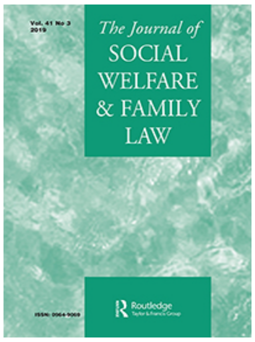

Journal of Social Welfare and Family Law

ISSN: 0964-9069 (Print) 1469-9621 (Online) Journal homepage: https://www.tandfonline.com/loi/rjsf20

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To cite this article: Lottie Giertz, Ulla Melin Emilsson & Emme-Li Vingare (2019) Family caregivers and decision-making for older people with dementia, Journal of Social Welfare and Family Law, 41:3, 321-338, DOI: 10.1080/09649069.2019.1627087

To link to this article: https://doi.org/10.1080/09649069.2019.1627087

JOURNAL OF SOCIAL WELFARE AND FAMILY LAW
2019, VOL. 41, NO. 3, 321–338
https://doi.org/10.1080/09649069.2019.1627087

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Family caregivers and decision-making for older people with dementia

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ABSTRACT

This article addresses the dilemmas concerning legislation, individual autonomy and the reality of everyday life for people coping with dementia. We describe and analyse decision-making in relation to older people with dementia in Sweden, within the area of social work regulated by the Social Services Act and the Parental Act. Swedish legislation is based on the individual's autonomy and capacity to consent to services without anyone having legal authority to decide on behalf of the individual. Based on data from interviews with family caregivers living at home, decision-making through family caregivers is discussed and formal guardianship is also considered. Swedish legislation leaves individuals with dementia and family caregivers in a vacuum between self-determination and full autonomy with the ideal of citizenship emphasised and recognised in the Social Services Act on the one hand, and on the other, a strong need for support in everyday life and with decision-making.

KEYWORDS

Decision-making; dementia; family caregiver; social services; Sweden

Introduction

An ageing population has a profound impact on the increasing prevalence of dementia in many countries worldwide, including in Sweden (WHO 2015). Dementia is characterised by progressive deterioration of cognitive abilities including the ability to make decisions and to manage independent living (Prince *et al*. 2013). This means there are an increasing number of people who are in need of support with the activities of daily living. As the population ages, more people face the prospect of having a parent or spouse with needs for assistance with personal care or the organisation of daily life (Doron 2014). At the same time, the aim of Swedish social care has been to transfer responsibility from the family to the state (Restgaard and Szebehely 2012). This is regulated by the Social Services Act (SFS 2001:453) which is based on the individual's autonomy and capacity to apply for and consent to services. This makes it increasingly important to learn more about what forms a barrier and what facilitates decision making by the individual, informal supported decision-making, and formal decision-making by guardians for older people with dementia. Our starting point is that the situation for people with dementia within the social welfare system in Sweden illustrates

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dilemmas arising in the ideal picture of the autonomous individual. In the UK, this discussion has arisen in relation to the Mental Capacity Act (Clough 2017; Harding 2017). In this article, the focus is on the Swedish Social Service and will offer a Swedish perspective in international debates on mental capacity and autonomy.

The study is based on interview data from *Living with dementia, care and social care systems (LwD)*, an interdisciplinary project carried out in nine Swedish municipalities. Decision-making through family caregivers is discussed and the effects of these decisions for people with dementia, and for the family caregiver. Formal guardianship is also considered. Decisions in everyday life are studied through interviews with individuals with dementia, and family members living in at home in ordinary housing with some support from municipality social care.

All human life and daily living requires a long series of decisions. These include everyday decisions involving choice of clothes, breakfast and leisure activities; and larger scale decisions that affect more basic conditions of life such as the choice of place of residence, employment or life partner. When a person suffers from illness, injury or age-related changes, their decision-making capacity may change (Alzheimer Society 2015). Difficulties affecting decision-making ability may be a consequence of external brain damage or of a disease such as dementia (Moye *et al.* 2011, Sinoff and Blaja-Lisnic 2014). Every individual's capacity is different, and does not depend solely on a diagnosis of dementia. With any form of broader limitations on decision-making ability, the person concerned will need assistance and support. Support for people with impaired decision-making ability is formalised in different ways in different countries (Doron 2002, Donnely, 2014). There are various kinds of formal and informal legal support available, and CRPD – United Nations Convention on Human Rights of Persons with Disabilities; Article 12 states that all individuals shall have support to exercise their legal capacity.

In Sweden, legal representatives as trustees (förmyndare), limited guardians ('god man') or legal administrators (förvaltare) handle legal questions according to the Parental Act (SFS 1949:381). There is legal regulation that to differing extents governs the legal position of the individual; in health care, there are some possibilities for decision-making through a proxy, and there is the Power of Attorney which primarily regulates the individual's financial situation. In addition there is also informal decision-making by a family member of the person with reduced decision-making ability. This kind of support may be both voluntary and necessary. All types of decision-making affect daily life and also contacts with the social welfare system, the health care system and other authorities (Nedlund and Taghizadeh Larsson 2016). A growing body of research highlights the importance of discussing the clash between individual autonomy and the right to self-determination, and social rights to a decent quality of life despite cognitive impairment (Arstein-Kerslake and Flynn 2017, Clough 2017, Harding 2017). One other area that will not be considered in this article is proxy decision-making in health care. Several studies have focused on caregivers and family members' views on theoretical scenarios concerning medical decisions in the final stages of life, such as whether life-sustaining treatment and resuscitation should be offered (Miola 2014, Lord *et al.* 2015). A further question concerns the decision to move a family member with dementia from home to residential care. (Caron *et al.* 2006, Nordh and Nedlund 2017). Spouses and children who provide care are taking on more and more responsibility in all areas: financial matters, household matters, personal care, and all the decisions necessary for daily life (Livingstone *et al.* 2010, Peel and Harding 2014). The family caregiver for someone with dementia may themselves become vulnerable to anxiety as a result of thinking about the future and risks to their loved one (for example fire, flood, or the person with dementia getting lost), and as a result they may find it hard to work, sleep or leave home for shopping (Timmermann, 2015).

Aim

All social care of older people in Sweden is governed by the Social Services Act (SFS 2001:453). According to this law, all care and support should be based on voluntary participation with consent from the recipient of care. Vulnerability is supported with an increasing emphasis on clients' rights and the idea of free choice at the same time as recognising altered cognitive ability. In reality, both the social rights and the abilities of older people with progressive dementia are fragile (Clough and Brazier 2014, Boyle 2014, Österholm *et al.* 2015).

The aim of this article is to describe and analyse decision-making concerning older people with dementia in Sweden, within the context of social work with elderly people, which is regulated by the Social Services Act. In Sweden, everyone is considered as an actor before the law, despite impairments. People with dementia may need more and more support in daily life, with decision-making and with carrying out decisions made (Samsi and Manthorpe 2013). Decision-making for those with impaired decision-making capacity due to dementia is examined here in the context of formal and legal representatives and informal assistance from family members both in relation to support in everyday living decisions and to contact with social welfare organisations. The present study is, to our knowledge, the first in Sweden to ask family caregivers about the decisions they have to make as part of daily life for a relative with dementia, and how they think about informal and formal guardianship. The following questions were asked:

- How can we understand how family caregivers of older people with dementia act in relation to decision-making?
- How does informal representation affect the person with dementia and the family caregiver in daily life?
- How do family caregivers describe their contacts with state provided elder care and other authorities as representatives?

Social services for people with dementia in sweden

Nordic welfare systems are recognised as offering more in the way of local eldercare services than other European welfare systems (Melin Emilsson 2009, Haberkern and Szydlik 2010). Legal spouses and adult children are not legally obliged to provide personal care to each other or to parents in old age, and eldercare is a public responsibility that lies with the municipality. Swedish policy on eldercare has changed in recent decades, with a shift from institutional care to home-based care (Ds 2003:47). The number of older people in institutional care was reduced by 24% between 2001 and 2012 (Ullmanen and Szebehely 2015). However, Szebehely and Trydegård (2007) point to the fact that homecare services for older people are declining in Sweden today and that receiving help from family members and others is becoming more common again, with both spouses and children becoming involved in all aspects of caregiving.

According to Swedish law, all support should be based on voluntary participation with consent from the recipient of care, as outlined in the Social Services Act 1:1, Part 3: ‘The activities should be based on respect for individual sovereignty and integrity,’ and Social Services Act 3:5, Part 1 states: ‘The Social Board’s support for the individual has to be formed and implemented together with him or her and, if necessary, in collaboration with other community agencies and with organisations and other associations.’

Most municipalities support the principle of ‘ageing at home’ and offer different social services to enable older people to continue to live at home while receiving care. Services vary across municipalities, but all offer homecare services that provide help with personal care such as bathing, using the toilet, feeding and dressing. There is also the possibility of assistance with domestic activities such as shopping, cleaning and laundry. Other services offered to older people include home nursing, personal alarms, assistive technology, and transport services. People with dementia may in some municipalities be offered a place at special dementia day care centres. There is also support available for family caregivers, such as homecare services allowing the family caregiver to leave the home for a while, respite care in the form of institutional care and individual or group counselling.

Family caregivers as representatives

The cognitive impairment associated with dementia simultaneously increases needs for assistance with everyday activities and with decision-making. With the increasing need for care at home, family members are often the ones to provide the most care regardless of the system of eldercare (Ablitt *et al.* 2009, Ullmanen and Szebehely 2015, Harding 2017).

Previous research has shown that family caregivers often experience considerable practical, economic and psychological strain (Bleijlevens *et al.* 2014, Harding 2014, Timmerman 2015), which stems from the pressure of assuming responsibility for decisions to be made in another person’s daily life, as well as for finances and care. The majority of people with dementia will be cared for at home by a family member and caring in the community often places a major burden on the informal caregiver (Peel and Harding 2014). Research has focused on identifying indicators of diminished capacity to manage finances (Moye and Marson 2007), rather than considering whether providing support might enhance capacity (Tyrell *et al.* 2006, Arstein-Kerslake and Flynn 2017). A study by Boyle (2013) showed that social factors need to be taken into account when assessing and facilitating financial decision-making in couples living with dementia. In particular, the influence of gender on decision-making processes is important. Family caregivers who took over the financial management role struggled due to lack of experience. Doron (2009) points out that an important way to safeguard the rights of older people is by targeting their family caregivers and social support networks. Scholars from different fields of research all find that decision-making can be an oppressive part of caregiving for people with dementia and this is of interest in all Western countries (Livingstone *et al.* 2010, St-Amant *et al.*, 2012, Samsi and Manthorpe 2013, Lord *et al.* 2015).

Legal representatives

The question of informal representation by family members and of formal guardianship is an issue of global interest in different fields (Schmidt 2014, Lord *et al.* 2015). In some countries, there is legislation on proxy decision-making, enabling family caregivers to make decisions on behalf of those without capacity, but legislation differs (Donnelly 2014). In the UK for example, the Mental Capacity Act (2005) mandates that a relative can be given lasting Power of Attorney to make medical or social decisions on behalf of a person who may lack the capacity to make such decisions themselves (Livingstone *et al.* 2010). This is discussed in several articles and there is a critical discussion about capacity, autonomy and cognitive impairment (Arstein-Kerslake and Flynn 2017, Clough 2017, Harding 2017).

In the USA, Australia and the UK there is a critical discussion about autonomy and self-determination in relation to formal guardianship. Formal guardianship involves the risk of limiting fundamental rights and autonomy by substituted decision-making (Wright 2010, Chesterman 2012, Hall 2014, Clough 2017). The current formal guardianship legislation in many countries is considered to marginalise individuals, and scholars have suggested a less restrictive form of support by the principle of minimum intervention. Scholars call for a more nuanced perception of capacity and consent (Clough 2017, Brosnan and Flynn 2017; Moye and Marson 2007). Formal guardianship can on the other hand be seen as a support to ensure self-determination in daily life and full participation in society, as long it is formulated as supported rather than substituted decision-making (Millar 2007, 2013, Flynn and Arstein-Kerslake 2014, Ryrstedt 2017).

Legal representatives in the swedish context

Reforms to Swedish guardianship began in 1974 in an effort to reduce the number of declarations of legal incompetence. The continuing reforms are characterised by an emphasis on the principle of minimum intervention (Odlöw 2005, Ryrstedt 2017). In 1989, new legislation came into effect. The possibility of disempowering an adult by appointing a *trustee* ('förmyndare') was removed, and this is now only used for individuals under the age of 18 (SFS 1988:1251).

The most common form of support for adults is a *limited guardian* ('god man'), a kind of supportive decision-maker. This is therefore considered less restrictive than the third form, *a legal administrator* ('förvaltare'), who acts as a substitute decision-maker without needing consent. In this article, a person receiving support by a limited guardian is called a *client* ('huvudman').

The contribution of this study is to discuss perspectives of family caregivers on informal decision-making and legal guardianship for people with dementia. Decision-making in everyday life is an issue affecting a large number of people with different impairments including dementia and also intellectual disability and autism.

Method and material

A mixed method study design was selected. To gain a holistic view, a methodological triangulation comprising several research methods was used (Silverman 1993/2004). The study was based on interviews with family caregivers for older people with dementia and on a questionnaire completed by all guardians in one municipality. The data consisted of three types of written material: transcribed interviews, field notes and a survey.

Interview data was collected within the context of the project *Living with dementia, care and social care systems (LwD)* conducted in 2014–2016, an autonomous project following the European project *RightTimePlaceCare (RTPC)*. *RTPC* compared care and care systems for people with dementia in eight European countries in 2010–2013 (Hallberg *et al.* 2013). The overarching aim of *LwD* was to study the living conditions of people with dementia and the situation for family caregivers. The aim was also to study support for family caregivers. *LwD* focused on people with dementia who were at the stage when homecare may become insufficient in the near future. Family caregivers were interviewed in face-to-face interviews. The inclusion criteria were that the person with dementia should be aged over 65 years, have a medical diagnosis of dementia and a score of 24 or lower on the standardised mini mental state examination (S-MMST). An informal caregiver was defined as an adult family member, neighbour or friend who provided support to a person with dementia at least twice a month.

Two groups were selected. The first group consisted of 88 people with dementia living in ordinary housing, receiving some social care from the municipality and from their informal caregivers. The second group had relocated from home to a long-term care setting, and had been living at a residential home for at least one month but not longer than three months, a total of 58 persons and their informal caregivers. In this article, there is a focus on the first group – people living at home.

Social workers, nurses and other professionals identified informal caregivers who matched the criteria set. They informed the caregivers about the study and confirmed their consent to be approached by researchers. Those who agreed were called by the researchers and the study was discussed with them in more detail. Those who gave their informed consent then participated after giving written consent. Altogether, 88 informal caregivers participated in the ordinary housing group. Of those interviewed, 43 were wives/partners of a person with dementia, 16 were husbands/partners, 25 were sons or daughters, one was a limited guardian, and three had a different family relationship. The informal caregiver in this article is therefore referred to as a *family caregiver*.

We offered to conduct the interviews in the location where participants felt most comfortable. Most family caregivers preferred their own home or the home of the person with dementia. A few of the interviews were conducted in places like libraries, workplaces or cafeterias. Data were collected through face-to-face interviews in two parts with persons with dementia/family caregiver dyads by trained interviewers. All participants were asked to take part in a follow up interview three months later, where possible.

The first part of the interview was inspired by the protocol of RightTimePlaceCare based on a set of standardised instruments including the background characteristics of the dyad (age, gender, living situation, relationship), as well as questions on quality of life, quality of care, and economic and health-related aspects of the informal caregiver and the person with dementia (Verbeek *et al.* 2012). The second part consisted of a short interview made up of additional questions concerning decision-making, choice of support, and questions of non-take-up. Questions were principally focused on the participants' views about their tasks and meetings with social welfare organisations as a representative of an older person with dementia. This was digitally recorded when permitted, or written down and transcribed as soon as possible after the interview. Field-notes were taken in connection with the interview focusing on relations and discussions between the family caregiver and the person with dementia. Reflective information as questions, concerns, and ways of handling decisions and relations were noted directly after the interview. Descriptive information such as time and date, the state of the physical setting, social environment, descriptions of persons being studied and their roles was also noted (Silverman 1993/2004).

The questionnaire study addressed all limited guardians and legal administrators in one municipality of 86,000 inhabitants, in 2014. The Chief Guardian Board in the municipality listed all persons in question: 364 in total. Participants received the questionnaire by post, and after two reminders 265 responses were received. The response rate was 73%, a satisfactory response rate for this type of study. The questionnaire consisted of two parts: the first part contained background questions about the guardian/administrator and open questions about their views on the assignment, content, obstacles and opportunities. The second part contained background questions about the clients.

Analyses and ethical considerations

The data consists of transcribed interviews, field notes, one survey and interview protocols. Quantitative data from the protocols and the questionnaire were analysed using SPSS version 22. The qualitative data from protocols, questionnaire and field notes were read repeatedly in order to generate familiarity with the content (Silverman 1993/2004). Then words and phrases that appeared to represent key thoughts of the respondents were highlighted. Initial codes subsequently were grouped and recoded into broader categories, which created meaningful themes (Alvesson 2011).

It is important to note that the responses obtained from the interview study do not represent the views of all family caregivers of people with dementia, but our findings nevertheless point to some important issues.

Ethical approval from the relevant legal authorities for research on human beings was obtained for the study (Dnr: 2010/538; 2014/765 Lund; Dnr: 2013/430–31 Linköping). For study participation, written informed consent was obtained from family caregivers. In the quotations, identifying information is removed.

Theoretical framework

The theoretical framework is Honneth's (2001, 2004) theory of recognition, an ethical frame-work for self-realization through interaction, respect, validation and mutual recognition. Honneth assumes that in order to develop an identity, persons fundamentally depend on the feedback of other subjects and of society as a whole. Recognition is simultaneously an individual and a social necessity. According to Honneth (2001, 2003)), identity is socially acquired and therefore the foundation of an individual's autonomy and legal agency. Recognition theory allows social work to situate its values in a practical relationship to legal and social justice. Honneth rejects the liberal conception of human subjects as autonomic, arguing that the inevitable dependence on others for identity makes people vulnerable to recognition. The concept of recognition is unpacked into three kinds of recognition, which support three distinct stages in the development of individuals, each with quite different social and political implications. Honneth (2003, 2004)) argues that there are three differentiated levels of recognition in modern society.

The first level requires love in the immediate interpersonal sphere to develop self-confidence for the individual. Recognition of autonomous rights in law offers the basis for self-respect at the second level. The formation of a co-operative member of society who is socially valued is necessary to build self-esteem at the third level. On all three levels, there are corresponding forms of disrespect (Honneth 2003, 2004). To this Taylor (1994) added the importance of recognition of similarity as well as difference. Identity crucially depends on experiencing dialogue with others. Everyone should be recognised for his or her unique identity. This means to be universally the same, but at the same time to be recognised as having a unique identity as an individual or group and as distinct from everyone else. Recognition of differences takes special needs into account without losing sight of the overall similarity of human beings and thus is an important perspective in relation to people with cognitive or other disability (Taylor 1994).

Findings

This article draws on findings from interviews with family caregivers and field notes in connections with the interviews. In addition, data from a survey is used to find answers on how legal guardians and family caregivers of older people with dementia act in relation to decision-making, and to what extent acting as a representative affects the person with dementia and the family caregiver in daily life. The findings also give a picture of how family caregivers describe their contacts with state provided elder care and other authorities, as representatives.

Decision-making in daily life

Data relating to decisions that have to be made in daily life for a person with dementia, and informal and formal guardianship in relationship to this, are reported in this section. Four conceptually distinct but empirically overlapping responses were identified in interviews with family caregivers, field notes and limited guardians' answers in the survey about handling decision-making for an older person with dementia. They have been named: shared decision-making, legal guardianship, resistance, and supported decision-making with influence; from Samsi and Manthorpe (2013). All citations are from the interviews.

Shared decision-making

Some of the family caregivers gave examples of involving the person with dementia in decision making as far as possible, even if they knew that that he or she would not remember anything of the discussion.

I'm discussing everything with my wife and tell her what I´m planning but she does not understand. But she wants to know and see bills. She wants to be asked and this more now than before. She is a little distrustful now. (106, husband)

My mother does not take part in financial decisions. She participated in the meeting with the care manager and then she was positive about residential housing. She can take part in a discussion, but she forgets it all. (104, daughter)

This way of acting can according to Honneth (2001) be seen as recognition of the person with dementia and his or her right to information and participation. It is a way for the family caregiver to safeguard the normality and respect of the person with dementia. The family caregiver makes efforts to ensure that the person with dementia is still seen and respected as a worthy member of the family and society. The family caregivers are aware of the inevitable dependence on others for identity and this gives the loved one recognition.

In some of the interviews, the person with dementia had expressed a wish for their family caregiver to take over in financial issues in the early stages of the disease, having begun to be aware of their imminent reduced capacity.

He was an economist and took care of everything automatically, but now I have to do it/ … /he is the owner of the forest and the first year we did it together. Afterwards he said that he trusted me, he thought I did better. (110, wife)

This active decision of the person with dementia was made possible by family members being willing to take on new areas of responsibility. An important perspective in relation to people with dementia is recognition of differences and this perspective takes special needs into account without losing sight of the overall similarity of human beings (Taylor 1994).

The interviews revealed thoughts about time, and the reality that all decisions will gradually be taken over by the partner or child as a proxy. It is a tragic development that also creates stress for the spouse and other family members, as shown in previous research (Timmerman 2015). The issue of impaired capacity for decision-making affects the lives of people with dementia both in daily life and in relation to decisions about the future. In the interviews, one issue is dementia as a progressive condition in which a person's cognitive abilities steadily decline and significant changes in behaviour and mood often occur. Family caregivers therefore face considerable difficulties in making decisions concerning the person with dementia; they make efforts to give their relative a kind of relational autonomy (Harding 2012, Clough 2014). As well as accepting and adjusting to these changes in the short term, family members have to be able to understand how the person's situation might develop in the future (Sinoff and Blaja-Lisnic 2014). It can be difficult in the struggles of daily life to see clearly how the roles of responsibility and decision-making will shift in the family over time.

It´s only now, when he has been to respite care for a week, that I realise how tired I am! And how much I really do! All the decisions I have to make, all the care … You don´t really see that until he has been away for some time. It´s hard to see, it´s small changes, slowly, slowly. (062, wife)

There is often a shift from shared decision-making to supported decision-making, where the family caregiver to begin with informs and helps the person with dementia in order to arrive at decisions more or less together. As the disease progresses, this may become substituted decision-making, with family caregivers making decisions themselves on behalf of the person with dementia. This is usually a gradual shift that takes place over several years, and is hard to face and plan. It is a gradual, growing understanding and recognition of the limitations and special needs that affect the individual, without losing sight of the identity of the person. Identity crucially depends on relations with others (Taylor 1994).

In the survey, the legal guardians did not mention any effort directed towards sharing decisions with the client. They described themselves as substituted decision-makers or 'in charge'. They did not describe any thoughts about the legal agency or nuances of capacity (Clough 2017, Arstein-Kerslake and Flynn 2017). Their approach had significant practical limitations for autonomy (Odlöw 2005).

Supported decision-making

Most of the informal caregivers are spouses and they see themselves as facilitators of supported rather than substituted decision-making, even if they describe themselves in such terms. However, they themselves need support to be able to give support. Some informants expressed difficulties knowing where to turn when they needed help, which Peel and Harding (2014) have also reported from the UK. Family caregivers needed support and information to maintain decision-making.

She [mother-in-law with dementia] got a place [at the residential home] four weeks ago because she was out at night, put on the stove and forgot, and she smoked in her bed. The neighborhood community found her one night far away in the industrial area and drove her home. She did not want to move, but we tricked her into the nursing home … I cannot sleep with anxiety about this decision, was it right? We have talked to the dementia nurse, the care manager and to her siblings. Everyone supports the decision so I trust them. (089, daughter-in-law)

Family caregivers who had access to a nurse responsible for people with dementia or a social worker whom they trusted seemed more comfortable in their position as a spokesperson. Sometimes other organisations also entered as supporting partners. It seems that healthcare providers, dementia day care centres and the care coordinator were very important as sources of information, as interlocutor and in coaching. The professional clarifies the importance of recognising the person as a deserving individual, but still seeing and acknowledging the effects of the disease. Recognition of general rights offers the basis for self-respect, and recognition of differences caused by disease offers an individual approach (Taylor 1994).

Findings show that family caregivers may need support from other authorities like a doctor or hospital. This may point out an anomaly between self-determination and respect for the individual's impairment (Clough 2017, Ryrstedt 2017).

Legal guardianship

The survey sampled all legal deputies for people over the age of 18, in a municipality of approximately 86,000 inhabitants in 2014. In the autumn of 2014, there were 582 acts on limited guardianship and 92 acts on legal administrators, and these assignments were spread among 362 legal representatives. The survey was answered by 265 representatives with a total of 514 assignments. The questionnaire stated that 55 of these 514 legal acts related to people with dementia, of whom 65% were women. In most of these cases, the deputy and the client had no family relationship (80%). Approximately 10% considered a diagnosis of dementia as grounds for judicial representation in the questionnaire, which is a low percentage according to the Swedish National Board of Social Welfare (SOU 2004, p. 112). The responsible authority (Chief Guardian) in participating municipalities recommends allocating a bank Power of Attorney to a family member before appointing a legal guardian according to interviews and the survey. If a person with dementia has no living or close relatives, it is more common to appoint a limited guardian, again according to the survey.

In the interviews, it was usually the spouse or the adult children of the person with dementia who, with or without a bank Power of Attorney, handled all financial matters.

Interviews showed that some of the family caregivers had considered legal guardianship, especially for people with larger assets.

Many of the caregivers reported that they had been rejected on applying for guardianship, by the Chief Guardian, referring to bank Power of Attorney as being enough. Among the respondents in the study group living at home, some of the informal caregivers had along with the rest of the family discussed guardianship as a solution, but most family caregivers had decided to continue to manage all financial affairs with bank Power of Attorney, perhaps not in consideration of what may be the best for the elder person, but to avoid bureaucracy.

There are differing views in previous research on the legal consequences of legal guardianship for a person with dementia when it comes to applying for support under Swedish social legislation. According to Ryrstedt (2017) and Fridström Montoya (2015) a legal guardian needs consent from the client to make an application for social care services, but according to our survey this is not what happens.

Family caregivers are recommended to have an assigned Power of Attorney for financial matters but there is still the question of who is to apply for social support and services, according to the interviews. A person with dementia who is assigned a limited guardian in Sweden does not lose civil rights or personal autonomy, but may gain a legal voice for dealing with authorities. This is not clear in the current legislation but according to findings, this is how some of the social workers and health care workers act and think. Some do and some do not see the legal guardian as a legal representative who can apply for social care on behalf of the person with dementia. In the Parental Act, capacity to consent is a question to a physician; in the Social Services Act, everyone has capacity regardless of disability. Recognition of autonomous rights in law offers the basis for self-respect according to Honneth (2001), but the question of autonomy is not clear in Swedish legislation. This form of recognition consists of universal and equal juridical treatment of everybody and is necessary for the individual's ability to participate in society with legal agency.

The interviews reveal a huge disparity between the practices of this by social workers (care managers) across the nine municipalities. According to the interviews, some social workers state that they are following the law and refuse to investigate the needs of the person with dementia if he or she has not signed the application.

They cannot move her against her will, they say to us at the municipality office. So they gave her more home care instead of a place at the nursing home. And even now they don't listen to us, the daughters, only to her, even though it does not actually work at all at home. No, they listen more to her than us, so it was good that xx (mental hospital) contacted them. (105, Daughter)

According to family caregivers, social workers refer to the text in the Social Services Act that emphasises the individual's self-determination (Nedlund and Taghizadeh Larsson 2016). Family caregivers find it hard to understand how social workers could ask a person with dementia to make decisions about social support and care when that person is incapable of making decisions in daily life about such things as money, medicine, driving, food and clothes. Those findings correspond to the more nuanced discussion of capacity that Clough (2017) introduces, as well as Ryrstedt (2017). Family caregivers themselves find it hard to determine whether their relative with dementia can provide consent.

In other interviews, respondents say that social workers do consider requests signed by the family caregiver or made in spoken form, or act on the social worker's own assessment of needs.

As soon as she [care manager] saw that I needed help, she fixed respite care. She saw that I needed help! … She did not ask for his opinion. … And then I have Doctor X, I can call a little spontaneously when I need help to speak with the municipality. (064, wife)

Findings showed an idea of advocacy, where the family caregiver on one hand was described as a strong spokesperson for the person with dementia. Some of the family members interviewed were well-informed about rights and what the municipality was obliged to offer them; others had no idea (Doron & Werner, 2008).

On the other hand, none of the family caregivers indicated contact with authorities or with the health care system as a reason for considering guardianship. The issue arose only in connection with economic issues. Of the total number of people with dementia included in the *LwD* study living at home (n = 88), two had a limited guardian. Respondents in the survey stated that they were mainly financially responsible. Guardianship seems not to be an option to help manage the stressful decision-making required in everyday life.

Decision-making and resistance

Family caregivers described a complex situation as the dementia progresses and home-care becomes fraught with complex, heavy-duty care and high risk. The question of making proxy decisions against active resistance was raised in the interviews. As dementia progresses, many people with the disease become resistant to all proposals of receiving any support. It is hard for a family member to make proxy decisions in the face of such active resistance. The person with dementia tended to increasingly say 'No' to proposed changes or measures.

He is at the day-care center two days a week. He has been there for two years now, he likes it. It was very hard to make him start, he said no, no. He's still very angry when he's going there, every morning. That is the worst, so many days I can´t make him go. I really need the two-day breathing space (or more) but it's not possible … even if he is happy after being there (093, wife)

Informal caregivers and family members express uncertainty about whether they have the right to override the person's will. They described many situations where they needed support and back-up but the person with dementia simply refused.

She has a say on some home care. But she does not want any help either with personal hygiene or housekeeping. So I go there and help her, and then I have to be there for hours, it's very mentally tiresome. … I wanted her to be at the respite care when I planned to visit my daughter for a couple of days but she just refused, so it did not work. A grandchild sometimes showers her; it's the only one she accepts. The home care must not do it. (090, daughter)

With a mixture of loyalty and fatigue, family caregivers accept the person's resistance and they themselves resist. Reasons given for family caregivers' refusal of support were various and complex: resistance by the person with dementia, feelings of guilt, a desire to remain as a couple at home, financial reasons, and a wish to protect family privacy were all cited. A poor level of take-up of services by people with dementia is reported, and family caregivers report a great deal of perceived strain (Peel and Harding 2014).

The will and ambition not to show disrespect prevents relatives from applying for and receiving support and assistance.

There is a gendered difference between which decisions are perceived as stressful and for whom (Boyle 2014). Family caregivers have a gendered resistance to different issues in the household. Of family caregivers interviewed at home, 80.7% were women aged 41–89. Several of them cite practical issues as burdensome to deal with alone. This might include changing the car, carrying out repairs in the home, or selling the house.

He has always dealt with both financial and practical issues. Now we must remake the driveway, and I do not know anything about those things. I would like to move to an apartment … but to sell the house … I do not know if I can do that. (073, wife)

The male caregivers, for their part, spoke about social issues as burdensome, e.g. keeping in touch with family and looking after the household. Both men and women also described the loneliness surrounding both small and large decisions, and find it depressing not having anyone with whom to discuss decisions about everyday issues.

I sit alone on the sofa in the evening, though there are two of us there. She is not mentally here. I don´t have anyone to talk to about all the issues that we need to think about or decide on. (092, husband)

These gradual changes in the degree of responsibility for decision-making and organising daily family life come to a head when it comes to arranging social care in the home, prompting access to care, making risk assessments, or making legal arrangements around finances.

Treating an older person with dementia with recognition as being an adult person with his/her own will, and at the same time with respect for the limitations that the disease involves, can be a challenge for family caregivers and society in general. There is an ideal of social acknowledgement for each individual for choice of lifestyle and autonomy. Honneth's third level of recognition implies a sense of being unique, with something of value to offer society. Honneth (2001, 2004)) uses the term *solidarity* to explain how to manifest this recognition; but how far is this from disrespect when there is no perspective on how it affects dignity and quality of life? We can only talk about solidarity where shared interests or values are at stake. For the relatives, this becomes a vacuum where resistance from the one with dementia is hard to solve and live with. Here the social workers may play an important role to see both persons in the relationship. Both have the right to be recognized universally as 'the same' but at the same time recognized as having unique identities. And they both need recognition of all difficulties in a strong relationship between a family caregiver and a person with dementia (Harding 2017).

Conclusion and discussion

Family caregivers for people with dementia have to make difficult decisions throughout the course of dementia. The disease impairs a person's decision-making capability and their capacity to understand information, their own situation, and the consequences of information and of the disease.

In this study, there is a focus on understanding how family caregivers think and act as informal decision-makers, and how legal guardians describe their mission. The consequences of these thoughts and actions for the person with dementia and for the caregiver are also of interest. Four conceptually distinct but empirically overlapping responses were identified: shared decision-making, supported decision-making, legal guardianship and resistance.

Participants emphasised the resistance of the person with dementia as a significant problem. Persons with dementia often deny all problems and reject support and social services' assistance. The development of dementia is slow and the effects are hard to understand and to oversee. There are bureaucratic explanations for this: informal caregivers describe problems with finding information in good time and with being listened to when they ask for support in daily life.

There is a paradox wherein dementia as a disease may involve impaired ability to make informed decisions and to understand the consequences of a decision, but people with dementia are required to give consent and apply for support and care. Someone who on one hand is totally dependent on help from others to make decisions in everyday life is on the other hand seen as an individual required to make autonomous legal decisions. Recognition theory allows us to examine the relationship between legal and social practice. Honneth (2001, 2004)) rejects the liberal conception of humans as autonomous individuals, and our findings are in line with that perception. All humans are inevitably dependent on others for recognition, self-confidence and self-respect.

The two different parts of this study show that guardians or family caregivers may in practice sometimes not have the legal right to be a spokesperson for a person with dementia. According to Nedlund and Taghizadeh Larsson (2016) and Fridström Montoya (2015), a legal guardian cannot make any medical decisions on behalf of another person and needs consent from the client to apply for social care services but according to findings this is not always practised.

Sweden does not have specific legislation about proxy decision-making, unlike for example Canada or the UK. In Sweden, the legislation is unclear regarding situations when an adult person lacks capacity to make their own social or medical decisions; there is a focus on universal independence. The two different parts of this study show that neither guardians nor family caregivers are in practise seen as spokespersons for a person with dementia. Legislation is unclear about the extent to which another person can act as legal spokesman.

At present, the philosophy of independence overrules the need to require guidance and support. This study shows on the one hand that guardianship may be underutilised for older people with dementia, and on the other hand that there is a need to rethink the protection of vulnerable older people.

Taylor (1994) refers to a double-sided recognition of similarity, but also inequality. In the study, we can see a growing awareness of this dual relationship as the disease progresses. However, society's regulations leave individuals with dementia and family caregivers in a vacuum, where self-determination in decision-making and full autonomy is part of ideal citizenship as emphasised and recognised in the Social Services Act (Honneth 2004).

Our findings show that, apart from the fact that the person with dementia is put in difficult situations, family members become overloaded and feel alone with a major responsibility for decision-making in both daily life and in matters of social services and care as a spokesperson for the person with dementia (Flynn and Arstein-Kerslake 2014, Arstein-Kerslake and Flynn 2017). Family caregivers are grown-up children of working age and/or partners who in many cases are elderly. On the personal level, it means interacting daily with a relative who may often express resistance and show increased dependency. The family caregiver has a great deal of responsibility but not a clear mandate (Doron 2009, Nedlund and Taghizadeh Larsson 2016). On a structural level, the legislation does not recognise family caregivers as spokespersons, which implies the questioning in various organisational contexts of their actions as responsible citizens. Both family members and professionals end up in a difficult situation when legislation does not contribute to legal certainty for the individual (Harding 2017). Therefore, the person with dementia is also suffering when care cannot be given or when municipalities and professionals choose different ways of interpreting the law and managing social care, self-determination and decision-making.

It is time to supplement the trend in Western legislation towards individual autonomy as the ideal goal with a discussion about how society can support the individual in need when it comes to decision-making (Harding 2017, Ryrstedt 2017). We need to approach this question for the individual by recognising both their equality as a human being and their inequality as an individual with impairments.

Disclosure statement

Funding

This work was supported by The Family Kamprad Foundation under Grant (Lund: 2013121) and The Swedish Alzheimer Foundation under Grant [nr Lnu: 4720 0054].

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References

Ablitt, A., Jones, G., and Muers, J., 2009. Living with dementia: A systematic review of the influence of relationship factors. *Aging & mental health*, 13 (4), 497–511.

Alvesson, M., 2011. *Interpreting interviews*. London: Sage.

Alzheimer Society. 2015. The progression of Alzheimer´s disease and other dementias. 458 https://www.alzheimers.org.uk/download/downloads/id/1772/factsheet_the_progression_of_alzheimers_disease_and_other_dementias.pdf [Accessed 13 febr 2018].

Arstein-Kerslake, A. and Flynn, E., 2017. The right to legal agency: domination, disability and protections of Article 12 of CRPD. *International journal of law in context*, 13 (1), 22–38.

Bleijlevens, M., *et al.*, 2014. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with dementia. *Journal of advanced nursing*, 71 (6), 1378–1391.

Boyle, G., 2013. `She`s usually quicker than the calculator´: financial management and decision-making in couples living with dementia. *Health and social care in the community*, 21 (5), 554–562.

Boyle, G., 2014. Recognising the agency of people with dementia. *Disability & society*, 29 (7), 1130–1144.

Brosnan, L. and Flynn, E., 2017. Freedom to negotiate: a proposal extricating `capacity´ from `consent`. *International journal of law in context*, 13 (1), 58–76.

Caron, C.D., Ducharme, F., and Griffith, J., 2006. Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian Journal of Psychiatric care*, 46, 108–118.

Chesterman, J., 2012. The future of adult guardianship in federal Australia. *Australian social work*, 66 (1), 26–38.

Clough, B., 2014. What about us? A case for legal recognition of interdependence in informal care relationships. *Journal of social welfare & family law*, 36 (2), 129–148.

Clough, B., 2017. Disability and Vulnerability: challenging the Capacity/Incapacity Binary. *Social policy & society*, 16 (3), 469–481.

Clough, B. and Brazier, M., 2014. Never too old for health and human rights? *Medical law international*, 14 (3), 133–156.

Donnelly, M., 2014. A Legal Overview. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 271–282.

Doron, I., 2002. Elder guardianship kaleidoscope – a comparative perspective. *International Journal of Law, Policy and the Family*, 16, 368–398.

Doron, I., 2009. A multi-dimensional model of elder law. *In*: I. Doron, ed. *Theories on Law and Ageing*. Heidelberg: Springer Press, 59–74.

Doron, I., 2014. The Demographics of Dementia. *In*: C. Forster, J. Herring, and D. Israel, eds. *The law and ethics of dementia*. Oxford: Hart Publishing, 15–24.

Doron, I. and Werner, P., 2008. Facts on Law and Ageing Quiz; older people´s knowledge of their legal rights. *Aging & Society*, 28, 1159–1174.

Ds 2003:47., 2003. *På väg mot en god demensvård. Samhällets insatser för personer med demenssjukdom och deras anhöriga*. Stockholm: Socialdepartementet.

Flynn, E. and Arstein-Kerslake, A., 2014. The support model of legal capacity: fact, fiction, or fantasy? *Berkeley Journal of International Law*, 32 (1), 124–143.

Fridström Montoya, T. 2015. *Leva som andra genom ställföreträdare – en rättslig och faktisk paradox*. [To Live Like Others Through Legal Representation – A Legal and Factual Paradox, summary in English]. PhD diss. Uppsala: Iustus.

Haberkern, K. and Szydlik, M., 2010. State care provision, societal opinion and children´s care of older parents in 11 European countries. *Aging & Society*, 30 (2), 299–323.

Hall, M.I., 2014. Dementia, Autonomy and Guardianship for the Old. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 339–350.

Hallberg, I., *et al.*, 2013. Dementia care in Eight European Countries: developing a mapping system to explore systems. *Journal of Nursing Scholarship*, 45 (4), 412–424.

Harding, R., 2012. Legal constructions of dementia: discourses of autonomy at the margins of capacity. *Journal of social welfare & family law*, 34 (4), 425–442.

Harding, R., 2014. Dementia and carers: relationality and Informal Carers´ Experiences. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 379–392.

Harding, R., 2017. *Duties to Care: dementia, Relationality and Law*. Cambridge: Cambridge University Press.

Honneth, A., 2001. Recognition or redistribution? Changing perspectives on the moral order of society. *Theory, Culture and Society*, 18 (2–3), 43–55.

Honneth, A., 2003. Redistribution as Recognition: A response to Nancy Fraser. *In*: N. Fraser and A. Honneth, eds. *Redistribution and Recogniation? A political– philosophical Exchange*. New York: Verso, 110–197.

Honneth, A., 2004. Recognition and Justice: outline a plural theory of justice. *Acta sociologica*, 47 (4), 351–364.

Livingstone, G., *et al.*, 2010. Making decisions for people with dementia who lack capacity: qualitative study of family cares in UK. *BMJ*, 341, 41–84.

Lord, K., Livingstone, G., and Cooper, C., 2015. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, 27 (8), 1301–1312.

Melin Emilsson, U., 2009. Health care, social care or both? A qualitative explorative study of different focuses in long-term care of older people in France, Portugal and Sweden. *European Journal of Social Work*, 12 (4), 419–434.

Mental Capacity Act 2005, Legislation.gov.uk

Millar, D.S., 2007. `I never put it together': the Disconnect Between Self-Determination and Guardianship - Implications for Practice. *Education and Training in Autism and Developmental Disabilities*, 42 (2), 119–129.

Millar, D.S., 2013. Guardianship Alternatives: their Use Affirms Self-determination of Individuals with Intellectual Disabilities. *Education and Training in Autism and Developmental Disabilities*, 48 (3), 291–305.

Miola, J., 2014. Proxy Decision-Making. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 149–158.

Moye, J. and Marson, D., 2007. Assessment of decision-making capacity in older adults: an Emerging Area of Practice and Research. *Journal of psychological sciences & social sciences*, 62 (1), 3–11.

Moye, J., *et al*. 2011. Decision-making capacity. *In*: K. Schaie and S. L. Willis, eds. *Handbook of the Psychology of Aging*. Vol. 7, 367–379.

Nedlund, A.-C. and Taghizadeh Larsson, A., 2016. To protect and to support: how citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden. *Dementia*, 15 (3), 343–357.

Nordh, J. and Nedlund, A.-C., 2017. To Coordinate Information in Practice: dilemmas and Strategies in Care Management for Citizens with Dementia. *Journal of social service research*, 43 (3), 319–335.

Odlöw, T. (2005). *Ställföreträdare för vuxna – kamrer eller handledare*? [Guardian of Incapable Adults – Accountant or Supervisor? summery in English] PhD diss., Stockholm: Jure.

Österholm, J., Taghizadeh Larsson, A., and Olaison, 2015. Handling the Dilemmas of Self-determination and Dementia. *Journal of gerontologicial social work*, 58, 613–636.

Peel, E. and Harding, R., 2014. 'It's a huge maze, the system, it's a terrible maze': dementia carers' constructions of navigating health and social care services. *Dementia*, 13 (5), 642–661.

Prince, M., *et al*., 2013. The global prevalence of dementia: A systematic review and meta-analysis. *Alzeimer´s and Dementia*, 9, 63–75.

Restgaard, T. and Szebehely, M., 2012. Changing policies, changing patterns of care: danish and Swedish home care at the crossroads. *European journal of ageing*, 9, 101-109.

Ryrstedt, E., 2017. Dementia and autonomy. *In*: A. Numhauser-Henning, ed. *Elder law: evolving European Perspectives*. UK: Elgar publishing, 358–378

St-Amant, O., *et al*., 2012. Making care decisions in home-based dementia care: why context matters. *Canadian Journal on Aging*, 31 (4), 423–434.

Samsi, K. and Manthorpe, J., 2013. Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics*, 25 (6), 949–961.

Schmidt, W.C., 2014. Proxy Decision-Making: A Legal Perspective. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 311–326.

SFS 1949:381, *Föräldrabalken [The Child and Parental Code]*.

SFS 1988:1251, *Lag om ändring i föräldrabalken [Law Concerning Changes in Parental Code]*.

SFS 2001:453, *Socialtjänstlagen [Social Service Act]*.

Silverman, D., 1993/2004. *Interpreting qualitative data: methods for analyzing talk, text*. London: Sage.

Sinoff, G. and Blaja-Lisnic, N., 2014. Advance decisions and proxy decision-making in the older: A medical perspective. *In*: C. Forster, J. Herring, and D. Israel, eds. *The Law and Ethics of Dementia*. Oxford: Hart Publishing, 97–104.

SOU, 2004. *112 Frågor om förmyndare och ställföreträdare för vuxna*.

Szebehely, M. and Trydegård, G.-B., 2007. Omsorgstjänster för äldre och funktionshindrade: skilda villkor, skilda trender? *Socialvetenskaplig Tidskrift*, 14 (2–3), 197–219.

Taylor, C., 1994. *Multiculturism and the Politics of Recognition*. Princeton, N.J: Princeton University Press.

Timmerman, S., 2015. Family Caregiving: making Decisions about Care, Living Arrangements, and Finances. *Journal of Financial Service Professionals*, 69 (3), 35–38.

Tyrell, J., Genin, N., and Myslinski, M., 2006. Freedom of choice and decision-making in health and social care: views of older patients with early-stage dementia and their carers. *Dementia*, 5, 479–501.

Ullmanen, P. and Szebehely, M., 2015. From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *International journal of social welfare*, 2015 (24), 81–92.

Verbeek, H., *et al.*, 2012. A European Study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare Study. *BioMed Central Public Health*, 12 (68).

WHO, 2015. *World health Statistics*. Geneva: World Health Organization.

Wright, J., 2010. Guardianship for your own good: improving the well-being of respondents and principals in the USA. *International Journal of Law and Psychiatric*, 33 (2010), 350–368.