

Family caregivers' involvement in decision-making processes regarding admission of persons with dementia to nursing homes

Abstract

The current Western health policy of ageing in place relies on a triad collaboration among patients, healthcare service providers and family caregivers. Such collaborations presuppose involvement in a vague juridical landscape. This article explores family caregivers' experiences with involvement in and influence on nursing home decision-making processes for persons with dementia. The data consist of twelve in-depth interviews with family caregivers. Using positioning theory, we demonstrate how family caregivers strive to balance their assumed duty to care for the person with their needs to care for themselves. Their involvement (or non-involvement) in the complex decision-making process is demonstrated through the following seven positions: 1) self-condemning determiner, 2) dominant, 3) proponent, 4) saluting, 5) pending, 6) prisoner, and 7) stooge. Furthermore, we discuss why expedient positions are more available for some individuals and the consequences of family caregivers' various positions on the healthcare policy aims of collaboration and equal healthcare services.

Keywords:

decision-making processes, dementia, family caregivers, involvement, home-based care, admission to nursing homes, positioning

Introduction

The large number of people affected by dementia diseases, posing major challenges for Norwegian public health, healthcare services and healthcare service providers (HcPs) (Ministry of Health and Care Services, 2013:41). According to Wiles, Leibing, Guberman, Reeve, and Allen (2012), the ideal of *ageing in place* has gained traction in Western countries. This ideal is associated with the assumption that living in the community rather than in institutional care enables people to maintain independence, autonomy and connection with family and friends, and postpone the costly option of institutionalization (Wiles et al., 2012). Ageing in place presupposes support from family caregivers, friends, volunteers and non-governmental organizations.

In Norway, most home-based care for people with dementia is provided by family caregivers with various sources of support from public, local healthcare services (Ceci, Björnsdóttir, & Purkis, 2012). The majority of Norwegian long-term eldercare is provided by nursing homes, but most Norwegian municipalities have ceased using nursing homes in recent decades and have instead opted to build assisted living facilities (Holmen, 2016). However, there is a scarcity of assisted living facilities, labour and healthcare competence (Bergh et al., 2015), and the family caregivers' role in home-based care has been more explicitly defined in recent governmental reports (Ministry of Health and Care Services, 2013, 2015a, 2015b, 2018). For example, in 2013, the Norwegian official report "Future Care" (Ministry of Health and Care Services, 2013) launched a programme aiming to appreciate family caregivers' efforts in home-based care and enable family caregivers to stay longer in the caregiving role through measures such as flexible respite arrangements, family caregiver support, increased collaboration with healthcare services and improved payment for informal care work. In 2018, a governmental report described family caregivers as priceless and "renewable resources" (Ministry of Health and Care Services, 2018:47 [Authors' translation]).

Thus, the ideal of ageing in place rests on the ability of healthcare services to support family caregivers and family caregivers' willingness and capacity to care for individuals with dementia at home.

Regarding family caregivers' willingness and capacity, numerous international studies have documented family caregivers' efforts as a potential physical, psychological and social burden (Graneheim, Johansson, & Lindgren, 2014; Murray & McDaid, 2002; Purkis & Ceci, 2015). During the month prior to the admission of persons with dementia to nursing homes,

Norwegian family caregivers provided approximately 160 hours of support to these individuals, whereas an average of 16 hours was provided by healthcare professionals in the persons' homes (The Norwegian Directorate of Health, 2016).

The amount of informal caregiving work leads to substantial consequences for family caregivers if the person with dementia refuses to apply for admission to a nursing home (or other healthcare services) (Miller, Withlatch, & Lyons, 2016). Following the Patients' Rights Act, users of healthcare services (in this case, home-dwelling persons with dementia) are entitled to user involvement; thus, users have the right to be informed of and involved in plans for and choices of treatment and care (Ministry of Health and Care Services, 2016). If a person with dementia does not consent to healthcare, HcPs (most often general practitioners) assess the need of the person with dementia for services and his/her capacity to consent and can make decisions on the patient's behalf. Nonetheless, HcPs should consult with family caregivers before making important decisions (Ministry of Health and Care Services, 2016). Thus, decision making regarding nursing home admissions is a complex negotiation process involving the construction of a shared understanding of the situation in which the autonomy of both the family caregivers and the persons with dementia is challenged (cf. Chrisp et al., 2013). Often, family caregivers initiate contact with local healthcare services without the person with dementia knowing (Chrisp, Tabberer, & Thomas, 2013). Studies have also documented family caregivers' decisional burden regarding nursing home admissions (Koenig, Lee, Macmillan, Fields, & Spano, 2014)

In the Norwegian context, the nursing home decision-making process generally occurs in phases. Initially, a person decides to apply and eventually makes a final decision when offered a space. However, it is a responsibility of healthcare services to determine the services that are best suited to meet the citizens' needs. Healthcare services must prioritize the needs of all citizens in the municipality and make decisions based on their knowledge of the available labour and competence (Ministry of Health and Care Services, 2016). Thus, the period between the application and a space being offered can be long.

Several researchers have highlighted the need for knowledge about decision-making processes regarding admission to nursing homes for persons with dementia (Afram, Verbeek, Bleijlevens, & Hamers, 2015; Koenig et al., 2014; Lord, Livingston, Robertson, & Cooper, 2016; Stephan et al., 2014; Taghizadeh Larsson & Osterholm, 2014). Decision-making

processes in Norwegian home-based care are sparsely investigated, and no studies have investigated Norwegian family caregivers' involvement in and influence on nursing home decision-making processes for persons with dementia.

Purpose and research question

The purpose of this study is to explore family caregivers' experiences with, involvement in and influence on nursing home decision-making processes for persons with dementia.

Knowledge of nursing home decision-making processes is essential for policymakers and healthcare services to approach the ideal of ageing in place. Furthermore, this knowledge can be important for safeguarding user involvement among persons with dementia and facilitating the involvement and reducing the decisional burden of family caregivers.

Literature review

Several international studies have explored *family caregivers'* experiences with decisions regarding admission to nursing homes (Taghizadeh Larsson & Osterholm, 2014). Studies have demonstrated that family caregivers pursue shared or supported decision making during the early stages of dementia and gradually change to surrogate decision making during the later stages (Fetherstonhaugh, McAuliffe, Shanley, Bauer, & Beattie, 2017; Lord, Livingston, & Cooper, 2015; Samsi & Manthorpe, 2013). The surrogate decision-maker position is seldom formalized, and the persons with dementia are sparsely involved in decisions concerning their admission to nursing homes (Koenig et al., 2014; Miller et al., 2016). A Norwegian study demonstrated that HcPs mainly relied on family caregivers' knowledge about the persons with dementia in making decisions regarding admission to nursing homes (Rognstad, Sagbakken, & Nåden, 2015).

Studies have demonstrated that family caregivers have a good sense of the values and preferences of the persons with dementia (Whitlatch, Pipiparinen, & Feinberg, 2009) and that family caregivers safeguard the autonomy of the person with dementia in decision making (Fetherstonhaugh, Rayner, & Tarzia, 2016; Samsi & Manthorpe, 2016). However, Koenig et al. (2014) found differing views between older adults and their family caregivers among two-thirds of the participants. The differing views were mostly related to involvement in the

decision of moving such that the family caregivers wanted the older adult to move, while the older adults did not consider moving necessary.

Several studies have demonstrated family caregivers' experiences of deep sorrow, exhaustion and fractured relationships while making decisions regarding admission to nursing homes (Butcher, Holkup, Park, & Maas, 2001; Lord et al., 2016; Park, Butcher, & Maas, 2004) and after the final decisions are made (Cheek & Ballantyne, 2001; Graneheim, Johansson, & Lindgren, 2014; Koenig et al., 2014). Based on a review study, Lord et al. (2015) presented the triggers and barriers of admission to nursing homes. The triggers included deterioration in the health of the person with dementia, deterioration in the health of the family caregivers, change in the living environment, and the ability of the persons with dementia to make decisions with which the family caregivers agreed. The barriers included resistance by the person with dementia, the family caregivers' desire to honour the person's wishes, the emotional impact of making a decision on the family caregivers, change in the roles in the family, varying symptoms of dementia, preconceived responsibilities, and discrepancies between the families' and HcPs' views of the needs of the person with dementia.

The nursing home decision-making process is complex, long-lasting, and emotionally challenging. Support and counselling by HcPs are crucial for helping persons with dementia and their family caregivers feel safe, safeguarding the rights of the persons with dementia and reducing the family caregivers' burden (Afram et al., 2015; Koenig et al., 2014; Kraijo, de Leeuw, & Schrijvers, 2015).

Despite their discomfort in making the decision, family caregivers have highlighted that controlling decisions is important in their interaction with formal healthcare services (Schaber, Blair, Jost, Schaffer, & Thurner, 2016). Family caregivers may attempt to control decisions to be able to meet the assumed normative expectations of their care work. Thus, if the family caregivers are not involved by HcPs in decision-making processes, they might question their own abilities to provide care (cf. Larsen, Normann, & Hamran, 2015). Several studies have demonstrated that family caregivers' perceptions of their abilities to meet the assumed normative expectations of their care work are a predictor of institutionalization (cf. Caron, Ducharme, & Grifffith J, 2006; Lord et al., 2015; Vernooij-Dassen, Felling, & Persoon, 1997; Zarit, Todd, & Zarit, 1986).

Methods

The purpose of this study is to explore family caregivers' experiences with, involvement in and influence on the nursing home decision-making process for persons with dementia. Family caregivers' experiences were reported in semi-structured interviews and analysed through the lens of positioning theory (cf. Harré, 2004) to identify various family caregiver positions.

Participants

The participants in this study (n=12) were recruited among participants in a survey study conducted in Northern Norway involving family caregivers for people with dementia (Table 1). In the survey, the participants indicated whether they were willing to participate in a qualitative interview regarding their experiences with being a family caregiver. Written information and consent forms were sent to 30 persons in five municipalities. After the signed consent forms were returned, we scheduled interviews directly with the participants.

Table 1: The participants

ID	Gender	Age	Relationships	Distance to PwD home
1	Female	60s	Daughter	Neighbour
2	Female	40s	Daughter	10-min driving distance
3	Male	70s	Spouse	Share home
4	Female	70s	Spouse	Share home
5	Female	50s	Daughter	10-min driving distance
6	Female	60s	Sibling	Neighbour
7	Male	60s	Nephew	Neighbour
8	Female	60s	Spouse	Share home
9	Male	80s	Spouse	Share home
10	Male	60s	Sibling	10-min driving distance
11	Male	70s	Spouse	Share home
12	Female	60s	Daughter	Neighbour

Data construction

The participants selected the meeting locations, including hotels, their homes or working offices. The interviews, which were conducted by the first author, lasted between 56 and 176 min and were audiotaped. A semi-structured interview guide including open-ended questions about the family caregivers' care situations, collaboration between the persons with dementia and healthcare services, decision-making processes and future prospects, was used. The

interviewer wrote field notes immediately after each interview session, and the interviews were transcribed.

Data analysis

The data consisted of transcribed audio files and field notes. We used the qualitative data analysis computer software NVIVO 11 for Windows to perform the analysis (QSR International Pty Ltd, 2014). The first author read the interview transcripts several times and wrote a preliminary interpretation of each interview. Key phrases in the transcripts were coded. Consistent with Tjora (2012), codes close to the original texts were constructed. The codes were gathered into six categories of relevance to the research question. Each interview transcript was reread during this stage to ensure the appropriateness of our interpretations.

According to Harré and Langenhove (1999), re-descriptions of interactions can be explored through the analytical concepts of “the positioning triad”, which has been described as the following intertwined basic features of interactions: storylines, position and illocutionary forces (Harré & Langenhove, 1999). Storylines are utterances that carry meaning, i.e., the tellers’ assumptions about what they and others are entitled to do or say. Moreover, tellers achieve something through their utterances; thus, storylines have illocutionary forces.

Individuals’ physical positions in time, place and history and the metaphorical positions of the storyline characters are significant to the meaning and illocutionary force of a storyline. People often become aware of positions when they are deprived of something or are rejected. Therefore, positions can be understood as people’s conscious or subconscious representations of themselves and others always in relation to the other (Van Langenhove & Harré, 1999). Negotiations of positions in decision-making processes are discursive processes. According to Harré and Dedaic (2012), discursive processes are the starting point of research.

By using positioning theory, we constructed the following two main storylines in which the family caregivers strived to achieve balance in the nursing home decision-making process: a) the assumed duty of caring for the person with dementia and b) the caregivers’ own needs. Based on the storylines and their illocutionary forces, we constructed seven positions. The positions of involvement (or non-involvement) in decisions can be taken or imposed on the family caregivers. The constructed positions are as follows: 1) self-condemning determiner, 2) dominant, 3) proponent, 4) saluting, 5) pending, 6) prisoner, and 7) stooge.

Ethical approval

This project was planned and conducted according to the Committee on Publication Ethics' International Standards for Authors (Wager E & Kleinert S, 2011). The project is registered with the Norwegian Social Science Data Services (NSD; no. 42469), and the material is stored according to NSD guidelines (cf. Norwegian Social Science Data Services, 2012).

Limitations

A large bias in this study is the author's pre-understanding, positioning and interpretation of the interview-setting and further analysis of the material. However, the structured methods, guidance by previous research, positioning theory and discussions regarding the findings with fellow researchers has helped us question our pre-understanding and guided further interpretation.

Furthermore, the participants involved in this study vary in gender, age, relationship with the person with dementia and described care-burden, but other sampling strategies could have also had an impact on the results. In this study, all participants were self-selected and might have a reflected aim in their participation. When asked, the participants described the topic of the study as important and stated that they want to help others in similar situations.

Results

The family caregivers experienced a dilemma regarding the following two conflicting storylines: (a) the assumed duty to care for the person with dementia and b) the caregivers' own needs. The family caregivers' positioning of themselves involved the positioning of the person with dementia and the HcP. Various situations and interactions resulted in various positions. An overview of the seven positions in connection with the two main storylines and illocutionary forces regarding the nursing home decision-making process is presented in Table 2.

Table 2. An overview of the positions and illocutionary forces connected to the two main storylines.

Position	Positioning of the others*	Illocutionary forces
Self-condemning determiner	-PwD: Confused and blameless HcP: Uninformed	Family caregiver presented as the responsible determiner of admission to nursing homes <ul style="list-style-type: none"> - Describes decisional burden and, in particular, bad conscience in addition to triggers and barriers of institutionalization - Legitimizes the decision
Dominant	PwD: Confused and subordinate HcP: Ignorant and a barrier to help	Family caregiver presented as resourceful and in charge <ul style="list-style-type: none"> - Describes involvement and fights on behalf of the person with dementia Claims to care for own needs - Legitimizes depriving the PwD of de facto consent
Proponent	PwD: Confused, significant partner HcP: Significant partner	Family caregiver presented as a valuable partner to the PwD and HcP <ul style="list-style-type: none"> - Describes initiative and involvement - Describes resources and strategies to team up with the PwD or HcP
Saluting	HcP: Principal	Family caregiver presented as humble and grateful but smart <ul style="list-style-type: none"> - Describes praising and strategic work
Pending	PwD: Confused and blameless HcP: Principal	Family caregiver presented as responsible but not in charge <ul style="list-style-type: none"> - Declares the caregiving duty - Renounces the responsibility for the decision
Prisoner	PwD: "Jailer" HcP: Ignorant "lawyer"	Family caregiver presented as trapped <ul style="list-style-type: none"> - Describes imprisonment - Questions the range of the family caregiver's responsibility for the PwD
Stooge	PwD: Burden HcP: Exploiter	Family caregiver presented as a stooge <ul style="list-style-type: none"> - Describes the feeling of being exploited - Questions the range of the family caregiver's responsibility for the PwD

*Abbreviations: person with dementia: PwD. Healthcare service providers: HcPs.

Self-condemning determiner position

All family caregivers in this study reported that the persons with dementia rejected admission to a nursing home. Nonetheless, the family caregivers eventually deemed admission to a nursing home necessary in the near future for both the person with dementia and their own needs. Thus, by virtue of their situation, all family caregivers were in the self-condemning determiner position. One daughter (ID12) noted the following: *"They are not dolls that I can put away in a drawer when I get tired"*.

The self-condemning determiner position may provide opportunities for family caregivers to become involved in decision-making processes if the other agents accept the position. Nonetheless, many family caregivers seemed to condemn themselves regardless of the choices they made. One wife (ID8) noted, *"My conscience bothers me even though I realize this is the only way to make life worth living for both parties."* The illocutionary force concerned the dilemma of attending to the needs of the person with dementia or their own needs in addition to legitimizing their decisions.

Given the self-condemning determiner position, the persons with dementia were positioned as confused and not to blame for the burden. Moreover, while assuming this position, the family caregivers presented the HcPs as uninformed about the complexity of the situation. Consequently, the family caregivers carried the decisional burden.

The family caregivers described acute illness in the persons with dementia as a socially accepted reason for transitioning to a nursing home and, consequently, experienced a relief of their decisional burden. One daughter (ID5) said, *"Luckily, he was too physically sick to be aware of the move."* Other reasons for admission to nursing homes appeared to be more difficult to speak about with HcPs and, thus, generated more decisional burden. Such reasons included a need for a life of their own, their feelings of a crowded house that no longer was a home because of the HcPs' interventions, the personal hygiene of the person with dementia, and their fear of offending, hurting or injuring the person with dementia. A husband (ID3) said: *"The most troublesome is that I build up a kind of suppression and have to restrain myself not to yell"*.

Dominant position

By assuming the dominant position, family caregivers attempted to strengthen their involvement. One wife (ID4) stated, *“the one who still can reason has to decide”*. However, the dominant position appeared to increase the decisional burden. One brother (ID10) noted, *“It is tough, but the family caregivers must accept the burden of the anger of the person with dementia”*.

The dominant position may be associated with the family caregivers' traits or capacities, e.g., management experience or being the dominant partner of the relationship. One sister (ID3) noted, *“I have to say that she signed because of my strong influence on her”*. One husband (ID3) related, *“I have managed this company for many years; so, I mostly take care of the big decisions at home”*. Management experiences and an understanding of general decision-making processes appeared to be crucial capacities for the dominant position. One brother (ID10) stated, *“If the healthcare service providers disagree with me, I will start a fight and we'll see (who wins).”*

Most family caregivers described that their dominance in decisions was imposed on them as a result of the progression of the disease. Moreover, decision making was described as a burden. Given the dominant position, the persons with dementia were positioned as confused and subordinate with regard to decisions. All family caregivers made statements that were somewhat similar to the following remarks of one wife (ID8): *“He tried to explain that he could stay at home alone, but he cannot. I have to make the decision for both of us”*. The illocutionary force of the storylines legitimized making decisions to which the person with dementia did not consent. One daughter (ID1) stated, *“We had to force him to move. Otherwise, he would have been dead by now”*.

By positioning themselves as dominant, family caregivers positioned the HcPs as informed but as a barrier to access to services. The family caregivers reported that they occasionally had to overrule the HcPs. In the storylines that concerned conflicts with healthcare services, several family caregivers (ID1, 2, 3, 6, 7, and 11) presented themselves as *“resourceful families”*. One daughter (ID2) stated, *“I have broad experiences in life from municipal offices; so, I make my way”*.

While assuming the dominant position, family caregivers emphasized the need to care for themselves. One husband (ID11) remarked that he refused to assist his wife with personal

hygiene after the application to a nursing home was rejected. He said, "*Getting her to shower was untenable, and I gave up. Then, her poor hygiene became a visible problem, and the nurses had to allocate a room for her at the nursing home*". He described this decision as "*a desperate choice*" because he treated his wife "*disgracefully*" to force the healthcare services to take responsibility for her.

Proponent position

Compared to those in the dominant position, family caregivers in the proponent position appeared to discuss the possible admission to a nursing home with both the person with dementia and the HcP. The storylines concerned varying initiatives and strategies to achieve involvement without fights or comprehensive decisional burden. One daughter (ID2) described, "*She is still somewhat headstrong and discusses the process with me and the healthcare service providers; however, now, I am able to supervise her*". Other family caregivers described teaming up with other family members as follows: "*I refused to be the only one to force him...we had to agree among us siblings, at least*" (ID5).

In most examples, the family caregivers teamed up with HcPs on different healthcare service levels. Several family caregivers said that "*the nurse took action*" (ID6) when notified. One daughter (ID5) related, "*I asked him to apply, but he was not in a hurry. Then, the healthcare service providers urged him to apply, and he did*". One husband (ID11) described how he strategically acted familiar by asking the HcPs about their parents when they met at local stores. He said, "*If it had not been for me, her (his wife's) admission to the nursing home would not have been established as quickly as it did. It's nice to know people.*"

When their applications to nursing homes were rejected by local healthcare services, some family caregivers emphasized the main storyline of caring for their own needs and teamed up with their general practitioner (GP). One wife (ID8) said, "*I got him admitted to the nursing home because my GP knows the doctor who is in charge of the nursing home, and they both backed me up. I was lucky.*" Other family caregivers approached specialized healthcare services for support as follows: "*At the hospital, they acknowledged my needs as well, and they met my demands that they could not send him home*" (ID2).

Three family caregivers described that their participation in this study was motivated by their feelings of not being listened to or acknowledged by healthcare services. One daughter (ID12) said, "*The main reason that I participate in this study is that the politicians need to*

know how it feels for us". Thus, some family caregivers assumed a proponent position, teamed up with researchers and, thus, were involved in healthcare decisions at a higher level of decision making.

Saluting position

Despite the comprehensive stories about problems related to conflicting views of decisions, many storylines, particularly the storylines from the older participants, focused on being thankful to HcPs. The illocutionary forces of the storylines regarding the saluting position involved praising the HcP and simultaneously presenting themselves as humble and grateful. One husband (ID3) stated, *"I shall not complain; however, they do fantastic work, the angels in white"*. Family caregivers seemed to assume that caring for the person with dementia was their duty and that the HcP, in line with their competence, should make decisions about services. Thus, the family caregivers in the saluting position seemed to depend on the HcPs' decisions for help.

However, the saluting position could also be a strategy for being offered more services. A daughter (ID1) described how she proceeded to make the HcP change their mind as follows: *"In a humouring manner, I praised them and further explained why my father needed to be admitted to a nursing home"*. One husband (ID9) said, *"I emphasize that they do a great job and I often praise them. Then, it is much easier for me to ask for services when I need it, and I probably make it harder for them to reject my request"*. These storylines' illocutionary forces describe how the family caregivers made themselves more "likeable" to give them an opportunity to present their view, show family resources, and consequently, influence decisions.

Pending position

The pending position seemed to mostly emphasize the assumed duty of caring for the person with dementia, and this position seemed to be associated with participants of old age. These participants performed most of the care work but gave the HcPs responsibility for the final decision of moving. One husband (ID9) said, *"I take it as a matter of course that healthcare service providers tell us if it is time for my wife to move"*. The illocutionary force in their utterances seemed to declare their own caregiving duty and renounce the responsibility for admission to nursing homes. Some family caregivers gave utterances similar to this husband (ID3): *"I told her that I would have taken care of her, but it was no longer my decision"*. The renouncement of responsibility seemed to be connected to the assumed loss of social

reputation if they gave up their caregiving duties as follows: *"It was not about me! The healthcare service providers decided that he should be in a nursing home. It was the house that was the problem. It's not built for old people"* (ID8).

The pending position may reduce the family caregivers' decisional burden and loss of social reputation. However, in this position, the family caregivers depend on HcPs to discover and acknowledge their needs and subsequently make the decision about admission to nursing homes as follows: *"It was probably someone working there who detected us and observed that I was not able to do all the care work myself; so, we have been lucky after all"* (ID5).

Prisoner position

The prisoner position concerned with family caregivers' frustrations, non-involvement and exclusion from society. One daughter (ID1) stated, *"I feel I am constantly on my toes and trapped in the caregiving role"*. These storylines described imprisonment and had the illocutionary force to question the range of family caregivers' responsibility. One daughter (ID12) cried, *"caring for my parent is a choice, but at the same time, it's not a real choice"*. One husband (ID9) noted, *"Our biggest problem is the blurred lines for responsibility the moment I leave the house. Thus, I cannot leave."* Thus, the prisoner position is an imposed position. The family caregivers strived for involvement but described themselves as powerless, disarranged or excluded. One husband (ID3) said, *"We are plucked out of context, and I have no idea what to do about it"*, and one wife (ID8) stated, *"I feel in a pinch without knowing what I can or cannot do"*. Simultaneously, the person with dementia was positioned as the jailer. One wife (ID4) stated, *"It is not right. He refused to apply, and thus, my life became more and more burdensome. I am exhausted, and whatever work tasks seem to drain me of energy"*.

Many family caregivers complained about the lack of arenas for contact with HcPs without the person with dementia present. One husband (ID3) said, *"I need to talk to nurses about potential services, but it is difficult when she (person with dementia) is always present"*. The family caregivers expected the HcPs to take initiative and free them from their demanding situations, similar to a lawyer's task for imprisoned persons, e.g., to conduct negotiations with a counterparty with the aim of achieving a fair trial and perhaps the hope of being released.

Stooge positions

Most family caregivers said that the local healthcare services took advantage of their efforts. Several participants expressed sentiments similar to this daughter (ID1) as follows: *"They rely on us to do care work in an effort to maintain the status quo"*. Several participants gave examples of persons with dementia without close relatives who had been rapidly offered admission to nursing homes. One nephew (ID7) described his uncle as *"far more mentally healthy than the other patients at the nursing home"* and noted, *"His being all alone was an important part of the rapid intervention"*. Thus, such storylines described feelings of being exploited and had the illocutionary force of questioning the range of family caregivers' responsibilities. One brother (ID10) stated, *"I want to question the use of family caregivers. It's impossible for most people to do this much care work."*

In the stooge position, family caregivers positioned healthcare services as exploiters. One daughter (ID1) said, *"My parents should have moved to the nursing home a long time ago. However, nobody in local healthcare services acknowledges our needs."* Several family caregivers expressed sentiments similar to this daughter (ID1): *"If he gets worse, I will just leave! [Long pause – crying] However, I know that I cannot leave him, and the healthcare service providers know that just as well as I do. I actually do not know what to do anymore."*

Some family caregivers had waited for as long as possible to apply for nursing home admission. Nonetheless, their first requests had been rejected due to capacity issues. One husband (ID9) with a severe illness, who told the interviewer that he would not live much longer, said, *"I could have helped her (wife with dementia) to make the decision, but there is no point when the nurses say that there is no capacity"*. A wife (ID8) noted, *"Someone must die for him to get a room there"*.

Discussion

This study explored family caregivers' experiences of, involvement in and influence on the nursing home decision-making process for persons with dementia. The results are congruent with those of previous studies that have described this decision as a complex, long-lasting and emotionally demanding process (cf. Afram et al., 2015; Graneheim et al., 2014; Koenig et al., 2014). The family caregivers in this study strove to balance the assumed duty to caring for the person with their needs to care for themselves.

Providing access to equal healthcare services is an important aim of Norwegian healthcare (Ministry of Health and Care Services, 2015c). The Norwegian Municipal Health Care Act states that local healthcare services must offer and provide necessary and justifiable services based on their assessment of individuals' needs (Ministry of Health and Care Services, 2011). Decisions regarding services are based not solely on the needs of the person with dementia but also on the overall resources of the municipality (Røiseland, 2016). This study demonstrated that decisions about admission to nursing homes are influenced by family caregivers' abilities to assume expedient positions in collaboration with the person with dementia, HcPs and healthcare services.

Positions are regarded to have dualistic dimensions, such as strong and weak (Harré & Slocum, 2003). In this study, the spouses and daughters who lived in the same home as the person with dementia appeared to have stronger positions with regard to decision-making processes than the other participants. Other studies have presented family caregivers' autonomy as bounded to the autonomy (and thus decisions) of the person with dementia (cf. Chrisp et al., 2013). If the person with dementia refuses healthcare, the family caregivers who share a home with the person cannot reduce or leave their responsibilities without leaving their own homes. Thus, these caregivers may make more vigorous attempts to influence decisions about admission to nursing homes.

Family caregivers highlight that controlling decisions is important in their interactions with formal healthcare services, although decision making is associated with discomfort (Schaber et al., 2016). The dominant position might increase the family caregivers' influence on decisions; however, this position is related to a *strong* self-condemning determiner position. In this study, the husband who stopped helping his wife with her personal hygiene managed to escape a burdensome situation. However, the price he described in the forms of decisional

burden, feelings of failure, sorrow and fractured relationships is congruent with observations reported in previous studies (Graneheim et al., 2014; cf. Lord et al., 2015).

The positions available to family caregivers depend on their capacities. The dominant, proponent and saluting positions appeared to provide opportunities for involvement and influence, and several participants who adopted or were imposed these positions reported to have management experience. These findings are congruent with those reported in previous studies demonstrating that “those who have information, contacts and personal skills for utilizing administrative and political power might encounter different rules for access to public resources than those who lack these resources” (Häikiö & Anttonen, 2011:193).

To be able to influence decisions through the dominant, proponent or saluting positions, family caregivers must have knowledge about local healthcare services and HcPs. The purchaser-provider divide has created more distance between those in need of services and healthcare services and between those who provide services and those who decide which services to use. Thus, it is challenging for family caregivers to describe their needs in a way that fits the structure of the services. To be able to be involved, family caregivers must know the system as shown in the proponent position in which the family caregivers spoke directly to healthcare services (purchaser) and not the HcP (provider).

Conversely, the pending, prisoner and stooge positions may be chosen to avoid involvement in or responsibility for the decision. These positions may also be imposed on family caregivers who are not able to describe their needs in ways that fit the structure of the services. Thus, the family caregivers depend on help from HcPs or healthcare services as shown in the prisoner position, and the persons with dementia and their family caregivers are at risk of receiving unmatched services if healthcare services are unaware of their position.

According to recent statistical projections, major municipal differences in the services offered to older citizens are expected. Moreover, home-based care may not be sustainable at the level of the currently offered services due to the scarcity of people providing care (Rogne & Syse, 2018). Hence, the family caregivers' role will most likely become more dominant in the future. Based on this study, we question whether family caregivers pay a harsh price for the ideal of *ageing in place*.

In this study, none of the persons with dementia had been assessed for their capacity to consent. Despite their severe care needs, they all refused admission to nursing homes. All

family caregivers questioned the capacities of the persons with dementia to make such solitary decisions. Thus, this study demonstrates that despite non de jure responsibility (Mol, 2008:20), family caregivers strive to escape the self-condemning *determiner* position. This finding is congruent with findings reported in previous studies investigating family caregivers' experiences of being responsible for decisions regarding admission to nursing homes (Graneheim et al., 2014).

Conversely, persons with dementia cannot be assumed to be incapable of making decisions solely on the basis of their diagnoses (Bartlett & O'Connor, 2010). For persons with dementia, user involvement is strengthened through international agreements (World Health Organization, 2017), Norwegian healthcare policy reforms (Ministry of Health and Care Services, 2015a) and legislative changes (Ministry of Health and Care Services, 2016). This study demonstrates that the empowerment of persons with dementia has consequences on the lives of family caregivers who strive to create a mutual understanding of the situation, a mutual experience of the need for collaboration, and the ability to find structures in healthcare services that enable collaborations. This long-lasting and emotionally challenging process must be acknowledged through structured decisional support by healthcare services that both safeguard the involvement of the persons with dementia and support family caregivers in setting limits to their care tasks and involvement.

It is crucial for HcPs to actively explore whether persons with dementia involve their families in their decisions. Healthcare services may overlook the family caregivers' needs and their democratic right to make autonomous choices in a situation in which their life situations are strongly affected by the choices made by others (the person with dementia and/or healthcare services). Furthermore, it is necessary to ask family caregivers about their own needs and the care tasks they want and are able to perform in home-based care. Given the positions described in this study, HcPs should, in particular, be aware of the decisional burden on family caregivers who adopt a dominant position and family caregivers who live with the persons with dementia.

Implications

To highlight the legislated user involvement of persons with dementia and reduce the family caregivers' decisional burden, politicians and healthcare services must understand,

acknowledge and emphasize family caregivers' own needs. Our model of family caregivers' positions can be useful for the further development of decisional aids to reduce conflicts and the negative effects of care on family caregivers in home-based care. If HcPs are aware of the potential positions in interactions with family caregivers for persons with dementia, they may enable more expedient positions for themselves and family caregivers. More expedient positions may result in fewer conflicts and reduce the decisional burden when demanding decisions, such as admission to nursing homes, must be made.

Conclusion

Health care policies regarding ageing in place rely on the following third party: family caregivers. This study contributes by describing family caregivers' experiences of involvement in and influence on the nursing home decision-making process for persons with dementia. Knowledge of how family caregivers present themselves and others within positions is useful for understanding how decisions regarding admission to nursing homes are made and evaluating individuals' access to healthcare. This knowledge is important for HcPs to provide tailored support and, thus, facilitate the involvement of family caregivers in nursing home decision-making processes for persons with dementia.

Conflicts of interest

None declared.

References

- Afram, B., Verbeek, H., Bleijlevens, M. H. C., & Hamers, J. P. H. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies. *International Psychogeriatrics*, 27(06), 891-902. doi:10.1017/S1041610214002154
- Bartlett, R., & O'Connor, D. (2010). *Broadening the Dementia Debate. Toward social citizenship*. Great Britain: The Policy Press.
- Bergh, S., Vossius, C., Selbæk, G., Ydstebø, A. E., Benth, J. S., Godager, G., & Lurås., H. (2015). *Ressursbruk og sykdomsforløp ved demens (REDIC). Kortversjon. (Resources and prognosis of dementia diseases)*. Retrieved from Hamar: https://www.fylkesmannen.no/Documents/Dokument%20FMHE/04%20Helse%20og%20omsorg/Demenskonferanse/REDIC_rapport.pdf
- Butcher, H. K., Holkup, P. A., Park, M., & Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Res Nurs Health*, 24(6), 470-480.
- Caron, C. D., Ducharme, F., & Gritffith J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. . *Can J Aging*, 25, 193-205.
- Ceci, C., Björnsdóttir, K., & Purkis, M. E. (2012). Introduction: Home, Care, Practices - Changing Perspectives on Care at Home for Older People. In C. Ceci, K. Björnsdóttir, & M. E. Purkis (Eds.), *Perspectives on Care at Home for Older People* (pp. 1-23). New York: Routledge.
- Cheek, J., & Ballantyne, A. (2001). Moving them on and in: The Process of Searching for and Selecting an Aged Care Facility. *Qualitative Health Research*, 11(2), 221-237. doi:10.1177/104973201129119064
- Chrisp, T., Tabberer, S., & Thomas, B. (2013). Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia. *Journal of Health Psychology*, 18(2), 272-281. doi:10.1177/1359105312437265
- Daatland, S. O., & Otnes, B. (2015). Scandinavian Contrasts and Norwegian. Variations in Special Housing for Older People. *Journal of Housing for the Elderly*, 29(1), 1-17. doi:10.1080/02763893.2015.989778
- Fetherstonhaugh, D., McAuliffe, L., Shanley, C., Bauer, M., & Beattie, E. (2017) "Did I make the right decision?": The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia. *Dementia*, 0(0), 1471301217721862. doi:10.1177/1471301217721862
- Fetherstonhaugh, D., Rayner, J.-A., & Tarzia, L. (2016). Hanging on to some autonomy in decision-making: How do spouse carers support this? *Dementia*. doi:10.1177/1471301216678104
- Graneheim, U. H., Johansson, A., & Lindgren, B. M. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: insights from a meta-ethnographic study. *Scand J Caring Sci*, 28(2), 215-224. doi:10.1111/scs.12046
- Harré, R. (2004). Positioning Theory: The True Domain of Thinking. Retrieved from <http://www.google.no/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uac>

[t=8&ved=0CCQQFjAAahUKEwi3pcDjvfvIAhXCiCwKHT5rCP8&url=http%3A%2F%2Fwww.massey.ac.nz%2F~alock%2Fvirtual%2Fpositioning.doc&usg=AFQjCNFqY2PMp6sH1grNiZSHtpKwF4UHYg](http://www.massey.ac.nz/~alock/virtual/positioning.doc&usg=AFQjCNFqY2PMp6sH1grNiZSHtpKwF4UHYg)

- Harré, R., & Dedaic, M. (2012). Positioning theory, narratology and pronoun analysis of discursive therapies. In A. Lock & T. Strong (Eds.), *Discursive Perspectives on Therapeutic Practice* (pp. 45-64). Oxford: Oxford University Press.
- Harré, R., & Langenhove, L. v. (1999). *Positioning theory: moral contexts of intentional action*. Oxford: Blackwell.
- Harré, R., & Slocum, N. (2003). Disputes as complex social events: On the uses of positioning theory. *Common Knowledge*, 9(1), 100-118.
- Holmen, J. (2016). Nedleggelse av sykehjemsplasser kan gi klassesdelt omsorg. [The termination of nursing homes may lead to unequal care]. Retrieved from <https://www.aftenposten.no/meninger/debatt/i/3EJ0/Nedleggelse-av-sykehjemsplasser-kan-gi-klassesdelt-omsorg--Jostein-Holmen>
- Häikiö, L., & Anttonen, A. (2011). Local welfare governance structuring informal carers' dual position. *International Journal of Sociology and Social Policy*, 31(3/4), 185-196. doi:10.1108/01443331111120636
- Koenig, T. L., Lee, J. H., Macmillan, K. R., Fields, N. L., & Spano, R. (2014). Older adult and family member perspectives of the decision-making process involved in moving to assisted living. *Qualitative Social Work*, 13(3), 335-350. doi:10.1177/1473325013475468
- Kraijjo, H., de Leeuw, R., & Schrijvers, G. (2015). How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Sciences*, 29(1), 101-109. doi:10.1111/scs.12137
- Larsen, L. S., Normann, H. K., & Hamran, T. (2015). Processes of user participation among formal and family caregivers in home-based care for persons with dementia. *Dementia*. doi:10.1177/1471301215584702
- Lord, K., Livingston, G., & Cooper, C. (2015). A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *Int Psychogeriatr*, 27(8), 1301-1312. doi:10.1017/s1041610215000411
- Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics*, 16(1), 68. doi:10.1186/s12877-016-0242-1
- Miller, L. M., Withlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *The international Journal of Dementia*, 15(5), 1141-1157. doi:<https://doi.org/10.1177/1471301214555542>
- Ministry of Health and Care Services. (2011). *Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven) [ACT 24/06/2011 no. 30: Act relating to municipal health and care services, etc. (Health and Care Services Act)]*. Oslo: www.lovdata.no Retrieved from <http://www.ub.uio.no/ujur/ulovdata/lov-20110624-030-eng.pdf>.

- Ministry of Health and Care Services. (2013). *St.mld. nr 29. (2012-2013). Morgendagens omsorg. [Report no. 29 (2012-2013). Future Care]*. Oslo: www.regjeringen.no
Retrieved from <https://www.regjeringen.no/no/dokumenter/meld-st-29-20122013/id723252/?ch=1>.
- Ministry of Health and Care Services. (2015a). *Demensplan 2020. Et mer demensvennlig samfunn. [The dementia strategy 2020. A more friendly society for people with dementia]*. Oslo: www.regjeringen.no Retrieved from https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/demensplan_2020.pdf.
- Ministry of Health and Care Services. (2015b). *Meld. St. 26. Fremtidens primærhelsetjeneste – nærhet og helhet. [Report no.26 (2014-2015) . The future primary health care services - proximity and entirety.]*. Oslo: www.regjeringen.no Retrieved from <https://www.regjeringen.no/contentassets/d30685b2829b41bf99edf3e3a7e95d97/no/pdfs/stm201420150026000dddpdfs.pdf>.
- Ministry of Health and Care Services. (2015c). *Nasjonale mål og prioriteringer på helse- og omsorgsområdet for 2015. [National aims and prioritizations for Health-and Careservices 2015]*. Oslo: www.regjeringen.no Retrieved from <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/884/IS-1%202015.pdf>.
- Ministry of Health and Care Services. (2016). *Lov om pasient- og brukerrettigheter. [Act of 2 July 1999 No. 63 relating to patients' rights (the Patiens' Rights Act)]*. Oslo: Ministry of Health and Care Services, Retrieved from www.lovdatab.no.
- Ministry of Health and Care Services. (2018). *Meld. St. 15 (2017-2018) Leve hele livet, en kvalitetsreform for eldre. [Report no.15 (2017-2018) To live the whole life, a qualityreform for people of old age.]*. Oslo: www.regjeringen.no Retrieved from <https://www.regjeringen.no/no/dokumenter/meld.-st.-15-20172018/id2599850/>.
- Mol, A. (2008). *The logic of care health and the problem of patient choice*. London New York: Routledge.
- Murray, J., & McDaid, D. (2002). Carer burden: the difficulties and rewards of care-giving. In M. Warner (Ed.), *Alzheimer's disease policy and practice across Europe* (pp. 1 online resource (viii, 200 s.)). Oxford: Radcliffe Medical Press.
- Norwegian Social Science Data Services. (2012). Personvernombudet for forskning - meldeskjema [Privacy policy in research. Notification form]. Retrieved from <http://www.nsd.uib.no/>
- Park, M., Butcher, H. K., & Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Res Nurs Health*, 27(5), 345-356. doi:10.1002/nur.20031
- Purkis, M. E., & Ceci, C. (2015). Problematizing care burden research. *Ageing & Society*, 35(07), 1410-1428. doi:doi:10.1017/S0144686X14000269
- QSR International Pty Ltd. (2014). *NVIVO 10 for Windows* (NVIVO 10 for Windows ed.). Melbourne, Australia: QSR International.
- Rogne, A. F., & Syse, A. (2018). *Framtidens eldre i by og bygd. Befolkningsframskrivninger, sosiodemografiske mønstre og helse. [The future for people of old age in urban and*

- rural areas. *Population projection, sociodemographic patterns and health*]. (978-82-537-9619-2). Oslo: Statistisk sentralbyrå Retrieved from <https://www.ssb.no/befolkning/artikler-og-publikasjoner/attachment/328026?ts=15f811146d0>.
- Rognstad, M.-K., Sagbakken, M., & Nåden, D. (2015). Pårørendes rolle som ressurs og samarbeidspartner: En studie med fokus på pårørende til pasienter med demenssykdom i sykehjem: Family members' role as resources and collaborating partners: A study focusing on dementia and long-term stay in a nursing home. *Nordic Journal of Nursing Research*, 35(1), 57-64. doi:10.1177/0107408314560478
- Røiseland, A. (2016). User Choice- Blessing or Curse? Exploring Democratic Participation in Swedish and Norwegian Local Governments. *Scandinavian Journal of Public Administration*, 20(4), 27-51.
- Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatr*, 25(6), 949-961. doi:10.1017/s1041610213000306
- Schaber, P., Blair, K., Jost, E., Schaffer, M., & Thurner, E. (2016). Understanding Family Interaction Patterns in Families With Alzheimer's Disease. *OTJR: Occupation, Participation and Health*, 36(1), 25-33. doi:10.1177/1539449215610566
- Stephan, A., Afram, B., Koskeniemi, J., Verbeek, H., Soto, M. E., Bleijlevens, M. H. C., . . . the RightTimePlaceCare, C. (2014). Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals. *J Adv Nurs*, n/a-n/a. doi:10.1111/jan.12493
- Taghizadeh Larsson, A., & Osterholm, J. H. (2014). How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings. *Int Psychogeriatr*, 26(11), 1849-1862. doi:10.1017/s104161021400132x
- The Norwegian Directorate of Health. (2016). *Analyse av utviklingstrekk i omsorgssektoren. [Analysis of trends in the health care services]*. Retrieved from Oslo: <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1184/IS-2469%20Analyserapporten%20-%20Analyse%20av%20utviklingstrekk%20i%20omsorgssektoren.pdf>
- Tjora, A. H. (2012). *Kvalitative forskningsmetoder i praksis [Qualitative research in practice]* (2. utg. ed.). Oslo: Gyldendal akademisk.
- Van Langenhove, L., & Harré, R. (1999). Introducing Positioning Theory. In R. Harré & L. Van Langenhove (Eds.), *Positioning Theory* (pp. 14-31). Oxford: Blackwell Publisher Ltd.
- Vernooij-Dassen, M., Felling, A., & Persoon, J. (1997). Predictors of change and continuity in home care for dementia patients. *Int J Geriatr Psychiatry*, 12(6), 671-677. doi:10.1002/(SICI)1099-1166(199706)12:6<671::AID-GPS599>3.0.CO;2-G
- Wager E & Kleinert S (2011) Responsible research publication: international standards for authors. A position statement developed at the 2nd World Conference on Research Integrity, Singapore, July 22-24, 2010. Chapter 50 in: Mayer T & Steneck N (eds) *Promoting Research*

Integrity in a Global Environment. Imperial College Press / World Scientific Publishing, Singapore (pp 309-16). (ISBN 978-981-4340-97-7)

Whitlatch, C. J., Pipparinen, R., & Feinberg, L. F. (2009). How well do family caregivers know their relatives' care values and preferences. *The international Journal of Dementia*, 8(2), 223-243.

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2012). The Meaning of "Aging in Place" to Older People. *The Gerontologist*, 52(3), 357-366. doi:10.1093/geront/gnr098

World Health Organization. (2017). Dementia: a public health priority [Internet]. Geneva: World Health Organization; 2012 Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*, 26. doi:10.1093/geront/26.3.260

Postprint version of article published in Dementia, DOI: 10.1177/1471301218814014