

Research Article

Shared Decision Making About Housing Transitions for Persons With Dementia: A Four-Case Care Network Perspective

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Abstract

Background: Persons with dementia (PWDs) and their caregivers often face difficult housing decisions, that is, decisions about their living arrangements, in which the perspectives of all members of the care network should be involved.

Objective: We performed a qualitative data analysis to assess the extent to which housing decisions for PWDs with their formal and informal caregivers correspond to an interprofessional shared decision making (IP-SDM) approach, and what light this approach sheds on their experiences with decision making.

Research Design and Methods: We used the IP-SDM model to content-code and analyze data from 4 care networks, each consisting of a PWD, 2 informal and 2 formal caregivers.

Results: Decision making in all networks corresponded to most IP-SDM elements, but never included all network members. Decision making was guided by the wishes of the PWD, but their actual involvement decreased over time.

Discussion: Results show that while the IP-SDM model was helpful, the options change with cognitive decline and moving to a nursing home can become inevitable in spite of preferences.

Implications: Timely and honest communication helps to mitigate the distress of deciding against patient preferences, as could advance care planning about future housing transitions.

Keywords: Advance care planning, Decision making, Dementia, Housing, Institutional care/residential care

Persons with dementia (PWDs) and their caregivers are often faced with difficult housing decisions, that is, decisions about their living arrangements (Caron, Ducharme, & Griffith, 2006). Housing decisions are sometimes characterized as the single decision to institutionalize, but are actually more of a *process* consisting of accumulated efforts to stay at home as long as possible using diverse strategies

(e.g., mobility equipment, home care, respite care) until this is no longer possible (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016; Roy, Dubé, Després, Freitas, & Légaré, 2018). This process is very complex due to contextual factors such as the changing health status of the senior, the characteristics of their informal caregivers, and the built environment (Caron et al., 2006). Moreover,

although most seniors prefer to stay at home as long as possible (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012), a move cannot always be avoided, as physical and cognitive decline increases their need for care and support.

In the Netherlands, about 18% of the 17 million inhabitants are aged 65 years or older, and 5% are 80 years or older (Bank, 2015). In 2011, the majority of persons of 80 years or older (6 out of 7) still lived independently at home (with or without additional supports (CBS, 2011; Verbeek-Oudijk & van Campen, 2017). The wish of most seniors to live at home and remain independent for as long as possible is reflected in many government policies, including in the Netherlands (Doekhie, de Veer, Rademakers, Schellevis, & Francke, 2014). As a consequence, the availability of nursing home places is limited, and eligibility requirements are exacting (Zorgvisie, 2016). In 2015, about 117,000 seniors lived in nursing homes or small-scale living environments. Increasingly, but still less common, other assisted or sheltered living options are chosen (Smits, van den Beld, Aartsen, & Schroot, 2014). More rooms are available in private nursing homes but moving there is for most people not an option due to the high associated costs.

The health care system for seniors is categorized into cure (i.e., curative health care provided by doctors and specialists, and covered by health insurance), care (i.e., from formal caregivers providing support in activities of daily living and instrumental support, and home care), housing and services, and welfare (products or services that keep seniors in control of their lives, including participation in social activities, and person-centred guidance (van der Grinten, 2001). These categories are for example used to determine how care is paid for or reimbursed, or who should deliver it. As most seniors need support in multiple categories, getting the support they need can sometimes be an administrative hassle.

The government aims to involve informal caregivers as much as possible in delivering (unpaid) care, the so-called “participation society”. A large part of care in the categories “care” and “welfare” is indeed provided by informal caregivers. This involves activities such as grocery shopping, transport, cooking, washing, and personal care. In fact, seniors who are still living at home are largely able to do so because of the support they receive from informal caregivers (Hootsen, Rozema, & van Grondelle, 2013).

Hence, a senior's care network consists of multiple actors in multiple domains, often including several different health professionals and both formal and informal caregivers. It is important to involve the perspectives of all members of the care network in housing decisions, and especially informal caregivers, as they are deeply affected by the decisions made. Moreover, involving all members of the care network leads to a common understanding of the different values of the involved parties, and bringing the knowledge and experience of all concerned individuals to the decision-making process may result in improved decision making and communication (Helitzer et al., 2011). In an interprofessional shared decision making (IP-SDM) approach, the views of the seniors and all who are important in caring for them are taken

into account, including informal caregivers and a multidisciplinary health care team (Garvelink et al., 2016; Légaré et al., 2014; Miller, Whitlatch, & Lyons, 2016). However, little is known about how or to what extent care network members are currently collaborating in housing decisions in the Netherlands (Smebye, Kirkevold, & Engedal, 2012). In the case of PWDs, even their own involvement in decision making about their care can be limited (Miller et al., 2016). This is due to age-related deterioration in hearing/vision/speech, comorbidities, and complex care situations (Holm, Berland, & Severinsson, 2016), and to cognitive decline, which makes them less able to process information, anticipate future events, and manage the consequences. Making housing decisions and other preference-sensitive decisions, where different options, values, preferences, and consequences have to be weighed up, is therefore a challenge.

This study thus sought to explore in usual care (a) to what extent the decision-making process about housing for PWDs with their formal and informal caregivers corresponds to an IP-SDM approach, and (b) what light this approach sheds on their experiences with decision making.

Design and Methods

Research Design and Participants

We performed secondary data analysis on material collected in a qualitative study with a longitudinal multiperspective design in which trained interviewers conducted semi-structured individual interviews (Groen-van de Ven et al., 2017). The aim of the parent study was to examine shared decision making (SDM) in care networks including people with dementia, their informal and formal caregivers.

The data were collected from care networks each consisting of one PWD (i.e., community-dwelling older adult in the Netherlands with early or moderate dementia), two informal caregivers (e.g., spouses, children, or other relatives) and two formal caregivers (i.e., home care workers who deliver care at home, day- and night care personnel who provide care and social activities in senior centers or nursing homes, or nursing home staff).

For this secondary analysis, we selected a purposeful sample of four (N1–N4) out of 23 care networks. Our main inclusion criteria were that the PWDs in the sample were living at home during the first interview and had faced housing decisions. We selected networks with varying characteristics in terms of the stage of dementia (early and moderate), sex (male and female), marital status (married, widowed, and single), and type of informal caregiver (spouse, adult child, other family).

Data Collection

The topic list was based on key issues in SDM (Elwyn et al., 2012), including the changes that had occurred (e.g., related to housing and health), the decisions made, what provoked decisions, who was involved, and how network members evaluated the decision made and the decision-making

process. Separate interviews were conducted with the network members at three consecutive moments at 6-month intervals between July 2010 and July 2012. The interviews were audio-taped and transcribed verbatim. More information about the procedure is available elsewhere (Groen-van de Ven et al., 2017).

Conceptual Model

The IP-SDM model was used as the conceptual framework for data analysis (Légaré et al., 2011). The model represents an SDM process from initiation of the decision until after decision making and includes the following elements: explanation of the decision to be made; information exchange; eliciting values and preferences; discussing the feasibility of the options; the preferred choice versus the decision made; planning and implementing the decisions; and outcomes. The model also emphasizes the context in which decision making takes place, and the people involved and their roles (Légaré et al., 2011). The IP-SDM model has proven useful when applied to decision making about housing decisions (Légaré et al., 2014) and it has informed multiple SDM studies (Dogba, Menear, Stacey, Brière, & Légaré, 2016).

Data Analysis

We content-coded and analyzed the data using the IP-SDM model. All data were coded and matched to the elements of the IP-SDM model independently by two researchers (M. M. Garvelink, R. Franken). We held consensus meetings in which the two coders compared all their codes and discussed text fragments that were coded differently. Together they decided which code fitted the model best. Based on the codes (categories), we summarized the PWD's changing living situation and transitions, as well as other contextual characteristics (Table 2). Sociodemographic characteristics were obtained over the course of the interviews and with structured questions at the first interview. We created subcategories when further clarity was necessary (Table 1). Although we analyzed only a subsample of the full data set, most codes reached data saturation, as no new codes came up in later coded interviews. Based on our coding tree, we observed the extent to which IP-SDM elements occurred at different times in each network. In addition, we compared (sub)codes within and between care networks, and compared variations in IP-SDM processes with network members' evaluations of the decision and the decision process. All analyses were done using Atlas.ti software V.7.1.

Ethical Considerations

This study was approved by the Isala Clinics' ethical board (number 10.11113; Groen-van de Ven et al., 2017). Informed consent was obtained from all participants, and signs that the participant might want to stop were continuously re-evaluated. For PWDs, additional informed consent

was obtained from an informal caregiver. Interview data were not shared with other network participants.

Results

Characteristics of the Four Networks and Decisions Made

For an overview of network characteristics, see Table 2. PWDs (two males, two females) were 70–89 years old and had early ($n = 2$) or advanced ($n = 2$) dementia. They were married ($n = 2$), widowed ($n = 1$), or single ($n = 1$), and were primarily looked after by their partner ($n = 2$), adult children ($n = 1$), or other family ($n = 1$). Social economic status was modal in all networks.

In all networks, PWDs preferred to stay at home, but by the third interview (after 1 year) they were all either living in a nursing home or were on a waiting list for one. Below, the decision-making process and the decisions made by the four investigated care networks are discussed, as structured by the elements of the IP-SDM model. Quotes are presented in Box 1.

Context

Personal characteristics, family roles, and relationships were of great importance for decision making and care processes and influenced the (often limited) availability and acceptance of options as well as decision-making roles.

The Impact of Working History

PWDs in N1 and N3 had had fulltime jobs and had been very independent, which was reflected in their desire for autonomy, which they valued highly. In N1, the PWD had worked at sea, so he was often away from home, and his wife made all the decisions. Because she was used to this, she had no problem making decisions now either, as long as she knew that her decisions were in line with his preferences.

Living Situation

Two PWDs had moved more than 15 years ago to one-level rental apartments (N3, N4), while two owned multistorey homes. Two PWDs were living alone with their caregivers close by but not in the same home (N2, N3).

Family Relations

In N1, the PWD received care from his wife and children. Although their relations had been good, his dementia caused negative behavior which made it difficult to care for him. The move to a nursing home made things even worse, as he now considered his wife as an enemy.

In N2 and N3, care was provided by children and cousins, and family relations were good, which made caregiving

Table 1. Coding Tree

IP-SDM model (categories)	Codes (subcodes)
Context	<ul style="list-style-type: none"> - PWD's health (how is the PWD doing: good, bad, evaluation of health and wellbeing) - PWD's identity (personality, previous jobs) - Characteristics of the situation (partner, family) - Characteristics of the respondent - Context (first interview, changes over time) - Care (formal, informal) - Support (yes, no) - Dementia diagnosis - Knowledge of dementia - Impact of dementia on relationship (yes, no) - Efforts to stay at home (care/services): ADL, grocery service, housekeeping, pedicure, home care, day care, night care, accompaniment, meal service, physiotherapist, financial support, medication support, buying clothes - Efforts to stay at home (adaptations in and around the house for staying independent): hiding valuable belongings, appliances, instructions for appliances, medication box, flash bell, gas alarm, incontinence supplies, vacuum cleaner ("kruimeldief"), mail, walker, wheelchair, alarm, key chain, alcohol restriction, trash, walking, stair lift - Efforts to stay at home (social): company, somebody who checks the situation regularly, digital social contacts - Efforts to stay at home (communication/planning): agenda, sticky notes - Evaluation context - Daily activities - Psychological characteristics (negative emotions, positive emotions, coping strategies)
People involved and roles	<ul style="list-style-type: none"> - Involved in decision making about living arrangements (yes/no)^a - Involved in care^a - Involved in decision making - Impact of dementia on decision making - Role in decision making (initiating a problem, advising, final decision-maker, legal decision-maker, mediating, communicating, comforting, implementing, indicating, touring rooms/moving leading, supporting, checking options, persuading, advocate for PWD) - Teams (full network, patient/family team, patient/professional team, family/ professional team, triad)
(Explanation of the) decision to be made	<ul style="list-style-type: none"> - Why decision needed - Explanation of decision
Information exchange	<ul style="list-style-type: none"> - Communication and information exchange between people involved - Explanation of decision (decision to be made) - Alternatives/options - Searching for information/options - Discussing preferences - Evaluation of information exchange
Values and preferences	<ul style="list-style-type: none"> - <i>Values related to autonomy of PWD</i>: autonomy, control over behavior, sense of responsibility, no choice, freedom of choice - <i>Values related to health/needs of PWD</i>: incontinence and personal hygiene, physical deterioration, mental deterioration, too well for nursing home, no unmet needs for daily activities, staying active keeps you healthy, increasing care needs, safety, social contacts, structure in daily living, PWD not nice - <i>Values related to current home</i>: emotional attachment to possessions, feasibility of staying at home, characteristics of the current location, house and garden too big - <i>Values related to nursing home/housing option</i>: do not want to be among strangers, negative attitude regarding transition option, negative expectations, positive expectations, distance to nursing home, finances, sharing sanitary facilities, nice room/house, room available, privacy, from house to "cage", different indications/ evaluations between PWD and partner, to feel at home, possibility of visits in nursing home - <i>Values related to caregiving efforts</i>: recognition of the caregiving efforts, respite for caregiver, need to have time for yourself, willingness to provide needed care, compatibility with current daily activities, caregiver perseverance - <i>Values related to roles/beliefs</i>: marriage, want to stay home, loneliness, philosophy, and religion, guilt, uncertainty about future situation, "you should not move old trees," quality of life

Table 1. Continued

IP-SDM model (categories)	Codes (subcodes)
	<ul style="list-style-type: none"> - Preferences re. housing - Internal conflict - Taboos
Feasibility of options	<ul style="list-style-type: none"> - Feasibility of staying at home - Feasibility of moving
Preferred choice	<ul style="list-style-type: none"> - Disagreements (between people) - Internal conflicts (within one person) - Discussion of preferences
Actual decision made	<ul style="list-style-type: none"> - Preferred vs actual decision made (concordance or discordance between the preferred and actual decision made) - Decisions
Implementation of the decision	<ul style="list-style-type: none"> - How were decisions implemented (waiting list, move, ...) - Future (plans, thoughts)
Outcomes	<ul style="list-style-type: none"> - Evaluation of decision (day care, night care, nursing home admission) - Evaluation of consequences of decision - Evaluation of decision-making process - Recommendations re. decision-making process

Note: ADL = activities of daily living; IP-SDM = interprofessional shared decision making; PWD = persons with dementia.

*All people that were involved in decision making/providing care and support were categorized, to give an overview.

easier for caregivers and more appreciated by the PWDs. In N4, the PWD received care from her husband and children. Family relations weren't always good, which affected their willingness and motivation to provide care and collaborate. The husband seemed to want to make things right with his wife (the PWD) by doing whatever she wanted, whereas the eldest daughter felt ambivalent about helping them because they were not there for her when she needed them in her youth. Interestingly, moving the PWD to a nursing home seemed to improve family relations, possibly because they now all shared a common "enemy": the nursing home, where the care was beneath their expectations.

People Involved and Their Roles

Persons with dementia

In the beginning of the decision-making process, values and preferences were often discussed by everyone involved, including the PWD, who steered the decision-making process. The PWD's opinion was sought, and caregivers acted upon it. As time passed and their cognitive abilities declined, the PWDs were less involved (quote 1, 2). When a transition decision was made, they were simply informed about it. As caregivers still valued the PWD's preferences above all, however, a final decision against their preferences was delayed as long as possible.

Primary caregivers

If the PWD had a partner, he/she was automatically the primary caregiver. When PWDs had no partner, the children

who lived closest by were primary caregivers (N2), and when no children were available, a nephew and niece were primary caregivers (N3). Secondary caregivers were often children who lived further away and neighbors.

Generally, primary caregivers were involved in or solely responsible for decisions made about the PWDs' care and living situation. They took upon themselves roles such as initiator (identifying that a decision needs to be made), final decision-maker (deciding, based on gathered information and opinions and especially on the PWD's preferences), implementer (moving the PWD), and persuader (persuading others involved about the best option).

All primary caregivers aimed to keep the PWD at home as long as possible, as this was the wish of the PWDs. Often this aim was so important for them that they did not realize the toll that caregiving took on them (caregiver burden).

Secondary informal caregivers and formal caregivers

Compared with primary caregivers (especially spouses), secondary caregivers (especially when out-of-home) were better able to observe the decline in the PWD's health, and what burden they and the primary caregivers were capable of sustaining. Yet, spouses could make (minor) housing decisions aimed at keeping the PWD at home, whereas other types of informal caregivers sometimes found it more challenging to decide (quote 3).

Both formal and secondary informal caregivers often supported the primary caregiver and the PWD in the decision-making process. They initiated, provided information, advised (about how to make a difficult decision or

Table 2. Sociodemographic and Contextual Characteristics of the Networks

Network (N) number (original network number ^a)	N1 (14)	N2 (19)	N3 (20)	N4 (21)
Characteristics of the PWD	70-year-old helmsman (merchant officer—supervisor aboard ship), unwanted, youngest child in his own family who always had to prove himself	86-year-old man, used to work in horticulture and vegetable farms, and the last 25 years in installing cable television; considers himself stubborn	89-year-old female, used to work in fabrics stall in the market	87-year-old female, office job in furniture until she married, then housewife; she likes things clean and tidy
Initial housing situation	Multistorey house (owned)	Multistorey house (owned); garden, and water	One-storey apartment (rented), nearby family	One-storey apartment (rented) in city center
Characteristics of dementia	Moderate dementia	Early stage dementia	Early stage dementia	Moderate dementia
Family situation	Married, two children (son and daughter). His wife “the boss” has always run the household, and makes most decisions.	Widower, three sons	Divorced (single), no children	Married, four children (two sons, two daughters). Youngest son died of colon cancer during study.
Primary caregiver	Spouse	Son	Nephew	Spouse
Secondary caregiver	Son	Son	Nephew's wife	Daughter
Formal care	Day care worker, nursing home staff, contact person day care	Home care worker, client coordinator, principal home care worker, nursing home staff	Client coordinator, home care worker, principal home care worker	Home care worker (1st and 2nd carer), team manager, nursing home (day care), principal home care worker, team leader nursing home
Team efforts to keep person at home	Care/services: home care, day care, night care, PWD-accompaniment Social: someone who checks the situation regularly, digital social contacts	Care/services: ADL, grocery service, day centre, meal services, housekeeping, medication support, home care, stair lift. Adaptations for staying independent: Sticky notes, high toilet, incontinence supplies, small vacuum cleaner, walker, alarm, wake up calls, wall support, cane. Communication/planning: agenda Social: someone checks the situation regularly, company	Care/services: ADL, financial support, grocery service, housekeeping, medication support, pedicure, somebody gets mail and puts away trash, homecare. Adaptations for staying independent: hiding valuable belongings, appliances + instructions, medication box, flash bell, gas alarm, incontinence supplies, small vacuum cleaner, walker, wheelchair, alarm, key chain, alcohol restriction Communication/planning: agenda, sticky notes Social: company	Care/services: ADL, meal service, physiotherapist, buying clothes, housekeeping, home care Adaptations for staying independent: instructions for appliances, walking
PWD's efforts to stay at home:	Suicide threats after initial discussions re. moving to a nursing home	Being appreciative of support, trying to do things himself (with safety concern)	Being appreciative of support, doing part of the ADL herself, acting as if she is still productive/active, suicidal comments when nursing home is mentioned	Trying to do things herself
Decision(s) to be made	Expanding day care from 3 to 4 times a week, night care, moving to nursing home	Expanding day care, implementation of efforts to stay at home (including home care), moving to nursing home	Expanding day care, implementation of efforts to stay at home (including home care), moving to nursing home	Trying day care, implementation of efforts to stay at home (including home care), moving to nursing home
Transitions made	From house to nursing home	From house to hospital to nursing home	From house to apartment (before first interview). In Interview 3, on waiting list for nursing home	From house to nursing home

^aGroen-van de Ven and colleagues (2017).

Box 1. Quotes^a

1. "Yes, of course it is a process... and at a given moment it shifts increasingly and he gets to decide less by himself. But he is not able to, so you see that it is not feasible. So, you have to [decide], if you don't do it, it ends here." (N2, secondary caregiver)
2. "It is not possible anymore [to involve the PWD in decision-making]. It was not negotiable. When I told him that he could not continue living at home, he erupted into anger and did not want to talk about it. He blamed me for everything, he accused me of trying to dump him. So, it was not possible to discuss it with my husband." (N1, primary caregiver)
3. "No, what I did think of is that you are nonstop making decisions. They are relatively small decisions, not the decision about admission to a nursing home, but I noticed that you are continuously making decisions. Also about your (own) dilemmas, eh? Like, uh, should I or shouldn't I do this? Should I make sure that the room is decorated, when my mum says no? Uh, you are always being strategic. No matter how small." (N4, secondary caregiver)
4. I: "And about that decision [admission to nursing home], did you have a role in decision-making?" R: "No, not at all. Neither has [names other home care worker]." (N2, home care worker)
5. "You feel like you are sort of the center of it [decision making] ... Of course, it is not about me, but it is primarily about my father. Only, you see that he is not able to, so do you have to take it over from him, you know, that is the question. And then you would ... indeed, it would be desirable to make a decision earlier in that process, with a group of people. Or [not] make a decision but at least discuss the situation and what you can do for him. What everybody can do for him and to then make some sort of care plan with everybody's roles and tasks. And you would have to evaluate that together every now and then, to see how we are doing and what is going well, or ... what is redundant or what you think is lacking. Try to communicate with each other. Those sort of moments never really happened, no." (N2, secondary caregiver)
6. "Well, I would have liked to be present during a multidisciplinary team meeting. To uh ... defend him and to represent our opinion [home care workers] about his dementia stage." (N2, Principal home care worker)
7. "And also, the multidisciplinary meeting, there, experts from various disciplines come together and discuss it [the PWD]. Like, what is going on with her and what do we need. How is the care going? That is all being discussed there." (N4, day care worker)
8. "Yes, and with cooking in the house, well, he does not do that a lot.. but he beats up his fish that he bought at the market or the supermarket.. and yes, such a shaky little man, messing around with his little kettle and all... You just know that is has to go wrong sometime ..." (N2, secondary caregiver)
9. "Because yes, I think it is awful [being in a nursing home]. I really hope she will die way before she is ever admitted there. Yes ... It is just not nice to be among other people with dementia. It is such a loss of decorum when you can no longer take care of yourself. Nobody else will do it for you, nobody has time, it is awful. I really think that it's a very bad future. So, I hope, to be honest, that she will die before that time comes. That, I think, is still a dignified end." (N4, secondary caregiver, second interview)
10. "[sigh] Man, I feel like I was put away with the trash". (N1, PWD, interview 3)
11. "Uh, and then she said to my mom, so, Mrs B, where would you prefer to go? Then she said, to Amsterdam. So, we packed her

Box 1. Continued

- stuff, [and said] we are going to Amsterdam. With her [home care worker], well I do not know how, or whether she drove around in circles, but eventually she drove to the nursing home and there she ... uh ... [silence] left my mom." (N4, secondary caregiver)
12. I: "Do you remember how you ended up here? What happened that day?" R: Well, I do not remember. I was dumped here: "Yes, come on, we are going out for a while". That was some kind of excuse. And I was dropped here with all my stuff. Good luck." (N1, PWD, 2 weeks after nursing home admission)
13. I: "Do you remember how you were admitted here 2 months ago?" R: It went very normally, just like I have always been part of the group [elderly in the nursing home], I thought." (N4, PWD, 2 months after nursing home admission)
14. I: "Are you happy that you came here?" R: well, happy, happy ... I have a roof over my head, but it is quite the change eh. You have lost the last bit of freedom that you had. Because everything is "[you] must". I: "How do you perceive that you have less freedom?" R: Well, eh, I, for example, I cannot just walk away from the house, that is not allowed on my own. There has to be a guide with me. That makes you feel exactly like a prisoner ..."
- I: "Would you rather still live in your own home?" R: "Yes of course! ... That is, uh, I think very few people would be happy to be taken from their homes [laughs]. I: "But it is also nice here, isn't it?" R: "Oh, I adapt easily, it is ok." (N2, PWD, third interview).
15. "Oh yes, it is ok. And yes, they are all very amiable towards me and I think that is also very important. Because, if they push you, give you a little push like that, that isn't pleasant either. That uh ... but I like it here. Is that maybe too cheerful? ... Yes I feel good here." (N4, PWD)
16. "And I think it is even worse because I, yes, the care is insufficient ... If you had the feeling that you had left her somewhere where they take good care of her, that she looks a bit fresh and, my mom is missing a breast after breast cancer, well, sometimes her bra is filled with a lump, other times she is not even wearing a bra. We meet her wearing no panties, then she is very cold. She has to wear support socks, well, the last time I was there she wore her support socks like regular socks, underneath it she was wearing support stockings and she was holding her shoes in her hand while she was walking in the hallway. ...that was around 3 pm, so she had probably walked around like that all day. ...she smelled really bad. The blanket on her bed smelled very much like poop ... How is this possible?" (N4, secondary caregiver)
17. "Well, so that is basically our story, and she is now there [in the nursing home] and I am not visiting her everyday but every other day, because I always get very sad afterwards [silence]. I, I, I, I listen then I have a drink afterwards as a matter of fact, when I get home, you hear her say "buy us another little cottage", because she wants to go home... Of course, she is completely disillusioned, and it has increased a lot, the dementia." (N4, primary caregiver)
18. "In my opinion this has been the best way to decide, indeed, to have many conversations about it, to weigh options. What is possible, what is not? What has to be, what could be? And if you take everything into account then I think that this way, we have found the best solution, indeed." (N1, secondary caregiver, third interview)

^aQuotes were chosen based on how illustrative they were for the issues that we have presented in the text.

cope with the PWD's behavior), implemented (moved the PWD), and persuaded (of the best option).

Formal caregivers tended to play a larger role in implementation than in other aspects of the decision-making process. They were also more involved in explaining decisions to the PWD and persuading them to agree, as PWDs were often more inclined to listen to them than to others. Many nursing home and home care staff members reported not being involved in the decision about nursing home admission but after decision making. Most thought it was not their role to participate in the decision-making process, but two homecare workers thought they should have been involved (quote 4).

Collaboration between formal and informal caregivers

Sometimes, decisions were made by two network members (e.g., an informal and a formal caregiver), without including other network members. Some formal and informal caregivers thought decision making would have benefited from more interprofessional communication and team decision making. Formal caregivers additionally mentioned a need for more inquiries for information from colleagues than were currently happening, and informal caregivers added the need for better information transfer (quote 5). Day care and nursing home staff held multidisciplinary meetings (quote 6, 7) while home care workers did not.

Explaining the Decisions

Most caregivers felt confident to make decisions about efforts to stay at home longer (e.g., home care, house-keeping, medication help, walking aids) without involving the PWD but tried to involve the PWD in decisions about day care, waiting lists for nursing home placement, partly because their agreement would facilitate its implementation. If a spouse was the primary caregiver, they rarely explained the decision, for example, for nursing home admission, as being because the PWD could no longer live at home (the actual reason). Some caregivers were content to use a hospital admission as a reason to move the PWD to a nursing home (N2/N4).

N2 and N3 did tell their PWD that staying at home was no longer feasible. Although the PWDs did not like it, they seemed understanding and were willing to try anything to keep them at home as long as possible. In both networks, they were told in advance about a decision to register them on a waiting list, but also that this decision could not be changed.

All networks put a lot of thought into who should inform the PWD about the decision, and when. They preferred formal caregivers and secondary caregivers to be involved, as PWDs were often more inclined to respect their opinions.

Information Exchange

Primary caregivers were often central in information exchanges between the PWD, secondary, and formal caregivers. Based on discussions and advice from the others,

primary caregivers were encouraged to initiate and make final decisions. Several caregivers informed themselves using the internet and books as well as consulting formal caregivers. Alzheimer support groups were tried, but not often to caregivers' satisfaction.

Most communication was face-to-face or by phone, but two networks also used notebooks to communicate with all who were involved in the care of the PWD, for example, about supplies needed. The book stayed in the PWD's house so that all caregivers could contribute and stay informed about what others were doing.

Most networks members were generally positive about the information exchange, but in all networks, negative aspects were mentioned too. In one network, informal caregivers criticized a lack of information sharing and the division of roles. Other network members commented on the poor communication between informal and formal caregivers. In N4, communication improved when the move to a nursing home became a fact, and the family became more of a team.

Values and Preferences

Participants' comments about values and preferences regarding housing for the PWD was often accompanied by negative emotions (feelings of guilt, sadness, anger) because, in the end, none of the options would keep the PWD at home, which was everybody's preference. PWDs often stated that they wanted to stay at home (no matter what), and often mentioned how important their autonomy was. These values were shared by either informal or formal caregivers but did not always lead to similar preferences. Caregivers' values were mostly related to the feasibility of staying at home, and especially to why staying at home was not feasible (e.g., in terms of safety, quote 8). On the contrary, safety issues were mentioned only once by a PWD.

Formal and secondary informal caregivers mentioned the primary informal caregivers' health as a value (they saw the toll on their health), whereas primary informal caregivers more often expressed this burden in terms of having to persevere with caregiving over time.

When a move became inevitable, values relating to the nursing home itself became more prevalent. Both PWDs and caregivers had positive and negative expectations of nursing homes, but negative feelings dominated. Especially the younger generation of secondary caregivers reported a negative attitude toward nursing homes. They said they would never want to move there themselves, and that they hoped the PWD would die before a move was needed, or at least that they would no longer be aware of it (quote 9). This made them more empathetic toward the PWD.

Feasibility of Options

Instead of discussing whether moving to long-term care was feasible, networks discussed if staying at home was still feasible, and if so, how. However, if a decision was

made to institutionalize or register the PWD on a waiting list, the feasibility of moving to the available nursing homes was discussed too (e.g., distance, characteristics of the rooms, the possibility of moving as a couple, the age of other residents, activities) (see [Supplemental material](#)).

An important aspect of the feasibility of staying at home was the caregiver's ability to continue providing care (in terms of the health or burden of the informal caregiver). This often depended on available support for the primary caregiver (especially for spouses) by secondary or formal caregivers and was mostly in terms of providing an ear, advice, or respite care.

Preferred Choice Versus Decision Made

All PWDs and caregivers preferred that the PWD stay in their home as long as possible. Yet by the third interview, there was no option but moving to a nursing home. However, this was postponed as long as possible. For some PWDs, the wish to stay at home was stronger than the wish to be alive. Two PWDs threatened suicide when admission to a nursing home was mentioned (N1: "*I will cut my wrists*"; N3: "*I will jump off the balcony*"). Yet even for them, a move was finally inevitable. One man, when he realized he was institutionalized, was very sad and angry at those who had put him there (quote 10). Even informal caregivers sometimes expressed a desire for their PWD to die before admission was necessary (N3 and N4), or at least not to be aware of the move (quote 9).

Planning and Implementing the Decision

In most cases, the move to a nursing home was preceded by many re-evaluations of the situation and efforts to keep the person at home. In two cases these efforts had included a move (at least two decades ago) to one-level apartments (Table 2, "efforts"). Although PWDs did not want most of these changes, most were eventually willing, except for one PWD (N4) who was lured into day care against her will. Later on, she was moved to a nursing home against her will (her husband was admitted to a hospital), but once she was there, she actually seemed happier.

Most networks tried to implement decisions as smoothly as possible so that the PWD would not be too aware of it and therefore less upset. Implementation of the decision about nursing home admission almost always meant placement on a waiting list first, which provoked feelings of dismay at first but also enabled people to get accustomed to the idea and to reconsider their decision every time a room became available. Also, being on a list was a security measure which allowed them to react quickly when a move became urgently needed. Most networks were not ready for an actual move at the time they were placed on the waiting list and rejected a couple of rooms before they were ready to move their PWD. Sometimes the person was tricked into

moving to a nursing home by both informal and formal caregivers (quote 11).

In the short term, tricking people did not help once people were moved, because PWDs all realized that they were no longer at home. Later on, they couldn't remember how it happened (quote 12, 13).

Outcomes

Evaluation of the decisions and their consequences

Decisions related to efforts to stay at home (home care, day care, respite care) were evaluated very differently than housing decisions (e.g., nursing home admission). Most found the former decisions easy to make, although one caregiver (N1) felt guilty about a decision to organize home care too because she felt she was not providing the care she should provide for her husband.

With regard to decisions about admission to a nursing home, many caregivers acknowledged that it was the best decision because staying at home was no longer possible, but they did not like that this decision had to be made. Also, the consequences of this decision were often evaluated negatively by both PWDs and caregivers. PWDs mentioned losing their autonomy, being separated from spouse/children, losing personal belongings, deteriorating health, and feeling like a prisoner. Informal caregivers mentioned small rooms ("living in a cage"), costs, being separated from their spouse, difficulty with visits (visiting hours, quarantines, physical and emotional distress) dependence on staff to provide care, bad care, and caregiver burden (decrease for primary caregivers but increase for secondary caregivers). Staff also mentioned the time needed to adapt to an unfamiliar environment.

For primary caregivers, the decision to move the PWD into a nursing home was the hardest, and they reported negative feelings such as guilt for having abandoned them and broken their marital promises. PWDs too felt negative emotions such as anger and sadness when asked about the consequences of the decision to move (quote 14).

Sometimes different network members evaluated consequences differently. For example, in N4, the PWD deteriorated cognitively soon after moving, but seemed happy about the move (quote 15), whereas her formal and informal caregivers said she wanted to go home, and informal caregivers said they too regretted the decision because of the disappointing care provided and because she was not happy (quote 16, 17).

Since PWDs wanted to stay at home as long as possible and caregivers wanted to respect these wishes, admission to the nursing home only happened once caregiver burden was at a maximum, and the PWD had lost all autonomy. As a consequence, both PWDs and caregivers were in a worse condition when the move finally took place.

Evaluation of the decision-making process

In general, evaluations of the decision-making process were positive (quote 18). One caregiver (spouse, N1) still stood completely behind her decision to have her husband attend day care and later on to have him institutionalized, even though she experienced feelings of doubt and guilt about “betraying” him. Although decision making was difficult, she and others in her network were very positive about the decision-making process. One caregiver indicated that the process of decision making could have been improved with better collaboration (see “interprofessional teams”). Caregivers appreciated the support of a number of formal caregivers. However, one caregiver was disappointed that once the decision was made, some formal caregivers immediately withdrew their involvement and left her alone with the consequences.

Discussion

This study sought to assess the extent to which decision making about housing in four care networks, each consisting of a PWD, two informal and two formal caregivers, corresponded to an IP-SDM approach, and what light this approach sheds on their experiences with decision making. The ease with which their decision-making experiences, as well as their recommendations for improving the decision-making process, could be categorized into the IP-SDM model suggests it is overall a useful model for evaluating SDM in dementia care networks. All networks adopted some sort of SDM procedure guided by the wishes of the PWD. However, some elements of the process in this context did not correspond to the IP-SDM model. The involvement of PWDs decreased over time. The SDM never involved *all* network members, and certain aspects of SDM were fulfilled by some members only and excluded the others. There was no deliberation among all network members to reach a common understanding, and some complained about lack of collaboration between network members. They did not always like the decision made or their role in decision making. Lastly, there was poor match between preferences and the actual decision made: both PWDs and caregivers would have preferred the PWD stay at home and had negative feelings about nursing homes, yet by the third interview all PWDs had moved or were waiting for a room, as there were no other options left due to intolerable caregiver burden. Yet, overall, the network members were positive about the decision-making process. These results lead us to make several observations.

First, although making the decision about a housing transition and especially the decision outcome seemed painful and difficult, respondents were positive in their evaluations of the process as a whole. This may reflect their true evaluation of the process or may have been a coping strategy to alleviate the cognitive dissonance of having made a decision against their own and their PWD's wishes. Especially in light of their limited options, it makes sense

that caregivers would justify their decision in retrospect, trying to reduce their guilt and sadness by positively evaluating the process of decision making, especially of their inclusion of the PWD in the process, as this would indicate that they still tried to act in line with his/her preferences. An earlier literature review on decision making among caregivers of seniors found similar coping mechanisms (Garvelink et al., 2016).

Second, our data suggest it is important to consider the decision-making process about housing transitions differently from that of many other clinical decisions. The process takes place in several phases, and the choices change over the course of the process (Forbes et al., 2012; Fortinsky & Downs, 2014). Decisions about efforts to keep the PWD at home as long as possible (e.g., mobility equipment, home care, respite care) were discussed and implemented without much difficulty as they were clearly in line with the PWD's preferences, but decisions that would require the PWD to leave home were not discussed but “told,” as by that time there was no other possibility left. All networks tried to act according to the PWD's preferences, but regarding housing transitions, few really involved the PWD in the discussions (Miller et al., 2016). Also, because the PWDs' preference to stay at home was the primary driver of the decision, decisions to admit the PWD to a nursing home was often made *in extremis*, long after caregiver burden (especially spousal caregivers) was intolerable. As a result, spouses were highly burdened (Cepoiu-Martin et al., 2016; Donnelly, Hickey, Burns, Murphy, & Doyle, 2015; Gallagher et al., 2011), the dementia was in a later phase, and the PWD was less able to adapt to the new environment. Thus, decisions about housing transitions for PWDs, and indeed any housing decisions for seniors where the decision process is phased according to the stage of the disease, would clearly benefit from advanced care planning (ACP). With ACP, preferences could be registered early in the dementia process when people are still cognitively able. ACP is currently used for end-of-life decisions, but not often regarding housing for people with dementia (Hirschman, Kapo, & Karlawish, 2008; Jethwa & Onalaja, 2015; van der Steen, Galway, Carter, & Brazil, 2016), where it seems particularly suitable (Groen-van de Ven et al., 2016; Hirschman et al., 2008). With ACP, caregivers may get a clearer view of what decision making demands of them in light of the PWDs' anticipated cognitive deterioration. This could make decision making easier for both the PWD and the caregiver as the options are reduced, and may lead to better decision-making outcomes, that is, less caregiver burden, regret and guilt, and better ability to adapt to the new situation for PWDs.

Third, nursing home admission was the actual and inevitable decision in all networks, but never the preferred choice. Indeed, it was the only option when staying at home was no longer feasible. Hence, when there are no real alternatives to nursing homes, speaking about preferred options in housing decisions may not be helpful in decision making, as it may lead to unrealistic expectations

and then internal conflict. To this end, the element focusing on eliciting preferences in the IP-SDM model seemed less appropriate for housing decisions of PWDs. Moreover, we should either make sure that viable alternatives exist (e.g., small-scale supported living, cohabiting with family or others; Doekhie et al., 2014), or discuss what matters most in relation to the only feasible eventuality, instead of asking “where would you/the PWD prefer to stay?” which suggests that multiple options are possible, when they are not. This way, decision making and the options presented can be structured in clear phases, according to the evolving needs of the PWD and their caregiver. For a long time, the options to stay at home or not may both be feasible, but later on, the options may change or no longer exist. When this latter phase is considered to have arrived could be determined by the network members and stated in the ACP. Discussing the different options available in each phase, one phase at a time, sets realistic boundaries to decision making and could facilitate the involvement of more network members, as it does not require weighing different options, but only discussing the different characteristics of the one eventuality. Additionally, dividing the process into phases provides opportunities to re-evaluate the values of all involved in light of changing needs and new sets of options (or no options). In fact, this had already happened to some extent in the networks, because when it was clear that a nursing home admission was the only solution, values were refocused on characteristics of the nursing home (e.g., distance, rooms, available care).

Fourth, network members mentioned many negative associations with nursing homes. Some caregivers reported that they would rather their senior loved ones die or completely lose their mind before ending up in a nursing home. Assuming this does not mean they hoped for their loved ones to get more demented (which would contradict the fear of dementia among many adults (Tang et al., 2017), this illustrates their negative attitude towards nursing homes, and empathy for their loved one's preference not to go there, as well as the fact that many PWD actually die before being admitted to a nursing home. Such attitudes may be different in other health care contexts and countries, and may depend on the availability of nursing homes versus how other housing and care options are arranged, costs related to admission, cultural norms and values regarding care for the elderly, and the general attitude toward nursing homes in the population (Bowblis, 2014; Kane et al., 2013; Oliver, 2017). Moreover, a possible explanation for the negative attitude towards nursing homes may be that in the last years, Dutch nursing homes have received much negative attention in the Dutch media.

Fifth, many reasons for the eventual institutionalization were mentioned by caregivers (Afram et al., 2014; Cepoiu-Martin et al., 2016; Donnelly et al., 2015; Grau, Berth, Lauterberg, Holle, & Gräsel, 2016), but these were often not the explanations that were communicated to their PWD, especially not by spouses. As caregivers knew

that PWDs preferred not to go to a nursing home, other reasons were given to lure the PWD into a nursing home. Additionally, striking differences in decision-making processes were seen between primary caregivers who were spouses of the PWD (and living in the same home) and primary caregivers who were other family members and not living with the PWD (Groen-van de Ven et al., 2017; Jacobs, Broese van Groenou, & Deeg, 2014; Oldenkamp et al., 2016). Spouses mention different considerations (marital promises, never having lived separately), and were also sometimes focused exclusively on the PWD's wishes, ignoring their own increasing burden and the ongoing deterioration of the PWD. They tried to be very careful in how they framed the decision (Légaré et al., 2014) and waited a long time before communicating and implementing the decision. Caregivers not living with the PWD were more aware of cognitive decline and of when the current living situation was no longer tenable. They were also able to continue a healthy level of caregiving for longer (Kraijbo, de Leeuw, & Schrijvers, 2015; van de Pol et al., 2017), better able to communicate the need for nursing home placement to the PWD, and came to this conclusion earlier than spousal caregivers living in. It seemed that in networks where the decision was explained to PWDs frankly in terms of the impossibility of staying at home, of needing to move before cognitive deterioration was too advanced, and where the decision was communicated well before the move took place to give them time to adapt, PWDs were more understanding and happier with the decision. Also, in networks in which the decision was explained in terms of the caregiver's (often spouse's) inability to continue caring for the PWD rather than the PWD's own needs, the caregiver tended to feel guiltier about the decision (Garvelink et al., 2016; Wendler & Rid, 2011). ACP for housing decisions could help caregivers anticipate their increasing caregiver burden and what the consequences might be for housing decisions.

Last, some responses indicated a need for decision-making support in terms of planning (deciding ahead of time), ways of communicating about painful issues, combining information from different sources, and collaboration among caregivers. For example, some suggested multidisciplinary team meetings, and appointing case managers who would stay involved until after nursing home admission (Afram et al., 2014). Indeed, in other networks not analyzed in the present study, case managers were more often present and fulfilled important roles in decision making, including connecting network members and initiating decisions and future decision processes (Groen-van de Ven et al., 2017). However, the effect of casework managers on how network teams evaluate decision-making processes has yet to be determined.

Limitations

Some limitations have to be taken into account in interpreting these results. First, this was a secondary analysis of interviews that were conducted almost 5 years ago. Some

important changes have taken place in Dutch geriatric care since. For example, municipalities are now responsible for personal and home care, and informal caregivers are deployed even more to reduce the cost of caring for an increasing elderly population. However, if anything, these developments have increased the need for IP-SDM, underlining the relevance of our data. Additionally, our results are based on a purposeful selection of four care networks only. Although our methods enabled us to have a very rich, longitudinal and multidisciplinary perspective on these networks, the results may not be generalizable to other contexts, and our sense of having reached data saturation may have been misled by our purposeful selection of networks. Future research should include more diverse care networks.

Implications

All networks adopted a sort of SDM procedure, which was guided by the wishes of the PWD, but in which the actual involvement of PWDs decreased over time. Although the IP aspect of the model seemed important for both informal and formal caregivers, especially with regard to being informed about changes and being able to provide their view on things, none of the networks followed a true IP-process in which all who were involved held team meetings and evaluated decisions together. Our results suggest the importance of including the PWD's views and the involvement of primary, secondary, and formal caregivers in determining the best living environment for PWDs. Timely and honest communication about decision making seemed important for a more satisfying implementation of decisions. We think there may be an important role for ACP in housing decisions for PWDs.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None reported.

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