care networks consisting of multiple participants: people with dementia, their informal caregivers, and their professionals. The perspectives of people with dementia themselves are often neglected in research.
- Data were collected by various interviewers, some of whom were undergraduate students. All the interviewers were trained, and received feedback on their interview style after each interview, but there were still differences in the extent to which they persisted in asking questions.
- We made sure that the interviews of each care network in a given interview round were conducted by one interviewer.
- This study involves people with dementia who were able to participate in an interview and who had informal caregivers present. Cases in which the person with dementia cannot communicate and cases in which no informal caregivers are present would likely present different or additional experiences.

Key-words: Shared decision-making, Dementia, Daycare

Introduction

People with dementia and their informal caregivers are repeatedly confronted with having to make decisions about managing daily life, arranging support, community living, and preparing for the future [1, 2]. One of the decisions involves daycare. Daycare is a regular form of care for community-dwelling people with dementia in various countries worldwide [3-7]. It aims to activate the person with dementia and relieve the burden on caregivers [5, 6]. Deciding about daycare may be complex, since it is often the first source of support outside the home – a time when people with dementia and their caregivers are not yet used to discussing support options with professionals. The subject of daycare arises when people with dementia increasingly have to rely on others to complete cognitive tasks, but are still aware of and able to express their wishes [7]. The daycare question becomes relevant when structuring the day becomes difficult for the person with dementia and the care becomes burdensome for informal caregivers. It is important to involve people with dementia in these decisions, since involvement contributes to the well-being and quality of life of both the people with dementia and their informal caregivers[8, 9].

Shared decision-making is the preferred way of reaching decisions with patients [10-12]. It is a method whereby professionals help patients choose health care options by exchanging information and evidence about options, as well as discussing the patient's values in order to elicit his or her preferences. However, although shared decision-making is recommended, in dementia care the professionals often doubt its feasibility. Decision-making in the context of dementia is complex, dynamic, time-consuming, and full of emotions [13]. Complex decision-making situations are characterized by insufficient clinical evidence, lack of clearly defined goals and options, and preferences that are contextual, provisional, and conditional [14]. In such situations, multiple participants contribute to decision-making over long periods of time [14]. Professionals who facilitate shared decision-making in complex situations need to combine all the participants' perspectives. Moreover, shared decision-making in dementia care networks may be challenged by tensions in the interactions between the participants, and the need to adapt to the diminishing independence of the person with dementia [15].

The diminishing independence also influences the roles of people with dementias in the decision-making. Decision-making is often described as a solely cognitive task, which makes it difficult for people with dementia [16]. However, decision-making involves more than mere analytical thinking, since preferences, for example, are also shaped by emotions and social interactions [17-19].

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3 Emotions and social interactions continue to be present during the course of the dementia
4 trajectory, making it possible to include people with dementia even when the dementia progresses.
5 For instance, informal caregivers and people with dementia deciding together gives the patients a
6 chance to maintain a role in decision-making by using their extant capacities [20, 21]. Professionals
7 who want to involve people with dementia in decision-making should also allow informal caregivers
8 to play a role. However, the informal caregivers have their own interests in the decisions, which
9 means that shared decision-making includes weighing up the different perspectives and interests
10 present [15]. In addition, informal caregivers can influence the level of involvement of the person
11 with dementia on the basis of their own judgments of the person's decision-making capacities [20-
12 22]. This takes place at the risk of marginalising the person with dementia [20-22]. Professionals are
13 challenged to involve informal caregivers in decision-making, elicit their perspectives and interests,
14 and at the same time acknowledge the preferences of persons with dementia. There is a lack of
15 evidence about how people with dementia, their informal caregivers, and their professionals
16 participate in the different stages of the decision-making. The decision about daycare is of particular
17 interest because it is a complex decision where the interests of both the person with dementia and
18 the informal caregivers are at stake.
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30 This study had two objectives: first, to explore how people with dementia, their informal caregivers,
31 and their professionals participate in decision-making about daycare and second, to develop a
32 typology of participation trajectories to get a clearer understanding about the way care networks
33 proceed through the decision-making process collaboratively. This information is for professionals
34 who support people with dementia and their informal caregivers in making decisions about health
35 and well-being.
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Methods

Design

We used a qualitative, prospective, multi-perspective design to gain in-depth insight into the experiences of participating in decision-making about daycare from the perspectives of people with dementia, their informal caregivers, and their professionals. The participants were interviewed three times over the course of a year. This study is part of a research program about shared decision-making in dementia care networks [1].

Setting

Community-living and institutionalized people with dementia in the Netherlands in the early, moderate, and advanced stages of dementia.

Participants

We purposefully selected care networks of people with dementia: networks consisting of a person with dementia, two of his or her informal caregivers, and two professional caregivers [23]. We aimed for maximum variation regarding the characteristics of the person with dementia (gender, socio-economic status, and stage of dementia) and the types of informal caregivers (spouses, adult children, other relatives, and friends). We used three recruitment routes: (1) health care organizations for people with dementia, (2) a local meeting for informal caregivers and people with dementia, 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. The exclusion criteria were: no confirmed diagnosis of dementia and the inability of the person with dementia to participate in an interview. We aimed to include 20 to 30 care networks in order to reach data saturation [24].

Data collection

We interviewed the individual participants of the care networks at 6-month intervals, between July 2010 and July 2012. Twenty-two interviewers had been trained to conduct the semi-structured interviews using an interview guide. The interviewers included three researchers from the research team (LG, MS and another researcher), and students studying for bachelor degrees (in nursing, speech therapy, or applied gerontology). The researchers (LG, and MS) trained the students in qualitative interviewing and interviewing people with dementia. The same interviewer interviewed all the care network members in a given interview round. The interviews lasted 1 hour on average,

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3 and they were audiotaped. The interview guides for the three rounds contained similar topics: the
4 changes that had occurred, the decisions that were made, what had happened before these
5 decisions, who was involved, and how people had experienced the decision-making. Interviews were
6 conducted at the home or workplace of the respondent. We stressed the importance of interviewing
7 the participants alone to avoid influence from others [25]. However, in three care networks the
8 person with dementia was willing to participate only in the presence of the informal caregiver.
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13 *Data analysis*

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15 The interviews were transcribed verbatim and analyzed with Atlas.ti software. To reach our two
16 study objectives, we used a two-step approach that combined a content analysis [26] with a
17 methodology of type construction [27]. We used constant comparison in both steps [28].
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22 Step 1: Content analysis (objective 1)

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24 The content analysis aimed at developing categories and themes related to the participation of
25 people with dementia, their informal caregivers, and their professionals in the decision-making about
26 daycare. This started with open coding of the individual interviews of each care network in the three
27 interview rounds, which meant reading the interview transcripts and labelling the relevant
28 fragments. Codes were thus constructed on the basis of: the information of the five perspectives in
29 each care network, and the three interview rounds [29, 30]. After the open coding, we developed
30 categories by grouping codes into meaningful clusters related to the participation in the decision-
31 making about daycare. The categories were then grouped into meaningful clusters representing the
32 themes of the participation in the decision-making about daycare [28].
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40 Step 2: Typology construction (objective 2)

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42 To develop our typology of the participation trajectories, we used a method for developing
43 empirically grounded typologies, which consists of the following components [27]: (1) development
44 of the relevant analysing dimensions and properties, (2) grouping the cases and analysis of the
45 empirical regularities, (3) analysis of meaningful relationships and type construction and (4)
46 characterization of the constructed types. For the first component, we developed our dimensions
47 and properties from the themes and categories elicited in the content analysis in step 1. For the
48 second component, we made matrices displaying the dimensions and properties for each member of
49 a care network. For the third component, we made comparisons within and between the care
50 networks to construct the types. Since the care network was our unit of analysis, our typology was
51 based on the differences in the combination of the properties of different care network members
52 within each care network. Thus, by comparing within and between care networks, we were able to
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3 group care networks that had similar combinations of properties between the care network
4 members. This resulted in three types of participation trajectories that were then described on the
5 basis of their properties (component 4).
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8 9 Constant comparison

10 Constant comparison was at the heart of our qualitative analysis in all steps. Constant comparison
11 implies comparing newly analyzed data with emerging ideas about the research question [28]. In our
12 analysis, we used comparisons at different levels: within individual interviews, between individual
13 interviews within a care network, between interviews of different types of respondents, between
14 interview rounds for a given care network, and between care networks [31].
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19 20 *Ethical considerations*

21 The Isala Clinics' ethical board approved this study (number 10.11113). Respondents received written
22 information about the study beforehand. Because of the vulnerability of people with dementia as
23 research subjects, participation in the study required the consent of both the person with dementia
24 and his or her primary informal caregiver. We treated the participants' consent, especially that of the
25 people with dementia, as a process [32], and remained alert to signs indicating that the participant
26 wanted to stop the interview [33]. We did not share interview information with other network
27 participants [29]. This study was supported by the Regional Attention and Action for Knowledge
28 circulation (RAAK) program of the Foundation Innovation Alliance (SIA—Stichting Innovatie Alliantie)
29 with funding from the Ministry of Education, Culture, and Science (project number PRO-1-014). The
30 funder had no role in the study design, data collection, analyses, and interpretation of the data, nor
31 in the writing of the article or the decision to submit it for publication. All researchers had access to
32 all the data.
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43 44 *Patient involvement*

45 The research question was developed after consulting professionals in dementia care, as well as
46 informal caregivers of people with dementia. The perspectives of people with dementia were
47 represented by the Dutch Alzheimers' Society, who also participated in the consortium of
48 organizations that monitored the study. Consortium partners were updated about the preliminary
49 results of the study during regular meetings. The Dutch Alzheimers' Society helped recruiting
50 patients for this study. The study participants were updated about the results through regular news
51 letters.
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Results

Respondent characteristics

Twenty-five of the 30 care networks we contacted, agreed to participate. The reason given by the five who declined to participate was caregiver burden. We excluded two care networks: one because the person with dementia was unable to participate in the interview at that time, and the other because the diagnosis had been reset to mild cognitive impairment during the study. Nineteen of the remaining 23 care networks discussed the daycare decision in the interviews. Two of 19 care networks had only one informal caregiver each who could be interviewed, which left 93 respondents altogether. The professional caregivers involved included case managers, home care nurses, daycare employees, and a psychotherapist. Two care networks opted out after the first interview round because of the burden of the study. We have used the information from the first interview rounds for these networks. One or more interviews in nine of the care networks could not be conducted during the second or third round because of circumstances such as holidays, moving house, or a change of the professionals involved. In total, we used 244 interviews in the analysis. We reached the intended variation in our sample with respect to gender, stage of dementia and type of informal caregivers. However, we reached mainly people with dementia with a mid level socio-economic status, and we reached only a few with low or high socio-economic status. We did reach data saturation regarding our study topic. Table 1 gives an overview of the participants' characteristics.

Results for objective 1: themes related to taking part in decision-making about daycare

We found three themes regarding participation in this decision-making: (1) initial expectations of daycare, (2) negotiating about trying daycare, and (3) trying daycare. Table 2 describes the themes with the related categories and codes on which they are based.

Theme 1: Initial expectations of daycare

This theme includes care network members starting to discuss and consider daycare for the person with dementia. This categories in this theme are: (1) initiating decision-making, (2) positive expectations, and (3) negative expectations. The care network members' initial expectations of daycare are critical for continuing the decision-making, because they have an impact on how the negotiation about trying daycare proceeds.

Initiating decision-making about daycare

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3 Decision-making about daycare is initiated when one of the care network members starts an
4 exchange about the idea of daycare with one or more other care network members. It is notable that
5 people with dementia and their spouses were not the ones to initiate conversations about daycare.
6 Adult children were often the ones who initiated the conversations. They wanted to prevent
7 overburdening of the spouse.
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12 *"I did raise the issue with my mother before: 'Wouldn't it be good for him to go to the daycare centre so that*
13 *you can catch your breath"* – Daughter of a man with dementia, care network 1
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17 The professionals also initiated discussions with couples about daycare. When no spouse was
18 present, the adult children (or other relatives), and the professionals initiated discussions about
19 daycare.
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23 *"The daycare is a result of the daughters-in-law telling us that there was one day in the week when actually no*
24 *one came by and then he used to call sometimes to say that he was feeling alone, and then they thought: 'Well,*
25 *we might try daycare. Well, I suggested that and discuss it with them."* – Case manager of a woman with
26 dementia living alone, care network 16
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30 31 Positive expectations of daycare

32 Children and other relatives, as well as health care professionals, were usually in favor of daycare for
33 the person with dementia. The people with dementia and their spouses were the participants who
34 did not always have positive expectations of daycare. Positive ideas and expectations about daycare
35 related to concerns about the deterioration of the person with dementia, well-being issues such as
36 loneliness of the person with dementia, caregiver burden, and conflicts between spouses that made
37 daycare necessary.
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44 *"We talked about daycare, partly because the spouse mentioned he couldn't cope at home with his wife.*
45 *Because of the tensions between them. And partly it was because we thought: 'This woman should have*
46 *something to do now and then, she just sits there at home."* Well, and that combination, it just adds up to, that
47 means daycare." – Case manager of a woman with dementia, care network 11
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51 Negative expectations of daycare

52 The people with dementia and their spouses sometimes had negative ideas and expectations of
53 daycare. They related to the idea that the person with dementia was not yet affected enough to
54 need daycare; that daycare would not be useful or suitable, possibly because the person with
55 dementia did not like being in groups; and that daycare would limit the autonomy of the person with
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3 dementia. Negative feelings associated with daycare included: mistrust; being or feeling abandoned;
4 fear, anger, grief, and shame due to loss of functioning; and guilt about putting someone away.
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8 *"I think she is far too good to go to daycare, then she would rapidly worsen. Because then she wouldn't be*
9 *activated anymore. And now her brother comes by for a walk with her, or he drops in once in a while, or people*
10 *come over for me, or she will go along with me, just for companionship. Well, it's out of necessity, she goes*
11 *along to a meeting or something with me."* – Spouse of a woman with dementia, care network 22.
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14 15 Theme 2: Negotiating about trying daycare

16 This theme involves care network members working towards getting the person with dementia to try
17 daycare. The theme includes: (1) participating in conversations about daycare, (2) promoting
18 daycare, (3) resisting daycare, and (4) attuning to others. The negotiation about trying daycare forms
19 a critical point in the decision-making process. Depending on how the negotiation proceeds, the
20 person with dementia may or may not move towards trying daycare.
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25 26 Participating in conversations about daycare

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28 Conversations about daycare occurred at different times, and places, as well as in different forms,
29 such as face-to-face, by phone, or e-mail. The interviews from different rounds showed that the issue
30 was often discussed multiple times before a decision was reached. In some care networks, the
31 person with dementia was deliberately not involved in these conversations. Openly discussing
32 daycare was seen as too confronting, or care network members were afraid that it would result in
33 resistance of the person with dementia to daycare.
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40 *"[The woman with dementia] is not present herself at this meeting of course. Because you want to protect your*
41 *client. Because matters may come up that the client doesn't judge the same way. You discuss the more heated*
42 *issues, so to speak. The results will be submitted to her afterwards, because she has to be up to date at a certain*
43 *point about the changes that are going to come."* – Daycare employee of a woman with dementia, care
44 network 22
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48 In most situations, the conversations focused on whether or not daycare was acceptable, without
49 really exploring the alternatives. The available or perceived options for daycare were often limited,
50 especially for those who did not feel comfortable in groups.
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54 55 Promoting daycare

56 Care network members in favor of daycare were adult children and other relatives, case managers,
57 general practitioners, and other health care professionals. They tried to promote daycare to the
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3 person with dementia and the spouse by encouraging them to try it. They did this by talking
4 positively about daycare, moving tactfully, repeatedly proposing the issue, and looking for support
5 from other care network members who had an influence on the person with dementia.
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9 *“The doctor did encourage me to go to the daycare here. And, I must say, up until now it has turned out to be*
10 *better than expected.”* – Woman with dementia, care network 5
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12
13 *“Well, it wasn’t during the first consultation, that she said: ‘Yes, that daycare, that’s what we’ll do’. Before*
14 *that, it was more like ‘[Let’s] think about it a little more’. I think that after two or three consultations she gave*
15 *her approval to arrange the daycare.”* – Case manager of a woman with dementia, care network 11
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18 19 20 Resisting daycare

21 People with dementia, and the spouses too in some cases, tended to resist the efforts of others to
22 get them to try daycare. They did this by rejecting daycare and by protesting or showing negative
23 emotions when daycare was discussed. Another way of resisting included expressing doubts about
24 daycare. The people with dementia and their spouses could resist daycare by postponing or delaying
25 discussions about it. In several care networks, reaching a decision about daycare was postponed and
26 the issue came up in different interview rounds.
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31 *“You really feel a bit pushed aside, you know, in the beginning. That made me fight in the beginning. I didn’t*
32 *want that.”* – Woman with dementia, care network 11
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37 *“We decided that we would visit a care farm, one that I had already seen before. She said that she agreed. But*
38 *well, she finds excuses not to go every time.”* – Spouse of a woman with dementia, care network 9
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41 42 Attuning to others

43 Attuning was necessary for reaching common ground, given the different perspectives and interests
44 of the participants. Attuning included listening to the ideas and advice of others and weighing
45 different perspectives. The people with dementia tended to stick to their own standpoints, with
46 other care network members attuning to their preferences. A commonly used phrase was, “You
47 cannot force someone to accept daycare.” Children were more likely to go against the wishes of the
48 person with dementia; however, those with decision-making responsibilities for a parent living alone
49 were cautious about overruling the person with dementia. Attuning is illustrated by the following
50 quotation, where the activity coach had a different point of view than the informal caregiver, but
51 tried to attune to her point of view.
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3 *“The spouse indeed really puts [the person with dementia] in the centre. I believe she talks about things with*
4 *[the person with dementia], how she sees them. With daycare too. She asked whether [the person with*
5 *dementia] really wanted to go there. Rightly of course. I mean, as long as it’s possible it is very important that*
6 *the client is the first one to express what she wants.”* – Activity coach of a woman with dementia, care network
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10 11 12 Theme 3 Trying daycare

13 This theme is about people with dementia trying and experiencing daycare as part of reaching a
14 decision about it. It includes the categories of: (1) working together to try daycare, (2) positive
15 reactions of people with dementia to daycare, (3) negative reactions of people with dementia to
16 daycare, and (4) deciding about daycare. Trying daycare is a critical point in the decision-making
17 because continuing or discontinuing daycare depends on the reactions of the person with dementia.
18 Therefore, this is a phase in the decision-making where people with dementia have an important say.
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24 25 Working together to try daycare

26 Arranging a try-out was often still part of the process of encouraging the person with dementia to
27 use daycare. Their children and home care nurses were eager to make the try-out as easy as possible
28 so that the person with dementia would not hesitate. They did this by visiting the daycare centre
29 together, bringing the person to the daycare, or by making sure that the person was ready to go
30 when the bus to the daycare arrived. In this way, the transport of people with dementia to the
31 daycare facility was not only a practical solution, but also part of encouragement to use daycare.
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38 *The first days that she went there [to the daycare centre] I tried to take time for her. That I would be there to*
39 *help her shower and dress and to stay until the taxi arrived. And after a few days she actually thought it was*
40 *great [to go there].”* – Home care nurse of a woman with dementia, care network 12
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44 A try-out took place once the person with dementia had consented to it. Only in cases where there
45 was risk of overburdening and the spouses had started to relinquish some of their care would the
46 person with dementia perhaps be forced to try daycare.
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49
50 *“My mother-in-law always said: ‘I won’t go to daycare’. But well, there comes a time when they ca no longer*
51 *make that kind of decision themselves. At least, the care became too burdensome for my father-in-law.”* –
52 Daughter-in-law of a woman with dementia, care network 12
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55 56 Positive reactions of people with dementia to daycare

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3 For care network members, the person with dementia's reactions to daycare, once he or she had
4 tried it out, were very important. Positive reactions included positive experiences, such as liking
5 daycare or enjoying the activities; positive feelings, such as relief, happiness, and trust; and positive
6 behaviour towards daycare.
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11 *"She goes with pleasure [to daycare]. She makes sure that she is downstairs on time. This morning I overslept a*
12 *bit. Well, she had everything all ready. She had set the table, because 'Yes, I have to be on time'."* – Spouse of a
13 woman with dementia, care network 22
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17 When people with dementia reacted positively to daycare, it helped the spouse and children decide
18 about daycare. Positive reactions reinforce the decision about daycare. Further, informal caregivers
19 show reactions based on their own experiences with the person with dementia visiting daycare.
20 Positive reactions of informal caregivers relate to feelings of relief and having a sense of control of
21 the situation.
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25 26 27 Negative reactions of people with dementia to daycare

28 Negative reactions to daycare include negative experiences, such as disliking daycare or being
29 dissatisfied, and negative behavior such as complaining, not participating in the activities, or walking
30 away. Care network members take negative reactions seriously. Daycare may be stopped, or
31 discussions about reducing daycare may be initiated.
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37 *"It seems as if he enjoys it all, only if you speak to him about it, he says: 'What am I doing here? Why am I here?*
38 *Why can't I be with my wife?' I do take that back to the care coordinator every time. In the sense of, 'Can we do*
39 *something about that?' We discussed the idea of him staying home one day a week. "* – Principal attendant of
40 man with dementia, care network 1
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44 However, care network members also think it is important to give time to the person with dementia
45 to adjust to daycare, as the reactions of people with dementia about daycare may shift over time
46 from negative to positive.
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52 *"We warned her [laughs]. Try it first. If you don't feel like going, you quit. So, just try, because, if you really think*
53 *it's terrible, all right, then no! We'll quit. Well, it took several months before she found her niche."* – Daughter of
54 a woman with dementia, care network 11
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58 Sometimes negative reactions are overruled by informal caregivers who are overburdened.
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"[Interviewer: Did she consent to extend the daycare to three days a week?] Well, not really consent. She was against it until the day it started. She didn't want to go another day. But, well, in the end, you can't really do anything else. Because the care becomes too much." – Daughter-in-law of a woman with dementia, care network 12

Deciding about daycare

Once daycare had been tried the care network members explicitly or implicitly reached a decision. The reactions of the person with dementia were important cues for the informal caregivers and professionals involved in reaching this decision.

"She signed her care plan last week and she has said that she feels comfortable here and that she enjoys coming here. And I believe that. Sometimes you see that clients say one thing here and at home it's a different story. That they are not motivated at all. But, with her, I think she is really motivated and enjoys coming here." – Day-care employee of a woman with dementia, care network 5

"Meanwhile, she went to the daycare, but she didn't like it because everyone was asleep according to her. [Both the interviewer and respondent laughed]. She was like: 'That dead place, I don't fancy that'. So, well, she made the choice herself. We showed her what it was like, she has been there twice, and the third time she was like: 'I won't go there anymore'. That was her choice, and there must have been someone trying to convince her otherwise, but no was no." – Case manager of a woman with dementia, care network 16

The whole process of deciding about daycare could start over once the situation of the person with dementia changed because of a decline in functioning or when the informal caregiver relinquished care. Follow-up decisions included extending or reducing daycare, and changing between groups.

Results objective 2: Types of participation trajectories

We distinguished three different types of participation trajectories on the basis of the manifestation of the four dimensions that we developed from our themes and categories. They are: (1) working together positively towards daycare, (2) bringing conflicting perspectives together to facilitate trying daycare, and (3) not reaching a commitment to try daycare. Table 3 displays the different types of participation trajectories

Type 1: Working together positively towards daycare

This type of participation trajectory consists of situations that are characterized by congruent positive expectations about daycare within the care network. There is no resistance to the idea of

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3 trying daycare in these situations, and once it has been tried out, the person with dementia and the
4 informal caregivers experience the daycare as positive. In these situations, the decision to reach
5 daycare is easy and things are promptly arranged without much discussion.
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10 *"It all went very fast...that she could go there [to the daycare]. And, at first she said: 'I'll just try it first, and then*
11 *we'll see'. But, she found it terrific from the first day."* – Daughter of a woman with dementia, care network 5
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14 Type 2: Bringing conflicting perspectives together towards trying daycare,

15 This trajectory type is characterized by conflicting perspectives of the care network members about
16 trying daycare. The person with dementia, and some of the spouse are negative about trying it,
17 whereas other care network members are positive. Sometimes there are multiple conversations or
18 attempts to take the person with dementia to try daycare. Care network members take the time to
19 think things over as long as they feel this is safe for the person with dementia, and do-able for the
20 informal caregivers.
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27 *"The way he is now, he is not wandering or anything, you know? I think he's very lonely, but he says he is doing*
28 *fine. I ask him all the time: 'How are you doing? Don't you want more?' Then he says: 'No, I'm fine'. Well, then I*
29 *may feel he is lonely, and think he needs more activities, but if he keeps saying he doesn't want that then, you*
30 *have to let it go. I had difficulties with that at first. But, my husband says it too: 'Let it go. You can't force it'."* –
31 Daughter of a man with dementia, care network 8
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36 It is notable that the professionals seldom discussed alternatives to daycare. Therefore, the choice
37 was either accepting or not accepting daycare. Continuing daycare after the try-out depends on the
38 reactions to daycare of the person with dementia. Positive and mixed experiences lead to a
39 continuation of daycare, whereas negative experiences imply that daycare stops.
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43
44 *"And wonder of wonders, she began to like it [daycare], and gradually she recovered physically, which made her*
45 *a lot clearer. You could see that. She was more approachable. She became a totally different lady."* – Case
46 manager of a woman with dementia, care network 11
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49
50 *"Daycare is something she absolutely does not want. We even went to the daycare one afternoon with her and*
51 *she experienced it all. But, she definitely does not want it."* – Team leader for nurses of the home care
52 organization of a woman with dementia, care network 21
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56 Type 3: Not reaching a commitment to try daycare
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3 This type of participation trajectory is characterized by the person with dementia being part of a
4 small network and resisting daycare. The secondary informal caregivers in these care networks do
5 not have a clear role in the decision-making. The primary informal caregivers are either negative or
6 have no clear role. The initiative for discussing daycare comes from the professionals. They tend to
7 have multiple conversations about daycare in which they try to encourage the person with dementia
8 and primary informal caregiver to try daycare. However, these discussions do not lead to trying
9 daycare. Then, finally the professionals accept the fact that daycare is not suitable in this situation.
10 The professionals do not discuss alternatives to daycare, even if the informal caregivers come up
11 with alternatives themselves. The situation is continued as it is, as best as one can.
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19 *"In the past I tried to guide her to a form of daycare. Because then she wouldn't have to have this private care,*
20 *because she would be taken care of for a few hours. She could get a meal there, she could go to the hairdresser*
21 *and the physiotherapy. But, she wouldn't go outside for all the tea in China. So, at a given moment, you*
22 *reconcile to the situation, and you accept that."* – Case manager of a woman with dementia, care network 15.
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26 *"They [community services] keep suggesting that he should first try daycare in a group. That he should undergo*
27 *daycare here at [name of a nursing home]. Well, the misery is that he doesn't hear anything in a great hall full*
28 *of people like that. And then the sort of things they do there. Old Dutch activities, that's wasted on him. I mean,*
29 *he is a musician with absolute pitch. That singing with all those different voices hurts his ears. [...] And, he*
30 *doesn't stand up for himself in groups. He gets more depressed and at home he complains. But, then they said*
31 *to me, 'You can just try it for a month and if it doesn't work, he will get another indication [for one-to-one*
32 *care]'. I said: 'So, he and I must be worn out for a month? It's pure fraud. You know in advance he can't do it. I*
33 *refuse to lie about it.'" – Spouse of a man with dementia, care network 10.*
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41 Discussion

42 We explored how people with dementia and their informal and professional caregivers participate in
43 decision-making about daycare. Three themes representing the critical points of the participation in
44 the decision-making about daycare emerged: (1) the initial positive or negative expectations of
45 daycare; (2) negotiating about trying daycare by promoting, resisting, or attuning to others; and (3)
46 trying daycare, resulting in positive or negative reactions from people with dementia, and leading to
47 a decision about daycare. The ways in which care networks proceeded through these three critical
48 points resulted in a typology of participation trajectories, including: (1) working positively together
49 towards daycare, (2) bringing conflicting perspectives together towards trying daycare, and (3) not
50 reaching no commitment to try daycare.
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Implications for practice and theory

Taken together, the results of our study make several important contributions to the current theory and understanding of the practice of shared decision-making. First, the findings demonstrate that a trial period is an essential element of the decision-making for people with dementia. For people with dementia it is often quite difficult to forecast their preferences on the basis of factual information about options [17]. Our results show that initial preferences based on information alone may change when people with dementia experience daycare. A trial period is important for them so that they can experience daycare without having to decide whether they want to continue it [14]. Whereas shared decision-making in general aims at moving from initial preferences to informed preferences professionals should focus more at moving from initial preferences to experienced preferences for people with dementia.

Second, the findings suggest that people with dementia exercise considerable influence with their preferences and reactions to daycare. During the trial period of daycare, the emotions and behaviors of the person with dementia are important cues for these preferences, in addition to their verbal expressions of their experiences with daycare [30]. In this way, they influence the decision-making pace as well as the direction of the decision. This is in line with the findings Boyle's findings [34] that people with dementia who lack deliberative capacity exercise agency in other non-verbal ways. Focusing solely on the cognitive contributions to decision-making ignores the other contributions of the person with dementia and does not fit in with the ways in which the various participants mutually influence each other. Professionals who want to facilitate shared decision-making with people need to acknowledge the non-verbal contributions of emotions and reactions as factors in decision-making.

Third, the types of decision-trajectories show the important role of informal caregivers in bringing together conflicting perspectives. The various participants have distinct perspectives, so that reaching a decision about daycare means negotiating these different points of view by promoting and resisting daycare, and by attuning to each other's views. Adult children or professionals are the ones who initiate decision-making about daycare. People with dementia, and sometimes their spouses as well, tend to start off with negative expectations of daycare. They resist daycare. Their children are often more positive from the beginning and tend to promote daycare. Their perspectives are more in line with those of the professionals involved. Shared decision-making models provide little attention to the involvement of informal caregivers in shared decision-making [35]. When their roles are described, they are often put together with those of the patient. Our study exemplifies that

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3 the perspectives of informal caregivers are different from those of the patient, and that the
4 perspectives of the different informal caregivers involved also vary.
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8 Fourth, our results indicate that the decision about daycare is often presented as a yes-or-no
9 decision by professionals. Alternatives to daycare are seldom discussed. This is especially
10 troublesome for those people with dementia who dislike groups, or who do not prefer the activities
11 at the daycare centre. Since daycare is not only aimed at the person with dementia, but also at
12 relieving caregiver burden [6, 7], it seems important to at least consider alternative options. Such
13 options may not be readily available. In complex situations such as the ones dementia creates,
14 shared decision-making requires professionals to engage in conversations with their patients that go
15 beyond merely informing them about the options they know of. Rather, they should have open
16 conversations with people with dementia and their informal caregivers that allow all the participants
17 to consider new information, perspectives, and options [14, 36]. This might result in “third ways” that
18 the professional had not yet thought about. The difficulty is that professionals may have their own
19 interests in the day-care decision as well, on the basis of the organisation of the health care in their
20 region [37]. This might be part of the reason why professionals do not always take the alternatives
21 into consideration as presented by the informal caregivers in the care networks that did not reach a
22 commitment for trying daycare.
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33 Strengths and limitations

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35 This is the first study to explore the participation of different participants in the decision-making
36 about daycare in dementia. The decision about daycare is an important one, since it often marks the
37 point time from which people with dementia engage in professional care on a regular basis. Our
38 study includes the perspectives of people with dementia, their informal caregivers, and the
39 professionals involved. As such, it provides rich stories about participation in the decision-making
40 regarding daycare [29]. The perspectives of people with dementia themselves is often neglected in
41 research [32].
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49 This study also has several limitations. There were various interviewers, some of whom were
50 undergraduate students. This may have led to variation in the quality of the interview data between
51 interview rounds. All the interviewers were trained, and received feedback on their interview style
52 after each interview, but there were still differences in the extent to which they persisted in asking
53 questions. To minimize the effect of different interviewers, we made sure that
54 the interviews of each care network in a given interview round were conducted by one interviewer.
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58 This study involves people with dementia who were able to participate in an interview and who had
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3 informal caregivers present. Cases in which the person with dementia cannot communicate and
4 cases in which no informal caregivers are present would likely present different or additional
5 experiences.
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9 10 **Conclusion**

11 Our results show that shared decision-making with people with dementia is challenging, but possible.
12 In order to involve people with dementia in a meaningful way, it seems necessary to shift the
13 attention from merely deliberating about daycare to trying it in order to move from initial
14 expectations of daycare to experienced preferences. Doing this allows people with dementia to have
15 an impact on the decision-making. The other participants usually honour the preferences based on
16 experiences with daycare. While shared decision-making in general aims at moving from initial
17 preferences to informed preferences, professionals should focus more on moving from initial
18 preferences to experienced preferences for people with dementia.
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25 26 **Acknowledgements**

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28 personal stories with us.
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Table 1. Characteristics of the care networks

ID ¹	Gender of PWD	Age of PWD	Socio-economic status	Stage of dementia ²	Living alone?	Living arrangements of PWD at baseline	Type of informal caregivers interviewed	Type of formal caregivers interviewed
1	Man	82	Middle income	M	T	Home for the elderly	Spouse Daughter	Principal attendant Case manager at nursing home
5	Woman	83	Middle income	I	A	Community dwelling	Daughter Friend	Employee of daycare centre Case manager at mental health organization
6	Woman	62	Middle income	M	T	Nursing home	Spouse Daughter	Principal attendant Head of department
7	Woman	?	High income	M	T	Community dwelling	Spouse -	Employee of daycare centre Case manager at mental health organization
8	Man	80	High income	I	A	Community dwelling	Daughter Son	Home care nurse Case manager at home care organization
9	Woman	74	Middle income	M	T	Community dwelling	Spouse Daughter	Domestic help Case manager at mental health organization
10	Man	?	High income	M	T	Community dwelling	Spouse -	Home care nurse Creative therapist
11	Woman	79	Middle income	I	T	Community dwelling	Spouse Daughter	Employee of daycare centre Case manager
12	Woman	80	Middle income	M	T	Community dwelling	Spouse Daughter-in-law	Employee of daycare centre Case manager
13	Woman	84	Low income	M	A	Community dwelling	Grandson Granddaughter-in-law	Principal home care nurse Team leader for nurses
14	Man	70	Middle income	M	T	Community dwelling	Spouse Son	Employee of daycare centre Principal home care nurse

15	Woman	89	Middle income	M	A	Community dwelling	Daughter Son-in-law	Principal home care nurse Case manager
16	Woman	87	Middle income	M	A	Community dwelling	Daughter-in-law Daughter-in-law	Principal home care attendant Case manager
17	Man	83	Low income	M	T	Community dwelling	Spouse Daughter	Employee of daycare centre Case manager
18	Woman	73	Middle income	M	T	Nursing home	Sister Niece	Principal attendant Case manager
19	Man	86	Middle income	I	A	Community dwelling	Son Son	Care coordinator Principal home care nurse
20	Woman	89	Middle income	I	A	Community dwelling	Nephew Niece	Principal home care nurse Care coordinator
21	Woman	87	Middle income	M	T	Community dwelling	Spouse Daughter	Principal home care nurse Team leader for nurses
22	Woman	?	Middle income	M	T	Community dwelling	Spouse Brother	Employee of daycare centre Case manager

A = a person with dementia living alone; I = initial stage, ID = the identification number of the care networks in our study; M = middle stage; PWD = a person with dementia; T = a person with dementia living with the spouse or other informal caregiver

¹Our total study consisted of 23 care networks. This paper focuses on the 19 care networks in the study that discussed the issue of daycare in the interviews. This is why some numbers are missing in this list. For an overview of all care networks, see Groen - van de Ven, Smits [1]

² The stage of the dementia was based on the professional expertise of the case manager or other professional interviewed

Table 2. Themes, categories, and codes for participation in decision-making about daycare

Themes	Categories	Codes
Initial expectations about daycare	Initiating decision-making about daycare	Anticipating
		Taking initiatives
	Positive expectations about daycare	Arguments in favour of daycare
		Preferences for daycare
	Negative expectations about daycare	Negative associations with daycare
		Arguments against daycare
Dislike of daycare		
Negotiating about trying daycare	Participating in conversations about daycare	Conversations about daycare
		Contributing to discussions about daycare
		Informing oneself about daycare
		Level of open communication
	Promoting daycare	Offering daycare services
		Encouraging daycare
		Repeatedly discussing daycare
	Resisting daycare	Rejecting daycare
		Being ambivalent about daycare
		Postponing daycare
	Attuning to others	Listening to others
		Attuning to the person with dementia
Weighing different perspectives		
Trying daycare	Working together to try out daycare	Resigning
		Giving in
		Trying daycare
		Supporting daycare
	Positive reactions of people with dementia towards daycare	Positive experiences
		Positive feelings
		Positive behaviour
	Negative reactions of people with dementia towards daycare	Negative experiences
		Negative behaviour
	Deciding about daycare	Determining
Arranging daycare		

Table 3 Types of participation trajectories of the decision-making about daycare

Trajectory type	Initial expectations	Negotiation about daycare	Try-out of daycare	Experiences with daycare	Care networks within this trajectory
1. Working together positively towards daycare	All participants have positive expectations	Promoting daycare	yes	Positive about daycare	5, 7, 13, 17
2. Bringing conflicting perspectives together towards trying daycare	Person with dementia has negative expectations and sometimes the spouse does too, while other participants are positive	Professionals and informal caregivers (adult children) promoting daycare. The person with dementia resists daycare or has no clear role in the negotiation. The spouse or other primary informal caregivers are ambivalent towards daycare. They tend to align with the person with dementia or resist daycare themselves. After multiple conversations about daycare, the person with dementia and the informal caregivers are willing to support trying daycare	Yes	Positive, negative or, mixed experiences	1, 6, 8, 9, 11, 12, 14, 16, 18, 19, 20, 21, 22
3. No commitment to try daycare	Person with dementia negative, the informal caregivers are negative or have no clear expectations about daycare, professionals are positive	The professionals in these situations promote daycare, while the person with dementia resists. The informal caregivers either resist as well or align with the person with dementia. Daycare does not suit the person with dementia because he or she dislikes	No	-	10, 15

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		groups or does not like being away from home. Professionals eventually accept that the person with dementia does not want to try daycare			
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For peer review only

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported in section, Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Data collection, page 6
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Title page
3. Occupation	What was their occupation at the time of the study?	Title page
4. Gender	Was the researcher male or female?	Title page
5. Experience and training	What experience or training did the researcher have?	Data collection, page 6
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Participants, page 6
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Data analysis, page 7
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants, page 6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Participants, page 6
12. Sample size	How many participants were in the study?	Respondent

		characteristics, page 9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Respondent characteristics, page 9
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data collection, page 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Data collection, page 7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Table 1, page 23
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Data collection, page 7
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	Data collection, page 6
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Data collection, page 7
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Data collection, page 6
22. Data saturation	Was data saturation discussed?	Results page 9
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Data analysis, page 7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Table 2
26. Derivation of themes	Were themes identified in advance or derived from the data?	Data analysis, page 7
27. Software	What software, if applicable, was used to manage the data?	Data analysis, page 7
28. Participant checking	Did participants provide feedback on the findings?	Strengths and limitations
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results and discussion

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4 **Once you have completed this checklist, please save a copy and upload it as part**
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