

Processes of user participation among formal and family caregivers in home-based care for people with dementia

Abstract

Scandinavian health policy supports prolonged home-based care for people with dementia. User participation is expected to reduce family burden. The aim of this study was to explore how formal and family caregivers experience collaboration while providing home-based dementia care, with a focus on user participation. Seventeen qualitative in-depth interviews were conducted among formal and family caregivers in rural municipalities. The theme identified during this process was ‘negotiating participation in decisions’. This theme was analysed using positioning theory. Concepts such as user participation are ambiguous, and caregivers negotiate positions during decision-making processes. Such negotiations are caused by the problematic relationships among patients’ legal consent, undefined spokespersons and pragmatic care practices. These constant negotiations enable or obstruct collaboration in several situations. User participation as a concept might contribute to conflicts during collaborations. Dialogues about user participation that focus on consent and spokespersons could reduce the burden created by negotiations in practice.

Keywords

Dementia patient, formal and family caregivers, health policy, home-based care, user participation

Introduction

Dementia disease (DD) is an incurable and progressive brain disease that typically results in cognitive deficits and losses. DD eventually necessitates a heavy reliance on health care services (Brodtkorb, Kirkevold, & Ranhoff, 2008). Because of Norway's growing and ageing population, it is estimated that in 2050, 160,000 people in Norway will suffer from DD, which is approximately double the current number (Ministry of Health and Care Services, 2013).

Scandinavian health policy supports prolonged home-based care for DD patients (Ministry of Health and Care Services, 2009). Government organisations (Norwegian Board of Health Supervision, 2011) describe the future challenges related to this health policy in terms of its social and economic costs to society and the physical, psychological, social and economic consequences for family caregivers. Official statements (Ministry of Health and Care Services, 2013; The Norwegian Directorate of Health, 2007) propose measures such as increased user participation and improved collaboration between formal care providers and family caregivers to alleviate these problems.

User participation was first introduced as a legal concept to equalise power in the health system (Ministry of Health and Care Services, 1999) and was further emphasised in national health care reforms (Ministry of Health and Care Services, 2009). Its importance continues to increase as future health policy plans are developed (Ministry of Health and Care Services, 2014). Government reports, supervision and plans for health care services establish new standards for patients, their relatives and formal health care providers (Juritzen, Engebretsen, & Heggen, 2012). The demands established by such governmental concepts as user participation will likely change care practices. Health policies and the nursing literature are optimistic about user participation, but critics object that the concept creates an illusion of choice and is oppressive (Juritzen et al., 2012).

This article explores how formal and family caregivers in rural municipalities experience collaboration and focuses on user participation in home-based care for DD patients.

The literature on user participation in care for DD patients

User participation is often considered synonymous with the highest quality of care, but few studies have been conducted to examine the stakeholders' experiences (Edvardsson, Fetherstonhaugh, & Nay, 2010). Research on user participation in DD care has primarily focused on ways to include the person with DD in the research (van Baalen, Vingerhoets, Sixma, & de Lange, 2011), patient involvement in the development of IT applications (Meiland et al., 2014; Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013) and strategies for making meaningful contributions to the development of care plans for DD patients (McCabe & Bradley, 2012).

A review of British policies seeking to extend the role of health service users indicated that, in practice, care is far from user-centred. The author suggested that managers and policy-makers must move from aspiration to reality (Bradshaw, 2008). Another review (Taghizadeh Larsson & Osterholm, 2014) concluded that DD patients are primarily involved in the informal part of the decision-making process. The authors emphasised that to meet government goals, updated research on the capabilities and rights of people with DD in formal care contexts was needed.

The policy of user participation in health care creates dilemmas for both users and providers. The negative consequences of DD activate the role of the family caregiver and prompt role changes within the family (Helgesen, Larsson, & Athlin, 2013). When a DD patient refuses to accept help, formal and family caregivers must decide whether to use force, pressure or persuasion (Fjelltun, 2009). Most of the previous research on home-based care for DD patients has examined the family caregivers' perspective, and there is an extensive body

of qualitative research describing the care burden associated with home-based care for persons with DD (Graneheim, Johansson, & Lindgren, 2014; Murray & McDaid, 2002). Several studies have investigated ways to ease families' care burden (Waldemar et al., 2007), and many studies suggest collaborative care interventions involving an interdisciplinary team, increased user participation and care partnerships between the patient and formal and family caregivers (Callahan et al., 2006; Dartington, 2008; Finkelstein, Forbes, & Richmond, 2012); however, formal caregivers' perceptions have not been explored (Jansen et al., 2009). In one study, formal caregivers working in home-based settings with DD patients were interviewed. The authors concluded that formal caregivers perceive family caregivers as both resources and burdens (Benzein, Johansson, & Saveman, 2004).

Therefore, the concept of user participation as it relates to caring for people with DD is important, but little is known about the formal and family caregivers' experiences of user participation in home-based care. To our knowledge, this study is the first to explore the collaborations between formal and family caregivers who provide home-based care for people with DD. This article is inspired by a government focus on increased user participation in care practice.

Methods

The participants gave oral and written informed consent before participating in the study. Digital audio files, transcribed interviews and notes from the study were registered by the Norwegian Social Science Data Services (NSD; nr. 32173) and were stored according to NSD guidelines (Norwegian Social Science Data Services, 2012).

Design

The project employed a qualitative research design. The methods used to explore and guide the interpretation and description of the caregivers' user participation experiences are based

on the weak social constructive perspective (cf. Lock & Strong, 2014) and inspired by interactional perspectives (cf. Järvinen & Mik-Meyer, 2005). This perspective accommodated the use of semi-structured interviews focusing on social and cultural patterns (i.e., the actors' positions and symbols, activities, actions and/or valuation of actions).

Sample

A purposeful sample (cf. Polit & Beck, 2008, p. 355) of sixteen women and one man from five rural municipalities in Norway participated in this study. All were formal or family caregivers for people with DD. Of the seventeen caregivers who participated, seven were family caregivers and ten were formal caregivers. The duration of their experience with health care services varied from five to forty years. Three of the family caregivers lived in the same house as the person with DD; four lived separate from the DD patient but within the same municipality.

Positioning theory

Positioning theory (cf. van Langenhove & Harré, 1999) informed the analysis. Positioning theory focuses on the relationship between what people believe they do or do not have the right or duty to perform and what they do in light of that belief (Harre & Slocum, 2003, p. 105). The participants in this study had formal roles as formal and family caregivers. The role of a formal caregiver has certain mandatory rights and duties defined within health policy, legal acts and the nursing literature. The formal caregiver can take or be given different positions in various situations regardless of his or her formal role. Positions are situation-specific, relational, defeasible and ephemeral (Harre & Slocum, 2003). For each position, expected duties and rights can be interpreted. People who attempt to collaborate will constantly adopt and revise position for themselves and for others. Actions must be made sense of within story-lines and either anticipatorily or retrospectively justified in utterances. The attempt to position oneself or others can be rejected or challenged during social

exchanges, which creates the need to negotiate both one's position and the understood context (van Langenhove & Harré, 1999). Correlative positions are displayed in people's acts, expectations, beliefs and presuppositions, and several story lines might occur at the same time (Harre & Slocum, 2003). Using positioning theory as an analytical tool to interpret these situations can offer insights into the mutual positioning, story lines and illocutionary forces that might inform the interpretation of one's own and others' acts during collaborations. Following Harré and Slocum's (2003, p. 100) advice, we also present some hypotheses about how an understanding of possible positions in various settings could be exploited for conflict resolution.

Limitation

In this paper, we present our understanding of the participants' presentations of dilemmas that arose during collaborations between formal and family caregivers in relation to user participation. We have no data regarding what the formal and family caregivers actually did during these situations; we only know what they said about the collaboration and their actions. There was first-order positioning (van Langenhove & Harré, 1999) only between the interviewer and the participants. The participants were positioned as people with knowledge about certain situations, and the interviewer likely served as a mouthpiece. These positions affect the findings and can be discussed as weaknesses; however, they are not the focus of this study. The interactional perspective describes the interviewer's interaction with the participants, and we sought transparency when presenting our methods and findings. The first author asked open questions from an interview guide pertaining to aspects of DD, the need for formal help, and the measures taken and collaboration that occurred when providing health care services. The stories were told as dynamic narratives and were sometimes detached from the original question. All of the presented positions can be considered a variety of third order (van Langenhove & Harré, 1999).

Data analysis

The analysis took place in an inductive way. The first author took notes on the interpretation of user participation when writing in the interview guide, after each interview, and during the transcriptions and the thematic analysis (cf. Coffey & Atkinson, 1996, p. 140). The computer software QSR NVIVO 10 (QSR International Pty Ltd 1999-2014, 2014) was used as a structural tool in the analysis. Transcripts from the interviews were read and re-read, and memos were written to record the initial interpretation of each interview. Inspired by the interview guide, the key phrases in the transcriptions were coded to organise the material. Two sorting categories, user participation and patients' needs, were identified. These portions of the text were analysed further to produce a set of codes that represented the meaning in close-to-text categories: help-seeking decisions, safety risks decisions, care measure decisions and care establishment decisions. The software's search function (QSR International Pty Ltd 1999-2014, 2014) was often applied to the entire text to look for words or sentences that related to the codes and categories that gradually emerged. The categories were analysed considering acts within possible story-lines, positions, duties and rights as informed by positioning theory (Harre & Slocum, 2003). The transcripts of each interview were also re-read at this stage of the analysis to ensure the appropriateness of the story-lines. The story-lines were used to create models and develop themes (cf. Tjora, 2012, pp. 175-195). The overarching theme that emerged was 'negotiating participation in decisions'. Three subthemes emerged that related to the story-lines presented: 1) negotiating consent, 2) negotiating intervention, and 3) negotiating the right to speak on the patient's behalf.

Findings: Negotiating participation in decisions

The findings illustrate how formal and family caregivers talk about each other and the person with DD in various situations where collaboration might occur. Conflicts and dilemmas in decision-making processes emerged in relation to stories about necessary care acts. The

negotiations related to decisions about patients' consent, times for formal care interventions and selecting spokespersons. Considering these three subthemes, we have categorised the collaboration in 11 interpreted story-lines and described the possible positions, rights and duties within these story-lines. (Insert table 1)

Negotiating to gain consent from the person with DD

They no longer know what is best for them

In this story-line, the patient is viewed as confused both by formal and family caregivers. Family caregivers talked about changes in their relatives and the person with DDs' attempts to hide the disease in different situations. A daughter said, 'She had trouble walking but started going to the shop several times a day. I suspected that she did not remember what she was supposed to buy.' Another daughter said, 'She tried to hide her incontinence, but she smelled bad, of course.' A formal caregiver said, 'People with DD cannot understand their own limitations; they seldom want to make changes, and they try to hide the symptoms.' The symptoms of DD are understood as requiring care, and the participants interpreted a need to take on the role of caregiver and the position of helper. The confused patient position has no described duties but has the right to be cared for. The patient is viewed as needing guidance in important decision-making processes. The caregivers expressed that many times, they wanted to do things differently to provide care for the person, and sometimes, they stretched boundaries to persuade the patient to do something differently. A family caregiver said, 'She could not decide all by herself. We had to persuade her. He (her husband) would have gotten sick, too.' The story-line worked to explain the suspicion of disease that both formal and family caregivers experienced.

The person living at home is the boss

In most cases, the caregivers described that the person with DD refused to be a patient during the early stage of the progressive disease. A family caregiver said, 'She turned it the other way around, like it was me there was something wrong with.' The dilemma for the caregivers is that while they consider the person with DD confused and unable to make correct decisions for their well-being, the person still has legal consent and has the right to refuse help. A person living at home is understood to be a rational individual with legal consent. Therefore, he or she has the right to choose or refuse help. Being a patient with DD might involve a threat to the rational position. A formal caregiver said, 'As long as they are at home, they are the boss.' Another one said, 'If they are not diagnosed, then they are considered rational.' The formal caregivers said that while they suspected that the person was confused, they still treated him or her as a citizen with the rights to make individual choices. A formal caregiver said, 'Despite a high MMS score, we still suspected something was wrong, but we could not do anything about it back then.' Another formal caregiver said: 'We cannot intervene just because the family wants us to.'

This dilemma relates to formal caregivers' desire to relieve family caregivers' heavy burdens while preserving the patient's autonomy, preventing coercion and remaining within legal boundaries. One formal caregiver said, 'The evaluation of legal consent is hard; it is really hard.' Another formal caregiver remarked, 'Consent is something we seldom take away from them. It is about user participation, and it is one of the few things they have left.'

Acute necessary health care

The caregivers noted that some situations changed the perceived understanding of necessary acts for both the formal and family caregivers. The preferences of the person with DD were apparently followed as long as the person's actions could be considered safe. A formal caregiver said,

My conscience is beating me about those still living at home. We want them to stay at home as long as possible, but it must be safe. How can we know if they are safe when we are not there?

The patient's ability to provide consent and participate in decisions was constantly evaluated in clinical practice. Both formal and family caregivers stated that the patient's choice had to be overruled at times, regardless of whether the patient could provide consent, and they said that, as caregivers, they sometimes worked in teams. A formal caregiver said,

We actively engage the family to persuade the old person. Sometimes we contact someone in the family and ask them to speak with their mother or father or we just say to the elderly person that we have spoken to their families and that they want us to help. It is also helpful to say that it is the doctor's prescription. Coercion is the last thing we do.

The exceptions to seeking legal consent arose when the person with DD acted in ways that were interpreted as serious safety risks. When the caregivers thought that the person with DD was in acute need of necessary health care, their own position changed to that of public and formal helper. One formal caregiver explained their legal duty to intervene. One said, 'She was out running in the night. In the end, we had to take her in. She could have frozen to death or gotten run over by a car.' The family caregivers often waited for this crisis to occur. One daughter said:

She started to fill a bucket with water. She was supposed to clean the house, but she forgot all about it. It resulted in extensive water damage to the house. I was so relieved when they (formal caregivers) took her in. Then they saw for themselves what we had tried to tell them.

This story-line provides an explanation for the caregivers' acts when they oppose the patient's choice. The dilemma pertains to the legal boundaries and discretionary necessary health care.

Negotiating formal care intervention

Family caregivers want to preserve normality

The family caregivers expressed their care as helping to hide the disease from society and thus preserve normality. This position was interpreted as that of a 'hidden helper'. The care was exemplified as help with shopping, hygiene, and food in public social contexts. A family caregiver who lived at home with the person with DD said, 'In public, I both ask and answer questions, but I try to include her in topics that I know she knows. In that way, I can help her if she stumbles in conversations.'

The way that the family caregiver made sense of what society in general understands and does in relation to a person with DD seemed to be important when they were deciding whether to keep the disease a secret. One family caregiver said, 'I do not want them to treat her differently, not yet.' The 'othering' position of society does imply the need for the 'hidden' position that the family caregiver adopts both for the person with DD and him- or herself. Some family caregivers expressed shame as a reason for hiding the disease. One family caregiver said, 'I was ashamed in the beginning. I could not have imagined that she could behave in such a manner.' Another daughter said, 'In my community, dementia is the

same as madness.’ Another family caregiver said, ‘It is not about shame; I just do not think it is any of their business.’

It makes sense, then, that the formal caregivers could be positioned as intruders who have the power to ruin the person with DD’s position in society, with the associated consequences for the family in general. Another family caregiver explained, ‘It will change the way people speak of and with her. Now, we are invited to dinners and stuff.’ Hiding the disease appears to be a strategy for preserving the former identity of the person with DD for the benefit of the whole family. The ‘hidden helper’ position may allow the family caregiver to be a participant and possibly to dominate in the decision-making processes for the person with DD.

Formal caregivers want early intervention

The formal caregivers preferred early interventions to prepare both the patient and their family for future situations. One formal caregiver said, ‘Some services are statutory. There is no doubt that they need help’. The challenge, however, was determining whether the person actually had DD and selecting the correct moment to intervene. A formal caregiver said, ‘One lady had always been properly dressed, but now we saw her with dishevelled hair and non-matching socks. We sent a nurse just for an informal visit.’ This utterance could be interpreted to indicate that the formal caregivers felt a duty to observe people in society for symptoms of DD. The formal caregivers are, because of their formal role, responsible for protecting and caring for the person with DD as soon as they understand the person’s role as a patient. Informal visits, or other ways of intervening in someone’s home, were often used as an attempt to provide early intervention and good quality treatment and care. The story ‘they no longer know what is best for them’ relates to this story-line of early intervention. In some situations, formal caregivers exchanged their observing positions for participating, intervening, advising and helping positions, and they often shared these positions with family caregivers, as presented in the story of acute necessary health care.

Family caregivers' care-burden break down

Family caregivers told vivid stories of a heavy care burden. Some of the family caregivers said that they had needed psychotherapy or other types of therapy to help them manage the difficult feelings that arose from trying to care for their family member with DD. One daughter cried, saying,

She (her mother) has said so many bad things to me after she got sick. I still do not know if it is caused by DD. Maybe she means every word and no longer has inhibitions that stop her from saying it.

The family caregivers expressed a break down point at which they could no longer care for the person with DD alone. They acted as a spokesperson and explained the person with DD's symptoms and problems to others. One said, 'I had to take the responsibility for informing the family and contacting health care services.' All of the family caregivers felt required to take on the public position of caregiver, and as a result, the person with DD was forced to be a patient. The idea of preserving normality had to be abandoned. A family caregiver admitted that she felt guilt for a long time after pressuring her mother: 'I could not stay with her all the time. In the end, I forced her to sign the application form to get help. She cried and accused me of not loving her.'

The family caregivers expressed the need for help both for the person with DD and for themselves; in contacting health care services, the formal caregivers had to act outside of their formal roles. One formal caregiver said, 'In the beginning, it is difficult for the person who gets the disease, but their relatives struggle until the end.' Family caregivers expressed relief when they received help from formal caregivers, and several family caregivers made

statements similar to this one: 'My advice to others in the same situation is to not be afraid to ask for help at an early stage.' This story-line is closely related to the discussion of consent and formal caregivers' attempts to intervene.

Formal caregivers guide decisions

The formal caregivers viewed themselves as formal helpers of the patient, with formal duties and rights. They also viewed the family as needing general help. With that understanding, the formal caregiver's duty was to care for the patient and his or her family in the best manner they knew. One formal caregiver said, 'Family caregivers need to feel secure.' Another formal caregiver said, 'We arrange schools so family caregivers can learn more about dementia and thereby feel more secure about providing care.' The formal caregivers may have viewed themselves as holding a superior position that gave them the right to advise and persuade both the patient and the family during decision-making processes. Some of the formal caregivers suggested that relatives lacked knowledge about DD and were therefore unqualified to assess what the affected person really needed. One formal caregiver said,

Many think their parent is more affected (by DD) than they actually are. They demand that we do a lot of things that I think are a part of the daily life training, such as bringing firewood for the house, buttering the bread or picking up mail. I think it is healthy for the people to try to remember and to do these things themselves, even if that means some days without mail.

The formal caregivers reported that they tried to provide individualised care. They sought regular meetings with the family and wanted to complete forms in advance so that they could be sent when they reflected the patient's needs. One formal caregiver explained, 'We carefully mention some possible measures and gauge their reactions. Home-based care is an

option, but sometimes we decide what they can choose between.’ This story-line presented the family caregivers in the position of needing help and the formal caregivers as guides for treatment, care and future plans.

Negotiating the right to speak on behalf

Family caregivers fight for resources

One family caregiver described the establishment of collaboration between formal and family caregivers as successful. The other family caregivers discussed collaboration using metaphors such as fight, battle, crisis and war, and they particularly complained that they received little information about the patient’s treatment and future care plans.

Family caregivers who did not live in the same house as the person with DD said that help from formal caregivers gave them psychological relief, and the ones living with the person described the physical relief that formal caregivers gave them. All of the family caregivers expressed how difficult it was for them to allow someone else to guide and advise decisions for their relative. They were not always pleased with the measures or resources the formal caregivers offered, and they assumed a protective position on behalf of what they thought the person with DD wanted. Family caregivers expressed the belief that their participation in decision-making processes could ensure the provision of individualised care. They were aware of the possible limitations and constraints created by the economy and the lack of resources within the municipality, but they still wanted to discuss how they could contribute to accomplishing what they considered the ideals of care. One family caregiver exemplified the principle of preserving the patient’s prior identity by ‘at least ensuring that the patient’s glasses and teeth were in place; maintaining their hair, clothes and house; and allowing them to fulfil their accustomed positions in society.’ Another family caregiver indicated that she wanted the formal caregivers to allow her mother to continue her religious observance: ‘My

mother has always listened to devotionals on Sundays. They could have helped her with things like that'. The family caregivers ceased to worry about the person's safety or the heavy care-burden of nursing tasks, but their care burdens were manifested in constant conflicts with formal caregivers.

The most troubling issue

Several family caregivers felt that the formal caregivers perceived their attempts to be a spokesperson and give advice as criticism. They stated that formal caregivers disregarded them in important decision-making processes. One family caregiver said that this problem was a recurring theme in the dementia association that she had joined. She said, 'I feel like I keep on talking, but no one is listening. It is like speaking to a wall. They do not care what I think anymore; it is like my Mum is their property now.' Another daughter said,

I sought meetings and wanted to explain why my Mum behaves the way she does. She is a bit... her personality is... Well, I wanted to help them so they would not step into her traps, but they did not contact me or call me back.

Several family caregivers cried when they recalled their conflicts with formal caregivers. One family caregiver spoke about resignation; crying, she said, 'It has been two years now, and I still think it is hard to cope with. It is hard knowing I could not make it better for her at the end.' Another family caregiver said, 'I wish I could have done more for her, but it is not in my hands anymore.' The conflicts between family members and formal caregivers typically arose when negotiating individual and psychosocial care measures. The family caregivers still assumed a demanding position on the patient's behalf but were more reserved than they had formerly been.

Formal caregivers protecting the patient

Over time, the establishment of care changed the formal caregiver's position. When formal caregivers first intervene in a home, they collaborate with family caregivers and develop care measures with the patient and family caregivers as a team. Eventually, this collaboration changes to focus on the patient's current desires.

The formal caregivers explained that many of the family caregivers had cared for the person with DD for so long that they thought they had obtained patient consent. The formal caregivers argued that the patient still had legal consent; although they required care, they also had to be given opportunities to make choices relevant to their new situation. For the formal caregivers, helping the family meant showing family caregivers how to free the person with DD from the constraints of their former identity and how to learn to value the changed person: 'We want to know the affected person's life story, but the former identity cannot be the guide for today's care.' The formal caregivers added that in many cases, the patient and the family caregivers disagreed on which measures were necessary. One formal caregiver said, 'A family caregiver may have great ideas and demands for the care, but quite often, the patient disagrees.' The formal caregivers believed they had a responsibility to support their patients' current wishes. One formal caregiver said,

Some relatives live far away and do not see their mother as we do. We have become her closest relatives in a way, and we understand her needs as they are expressed today. Of course, they get frustrated when they come home and see that their mother is not like she used to be and that we do not do the things they want us to do.

The formal caregivers focused on avoiding difficult situations and patient coercion, often taking a pragmatic perspective. One formal caregiver said, 'We do what we think is best in the situation; they [the family caregivers] are not there.' The formal caregivers rejected the family caregiver's assumption of presumed or surrogate consent in some situations. They assumed the position of the protector of the patients' rights and positioned themselves as the person's spokesperson, replacing the family caregiver. The collaboration between formal and family caregivers during this phase seemed to be non-existent.

Formal care is difficult within organisational constraints

The formal caregivers offered services that assessed both the individual patients' and their families' needs and the limits of the municipalities' available resources. The patients and their relatives were given the opportunity to choose from a pre-selected set of health care services constrained by organisational limitations. The formal caregivers expressed a kind of victimised position. They wanted to provide care differently but knew that the organisational resources were limited. One formal caregiver said, 'I often feel guilty about not having enough time. Sometimes I see that I should have acted more like a relative. Still, I have to be practical and do what I have time to do.' The municipalities' economic situations were repeatedly cited as the reason why formal caregivers' nursing ideals were impossible to achieve. Family caregivers' complaints, especially written complaints, were used to request more resources from the system. One formal caregiver said, 'Devoted relatives that dare to make demands are necessary to achieve good-quality health care service. It is very unfortunate, but that's the way it is'. Nevertheless, some formal caregivers stated that they became upset if someone complained about their work: 'It is easier to complain than to say a few words of praise about our everyday work. We need relatives to uplift us, too.'

Discussion: The conflicting user-participation

The symptoms of DD activated the roles of formal and family caregivers and changed these positions. These findings are in line with previous research (Helgesen et al., 2013). The findings in this paper illustrate the formal and family caregivers' descriptions of their acts within these roles. To investigate enabling and inhibiting types of collaboration in relation to the discussion of consent, intervention and the right to speak on behalf of a person with DD, we have interpreted the caregivers' descriptions of acts as story-lines with accompanying positions, duties and rights. These discussions are understood within the broader discourse of user participation in the field of dementia care. (Insert table 2)

Enabling collaboration

Possible enabling collaboration is believed to occur most often during the first connection between formal and family caregivers and relates to the discussion of consent and intervention. Collaboration is enabled when the parties describe mutual story-lines that position the person with DD as a patient who is confused and in need of care. The caregivers were in conflict with the person with DD, and the person's refusal of help and legal consent presented a dilemma. Most patients with DD retain legal consent even when they are in nursing homes. The caregivers described stretching and overruling consent in various situations and did so most definitively when the patient was a safety risk. The formal caregivers described the need for early involvement to secure proper treatment and care, and the family caregivers expressed experiencing a heavy care burden. The progressive nature of DD eventually necessitates a heavy reliance on health care services (Brodtkorb et al., 2008), and determining the correct moment for intervention is often challenging. In our study, the caregivers stated that the patient's decision to ask for or accept assistance was often made after strong persuasion from family caregivers. These findings support Fjelltun's findings (2009). There is a tipping point at which the burden is too heavy for family caregivers, and

they transfer decision-making power to the health-care providers (Grimen, 2010). This can be difficult to do for several reasons, and conflicts arise regarding participation in decision-making processes. The formal caregiver should consider the arduous position that family caregivers feel they are in when they have to destroy the perception of the patient as a rational person. Nonetheless, the findings show that formal caregivers should continue to attempt to provide early intervention to reduce the family burden, as official statements recommend (Ministry of Health and Care Services, 2013; The Norwegian Directorate of Health, 2007). Although family caregivers might at times position the formal caregivers as observers and intruders, in retrospect, they request and accept the formal caregivers' official roles.

Inhibiting collaboration

The story-lines that inhibited collaboration were interpreted to be about consent, intervention and the right to speak on the patient's behalf. The right moment for formal caregivers to intervene when a person with DD needs help relates to their ability to observe symptoms. Family caregivers, as helpers in hiding the disease, inhibit collaboration with formal caregivers, which can lead to a heavy family care burden.

The story of the 'the person living at home is the boss' also inhibits collaboration. If family caregivers want help for the person with DD and are not able to persuade the patient, they depend on the formal caregiver's mapping and considerations to overrule the patient's choice. Formal caregivers emphasise the person with DD's consent and thereby make the person responsible for the possible negative consequences of his or her own choices. However, these consequences can result in a heavy family care burden. Formal caregivers describe legal consent as discretionary and difficult to judge. By acting conscientiously according to their sense of legal consent, they ensure that they are not doing anything legally wrong. Still, the situation creates dilemmas for formal caregivers who intend to follow the

health policy of providing early intervention and alleviating the family care burden (cf. Ministry of Health and Care Services, 2013).

‘The right to speak on behalf’ of the patient seems to be the most conflicted story-line. The family caregivers wanted to implement more individual care measures to preserve the person with DD’s former identity. They regarded themselves as spokespersons for the person with DD and assumed that they could take on the patient’s right to consent (cf. Appelbaum, 2004). Both ethically and legally, such consent is problematic because the person with DD still legally has the power to grant consent. Family caregivers acting as spokespersons take a position that is unacceptable to formal caregivers in several situations. In those situations, the formal caregivers assumed the position of the protector of the patient’s right to give consent. The family caregivers were regarded as resources when they facilitated the formal caregiver’s access to the patient in their home. They were considered burdens when conflicts arose about the actual implementation of formal care. These findings support previous results showing that formal caregivers view family caregivers as both resources and burdens (Benzein et al., 2004).

Organisational limitations created further difficulties. Both the formal and family caregivers believed that organisational constraints had negative consequences for the care that the person with DD received. The family caregivers reported experiencing a heavy care burden because of the fight for resources and conflicts with formal caregivers. The formal caregivers expressed having asked the family members to speak out to organisations and complain about the limitations to services; however, they also felt burdened by feeling blamed and receiving too little praise. Formal and family caregivers engaged in conflicts about participation in important decision-making processes. These conflicts were often about what was best or necessary for the patient, but they were mostly about who has the right to define it. When formal caregivers adopt the position of the patient’s protector or spokesperson, the

power in the decision-making process shifts from the family caregivers to the patient or even the formal caregiver. The reasons for these changes in positioning are not openly discussed between the formal and family caregivers. The family caregivers may feel disregarded and deprived of their position as spokespersons. This rejection both inhibits collaboration and creates a psychological care burden that can last for years.

Change in practice regarding the demands of the ‘user participation’ concept

The discussion about consent, intervention and the right to speak on behalf of someone are related to the broader discourse regarding user participation. Current health policies explicitly dictate that user participation is a right of patients with DD (Ministry of Health and Care Services, 2013). Such governmental dictates focus more attention on patient choice in practice and are expected to prevent abuse. The shift in focus towards user participation may make formal caregivers especially careful to avoid depriving their patients of their legal consent. This might be one reason for the constant negotiations about consent, necessary interventions and spokespersons between formal caregivers and family members.

Previous research has found clear evidence of the family burden that exists before formal health care intervention is initiated (Graneheim et al., 2014; Murray & McDaid, 2002). Our research indicates that the most exhausting situations for family members arose from the need to negotiate consent and the right to speak on behalf of the person with DD long after formal care had been established. To date, the governmental focus has been on easing the family burden by encouraging early intervention and user participation. From our perspective, early intervention is a goal that could be easily integrated into several story-lines and can enable collaboration between formal and family caregivers. We present and support the need for care partnerships, as previous research has suggested (Callahan et al., 2006; Dartington, 2008; Finkelstein et al., 2012). Both formal and family caregivers would benefit from having a dialogue with one another at an early stage. Knowledge about DD and the DD patient, in

addition to knowledge about available services, can significantly reduce the shame and stigma that some of the family caregivers in our sample associated with the disease. Increased knowledge, dialogue and collaboration may accommodate both the desire for normality and the preservation of the person's identity and allow all parties to prepare for the progressive stages of DD.

However, the story-lines also present a need to shift the governmental focus from early intervention towards the increased and long-term psychological burden created by conflicting interactions with formal health care providers. User participation in the form of choices made by a rational individual conflicts with dementia care practice, especially in terms of the issue of spokespersons. This conflict seems to create a major psychological care burden for the family. Critics have objected that the concept of user participation creates an illusion of choice and is oppressive (Juritzen et al., 2012; Mol, 2008). According to this study, the principle of user participation has shortcomings when applied to the care of DD patients because of the progressive nature of the disease. The caregivers gave many examples of needing to use force and persuasion, and the person with DD was unable to refuse health care when the formal and family caregivers decided together to pursue intervention. The disease eventually impairs the person's ability to make decisions and presents an eventual need for patient spokespersons. As a principle of DD care, user participation cannot be fully discussed without also discussing the vagueness of the term 'consent' (cf. Beauchamp & Childress, 2009).

The goal of user participation as a legal concept is to equalise power in the health system (Ministry of Health and Care Services, 1999). It is highly unclear how formal caregivers should pursue this goal in practice or whether it actually increases the potential for conflict situations. We wonder whether the situations that our participants most often described presented only a semblance of user-centred care. The practices described are indeed user

centred, but given the shifting understanding of consent, these practices seem to be affected by other concerns. This finding elaborates the research of Bradshaw (Bradshaw, 2008).

Despite how gravely these issues affect the perceived quality of care for people with DD, there is evidence that none of these issues is discussed openly in practice.

To prevent feelings of guilt that add to the care burden, formal and family caregivers should engage in dialogues to discuss the decisions made in situations where the term 'consent' is vague and conflicting. It might be helpful to examine the potential consequences of legally presumed or surrogate consent in situations in which legal consent has been clarified but poses problems in practice. Discussions of these topics are important when offering or claiming to include user participation in practice.

Conclusion

Current government health policy seeks to ease the family burden and increase user participation in home-based dementia care. Both formal and family caregivers consider user participation a common good; however, in practice, caregivers' understanding of user participation differs across the phases of DD. The definitions of consent differ, and disagreements arise about who can claim to be promoting user participation and for what reason. The home-based care for DD patients that was examined in this study included negotiations about consent, intervention and the right to speak on behalf of the patient. The positions related to the roles of formal and family caregivers are constantly in flux. Changes in position enable or inhibit collaboration between formal and family caregivers, and the positions assumed when negotiating the right to speak on behalf of the patient are the most problematic. Negotiating positions affects all parties' participation in decisions and the decisions made. Such negotiations are therefore the foundation of user participation. Formal

and family caregivers' negotiations are the process by which power is redistributed in home-based dementia care.

The decision-making process is difficult for both formal and family caregivers and establishes ambiguous roles for all of the positions taken during the interactions among caregivers. The political demands for user participation increase the need for dialogue in each interaction. Future health policies need to encompass more than user participation; they must discuss the activities to which user participation can be applied and clarify the guidelines for consent in DD care. Discussions of user participation for people with DD as a health policy concept must become more transparent in practice, within patient organisations and among policy makers to achieve the best possible care for people with DD.

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Tables

Table 1. The interpreted dynamic positions, duties and rights within various story-lines

Role	Positions	Story-line	Duty	Rights	Example of acts	Negotiating
Person with DD	Confused patient	People with DD no longer know what is best for them	None	To be cared for To be listened to	Hiding incontinence Having driving trouble Feeling angry/suspicious Refusing help	Consent
	Rational person	The person living at home is the boss	Acting normal	To have individual choices	Living at home Showing a high MMS score	Consent
	Patient in danger	Acute need for health care	None	To be cared for	Wandering in the night	Consent
Family caregiver	Hidden helper	Preserving normality	Caring for the person Hiding the person's disease	To participate in decisions	Speaking for the person Shopping Washing clothes Accepting anger/suspicion Feeling burdened	Intervention
	Public helper	Feeling the break down of a heavy care-burden	Providing care	To act as a spokesperson	Contacting formal caregivers Informing family members Persuading the person with DD	Intervention
	Protector	Fighting for resources	Preserving the identity of the person with DD	To act as a spokesperson To demand measures from formal caregivers	Making oral and written demands for measures Requesting meetings	Speaking on the person's behalf
	Disregarded	The most troublesome issue	Trusting formal caregivers	To be listened to	Lodging oral and written complaints Asking for meetings Feeling angry and hurt	Speaking on the person's behalf
Formal caregiver	Observer	Early intervention	To observe	To intervene if necessary	Observing society Making formal visits Hiding the MMS score	Intervention
	Helper of the family	Guiding decisions	To care for the patient To care for the family To participate using professional knowledge	To advise and persuade during decision-making processes	Contacting the family Intervening with the patient at home Arranging paperwork and	Intervention

			and organisational resources		measures Educating the family	
Protector of the patient	Family caregivers do not know what is best for the patient	To prevent coercion To be present in the present time To help the person and his/her family accept his/her changed identity	To serve as a spokesperson	Helping the patient make choices in present time Protecting the patient from the family's unrealistic suggestions Feeling sorry (about the care perspective and resources)	Speaking on the person's behalf	
Victim	It is difficult to provide care within organisational constrains	To think economically To act pragmatically	To defend themselves	Limiting measures Accepting and encouraging complains	Speaking on the person's behalf	

Table 2. Story-lines that enable or inhibit collaboration within three possible discussions

	Consent	Intervention	Right to speak on behalf
Enabling collaboration story-lines	1. They no longer know what is best for them (C) 2. Acute necessary health care (C)	4. Early intervention (Fo.C) 5. Formal care guides decisions (Fo.C) 6. Care-burden break down (F.C)	
Inhibiting collaboration story-lines	3. The person living at home is the boss (Fo.C)	7. Preserving normality (F.C)	8. The fight for resources (F.C) 9. The most troublesome issue (F.C) 10. Protecting the patient (Fo.C) 11. Formal care is difficult within organisational constraints (Fo.C)

Note: C – both formal and family caregivers, Fo.C – formal caregivers, F.C – family caregivers

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