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People with memory illnesses and their spouses as actors in the hybrid care model

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Abstract

Objective: The study analysed how its participants positioned themselves and other people as actors in daily life, and what matters they portrayed as meaningful in seeking and receiving support in daily life.

Background: Family care has traditionally played an important role in elder care in Finland. Current policy goals will further increase the importance of family care, yet research on how people with memory illnesses and their spouses perceive care arrangements is scarce.

Method: The study drew from theory of relational agency and positioning theory. The data came from semi-structured, in-depth interviews (10) of home-dwelling people diagnosed with a memory illness and their spouses. The interviewees' age varied from 62 to 88. The analysis focused on the participants' self-descriptions and descriptions of their experiences and actions in relation to informal and formal care arrangements.

Results: The participants with a memory illness positioned themselves together with their spouses as a couple, as satisfied service recipients, as active and knowledgeable service users, or even as consumers who critically evaluated social and health care services. People with memory illnesses are capable of expressing their self-reflexive agentic self and adopting different positions to that of a person with dementia.

Conclusion: There is need to better acknowledge agency of people with memory illnesses and to develop different data collection and analysis methods that enable them to convey their views.

Key words: dementia, informal care, formal care, qualitative research, relational agency, positioning theory, agentic self



1. Introduction

The current number of people with memory illnesses is projected to double by 2030 and even triple by 2050 (WHO, 2021). Information on memory illnesses and their effects on the health of older adults has increased in recent years, and medical information and personal stories of people with memory illnesses and their close ones abound on the internet. This increase in information does not, however, mean that the effect of memory illnesses on various areas of societies and memory illness as a factor increasing the needs for service is sufficiently acknowledged (WHO, 2021). In Finland as in many other countries, the aim of old age policy has long been to enable people to age in place in their familiar communities and to receive support and care services at home. In practice, this policy means that family members or other close ones play an important role in helping older people who need care to continue living at home (Colombo et al., 2011; Kröger & Bagnato, 2017). Care is provided by family members and friends in a vast proportion of the populations in different countries and the estimated monetary value exceeds public funding for care (Colombo et al., 2011). The forms and the degree of support provided for family carers varies considerably, and Northern European countries are an example of wide coverage of public care services, whereas Southern European countries rely heavily on informal care as public spending on old age care services is scant with most countries having different care–mix combinations (Kröger & Bagnato, 2017; see also Zechner & Valokivi, 2012). However, the overall trend in Europe has been from formal care to informal care and increased reliance on families to take on care responsibilities (Kröger & Bagnato, 2017).

Formal care usually refers to care services provided by public, profit or non-profit organizations and their paid care workers as opposed to informal care provided by close family members or other relatives or friends in the elderly person's social network. Care provided by the grey market, outside the formal economy, is also considered informal care. (Colombo et al., 2011). In Finland, informal care is mainly provided by family members, and in this study, we refer to informal care as unpaid, ongoing help with activities of daily living given to family members or other close ones with a chronic illness or disability (Plöthner et al., 2019).

Finland is one of the countries that has taken steps to support family carers and developed various ways to assist them with monetary benefits and services (STM, 2017; 2020). Finnish old age care can be defined as a hybrid model that combines family care supported by the state and municipalities (local governments), home care provided by municipalities and respite care and residential care mainly provided by the third sector and private sector, occasionally complemented by other privately purchased support services such as cleaning (Halonen, van Aerschot & Oinas, 2021). Thus, Finnish family carers can receive monetary compensation and other formal support from the state or municipalities. In Finland, family care has become an established part of formal elder care through care allowances, home care services, and respite care arrangements, all provided by municipalities (Ministry of Social Affairs and Health, <https://stm.fi/omaishoito>). Although families' roles in assisting older adults and even giving daily care has always been important, it can be argued that Finland has joined many other European countries in 'activating' policies that encourage citizens to take responsibility for their own wellbeing and care, and take on care roles (Geissler, 2005; Zechner & Valokivi, 2012). Comparative studies have shown that Norway and Finland favour family care more than other Nordic countries (Rostgaard et al., 2022). It can be argued that family care belongs to the 'landscape of care' (Milligan & Wiles, 2010) that is part of the mental, social and institutional landscape of care solutions considered socially acceptable and applicable by both people and political decision-makers.

Another old age policy goal linked to family care is the aim to further increase the number of older people ageing in place with the support of public home care services and family carers (STM, 2020; Rostgaard et al., 2022). Research on family care and carers has shown that many family carers want to look after their close ones, find it rewarding (Jolanki, 2016; Lindeza et al., 2020; Quinn & Toms, 2018; Quinn et al., 2019; Tolhurst et al., 2019) and feel that it gives meaning to their own lives (Jolanki, 2016; Yu et al., 2017). Although family carers' experiences and situations vary greatly between and even within countries (Colombo et al., 2011), family carers can become overburdened and experience mental problems such as stress and depression, and even physical health problems (Chan et al., 2021; Gaugler et al., 2003; Jolanki et al., 2013; Kûrten et al., 2021). Especially those carers who are engaged in intensive care (care provided more than 20 hours/week) struggle to cope and suffer from mental health problems (Colombo et al., 2011). The recent COVID-19 pandemic showed that being confined to one's own home and losing contact with other people and access to formal care services can have a detrimental effect on the wellbeing of both those being

cared for and their family members (Bacscu et al., 2021; Hanna et al., 2012; Losada et al., 2022). To summarize, caring for a close one can be described as an ambivalent experience that has both a positive and negative aspect attached to it from the point of view of family carers themselves (Lindeza et al., 2020; Quinn & Toms, 2018; Tolhurst et al., 2019).

Family members may have their own emotion-based reasons for being the sole carers for their close ones (Quinn & Toms, 2018), but they usually benefit from support from other people or from either public or private services (Jacobs et al., 2016; Halonen, van Aerschot & Oinas, 2021; Lauritzen et al., 2015; McCabe et al., 2016; Phillipson et al., 2014; Zechner, 2017). In relation to formal care services and care workers, the seminal research of Twigg & Atkin (1994) has shown that family carers can be seen as partners, care recipients and co-workers. Later studies in other countries have shown that family carers adopt and are assigned similar positions (Halonen et al., 2021; Jolanki, 2016, Peel & Harding 2014; Zechner, 2017). Sharing the responsibility for care between family carers and professional carers may promote the well-being of the family carer as well the person being cared for (Sims-Gould & Martin-Matthews, 2010).

The situation and positions of family carers in relation to the person needing help and support and in relation to formal care workers has been fairly widely researched, but the views of people with memory illnesses and how they see their own position in relation to their spouse and in the care-mix of old age care has received much less attention. We do know that people with cognitive illnesses often lose their agentic role in the eyes of other people, including professional carers (Aaltonen et al., 2021; Boyle, 2014; Kontos, 2004; Sabat, 2005). People with dementia are easily deemed unable to voice their views, and often seen as unreliable sources of information, which leads to researchers trusting other people to convey their experiences and wishes (Boyle, 2014). Dementia is often seen to signify a loss of self and personality. However, other studies argue that in fact, the inability to express oneself in an organized way with language may be confused with the loss of selfhood (Kontos, 2004). In addition, spouses who act as carers may take over the decision-making in daily life simply because their spouse is not able to express their views in the same way as earlier during their shared life (Boyle, 2013). Couples may also disagree on the meaning of memory illness in daily life, or on how well they cope with the challenges that memory illness brings (Eskola et al., 2022). In contrast, several studies have shown that although memory illness affects spousal relations, couples are still able to cope with the consequences of the illness and maintain their togetherness (Hellström et al., 2007; Molyneaux et al., 2012). In this study, we were interested in the views on care arrangements and the services and support available, as well the views on appropriate places to live in old age of people with memory illness and their spouses who act as family carers. Various forms of support and public services are considered important for the wellbeing of spousal carer, but much less is known about the views of the spouse with memory illness. In addition, research on how couples handle and manage the acquisition of support and services from actors other than family members is scarce. This paper studies these issues through a qualitative analysis of interviews in which both spouses voice their views.

2. Research questions

The study examined how the participants portrayed themselves, their spouses and other people as actors in daily life, and what matters they considered meaningful when seeking and receiving support in everyday life. Since family care is part of broader societal structures and the welfare system, it is important to look at how couples situate themselves in relation to these broader societal structures and the various actors that represent welfare services.

3. Theoretical and methodological framework

The study draws on theories of relational agency (Burkitt, 2016) and positioning (Harré et al., 2009). The concept of relational agency questions the traditional individualistic view of agency as the ability of rational individuals to make decisions and take actions irrespective of other people and the social and cultural context (Burkitt, 2016). The traditional view of agency also emphasizes linguistic abilities and the coherent and logical expression of one's views whereas incoherent, fragmented and emotional speech is interpreted as a sign of lacking agency (Burkitt, 2016). In contrast, Burkitt (2016) argues that agency is always social and

cannot take place without a connection to the external social environment. Thus, in this paper we see agency as concerning spouses' preferences and actions in relation to other people and the whole living environment, as well as national and regional policymaking (cf. Burkitt, 2016). Moreover, as people with memory illnesses are easily seen as lacking self-reflexivity and intentional action is seen as a central feature of the individual agentic self, Boyle calls for research that is attentive to the different ways in which people express their views and make their preferences known (2014).

Positioning theory simultaneously offers the theory of social action and human relations and guidelines for scrutinizing talk (Harré et al., 2009). Thus, positioning theory is linked to the concept of agency but also offers a means with which to analyse how agency is expressed in talk. The theory claims that, as members of communities and societies, we all inhabit different positions that entail personal qualities, relations with other human and non-human actors, skills, abilities, and rights and duties attached to and expected of the holders of these positions (Harré et al., 2009). Positions are relational, that is, positions bring with them an array of other positions that place actors in relation to one another. We can either adopt these different positions offered to us or refute them and seek to position ourselves differently. Resisting social positions may require considerable argumentation work and may not be accepted by other people. For example, people with dementia are often labelled or 'prepositioned' by other people as vulnerable, lacking cognitive skills and the ability to make rational decisions, and prone to behaving irrationally (Sabat, 2019). Although cognitive illness does make self-expression and eventually cognitive abilities difficult in various ways, from the perspective of positioning theory analysis we need to study how these or other positions become visible in talk, and how the speaker adopts, refutes, or redefines them and adopts other alternative positions. In research the 'target' group must be defined, that is, the participants are 'prepositioned' (Harré et al., 2009) in a certain way. Here, the participants were approached as people with memory illnesses and their spouse carers, positions which they had accepted by agreeing to participate in the study. Still, during the interviews they also redefined these positions, and at times refuted them and adopted other positions.

In this study we looked at how people with memory illnesses and their spouses talked about themselves, their relations with other people, and the meaning of various support services in their lives. We also examined their views on where they preferred to live. In the analysis, we first read the interviews carefully as a whole, after which we searched and marked the parts of the interviews that were linked to our research questions. Consequently, in the second phase we searched for talk in which the spouses spoke about public and private social and health care services; encounters with care professionals; their own sentiments, the decisions and actions taken to obtain a diagnosis, receive and organize services and other support; and their anticipations, preferences and fears linked to the future and where they would live if and when their illness worsened. In the third phase we identified and named the different positions in the talk that were linked to their illness, spousal relationship, people in their social network and relations with social and health care professionals. In this context, we also identified the different wishes, decisions, actions and preferences that the speakers attached to the different positions. Our aim was to identify the common positionings and actions, as well as the rarer ones, to grasp the variety and recurrent elements in the talk. We chose to present the results through three (3) interviews to enable us to show in detail the richness of the data of the individual interviews and the multiple positions that the same interviewee adopted other than a 'person with a memory illness'.

4. Ethical issues

The study received approval from the National Ethics Committee of the Pirkanmaa Region. The participants were informed of how the data would be collected and handled, and of their right to withdraw from the study at any time. In addition, the participants gave their written consent to the interview and its recording. The study followed the General Data Protection Regulation (European Commission 2018). According to the assessment of the memory disorder of the interviewees, the disorders ranged from mild to moderate. Data were collected in close collaboration with the spouse carers to make sure that their spouses with memory illness understood the aims of the study and were able to participate in the interviews.

5. Data

Our data came from qualitative, semi-structured, in-depth interviews (10) of home-dwelling people diagnosed with a memory disorder and their spouses. The interviewees' age varied from 62 to 88. All the couples were married. The study was part of a larger project in which 20 spousal carers and 15 spouses with memory illnesses were interviewed. For this study, we selected couples (10) in which both spouses expressed their views on the topic studied. The participants were home-dwelling people living in different regions of Finland. The interviewees had a diagnosed memory illness (Alzheimer's disease, frontotemporal dementia, vascular dementia, mixed dementia). All participants took part voluntarily.

The interviews lasted from 60 to 90 minutes and were audio-recorded and transcribed. The participants were asked questions about their memory illness diagnosis and the effect of the illness on their spousal relationship and on other social relations, their need for support and the availability of social and health care services, their use of information technology, and their views on the best place to live in old age. We analysed the interviews in which both spouses actively took part and voiced their views. The spouse with a memory illness is usually less vocal and their replies may be minimal (nodding, agreeing, murmuring). Many have a less audible voice than their spouse, which may be due to problems with producing voice. Nevertheless, they still interacted with their spouse and the interviewer during the interviews.

Only two of the couples had a family care contract with the municipality. Only one couple regularly used 'interval care' (family carer has a day off). None of the couples had formal home care (from the municipality), but some used a private cleaning service. Almost all of them were in contact with a doctor in either a primary health care clinic (general practitioner) or a neurologist (in a hospital), and with a memory nurse or registered nurse. However, some of the participants told us that they did not know who was responsible for coordinating care for the spouse with a memory illness. Half of the couples attended peer-support groups sessions in local memory clinics (run by a third sector association). Peer-support group sessions were arranged separately for the carer and the person with the memory illness.

Names and other identifying information were changed in the transcripts. In the data extracts, the interviewer is marked as I (interviewer). Inaudible text is marked with (--), a pause is marked with three dots without brackets, and if text is omitted between pieces of the text this is marked (omitted text). To improve the readability of the text, minimum feedback (yeah, mm, right) has been omitted. Feedback and comments made by the interviewer or the spouse during the speech turn of the primary speaker is retained if the speaker reacted to it in their own speech. The Finnish language has no separate personal pronouns (he/she), but one pronoun (hän), which can refer to either a man or a woman. Therefore, in the extracts we use singular they to replace the Finnish word 'hän'. The quotations of the participants' speech is marked with 'xxxx' or is in brackets (xxx).

6. Analysis

The analysis showed that apart from positioning oneself and one's spouse in one's talk, the positioning process involved several other actors, such as family and friends, representatives of social and health care services, social and health care workers and third sector workers, all of whom were sometimes named and sometimes unnamed actors representing the whole public sector. In the following we present a detailed analysis of three (3) couples' interviews and show how the participants positioned themselves, the multitude of actors with whom they were involved in their daily lives, and how in the positioning process they depicted their understanding of their need for support and care. These three interviews were selected because they illuminated the diversity of the interviews and positioning well, but also because they exemplified the shared and recurrent patterns in the talk and enabled us to show the complexity of the spouses' situations. Small qualitative data do not enable the results to be generalized to a larger population, but we aim to show that this kind of analysis can address nuances that remain untouched in other types of analysis, and to provide material for further studies.

6.1 *We are safe' – Network of supporters*

In the following extract, the speakers are Ilpo and his wife, who depict their various support groups and non-kin relations as meaningful in coping with illness and supporting one another. This extract is also an example of how spouses' talk flows as a joint endeavour, and how spouses pick up ideas from each other and complete the other's sentences.

6.1.1 Extract 1: Ilpo (husband with memory illness) and Iris (wife)

I: Joo. Well then, if we talk about these official services like what health care offers, cleaning or home care or such, do you have these?

Iris: Yes, we have had cleaning help twice a month.

I: Yes, yes. Is it from municipality or other?

Iris: No, it is, it is not municipal (Ilpo: It is not) Iris: It is (mentions the name of the private cleaning company).

I: Right. Do you go to any of these regular controls because of the memory illness or anything like that, do you have to go, or is it just according to the needs or?

Iris: You have that (--) thing sometimes (Ilpo (--)) every now and then you must go. But not that kind of...well, except now a neurologist there. An invitation comes twice a year from there. We are going there the eighteenth day. So that is like...but the kind of normal health (--) there at the health care centre.

I: How about that neurologist, is he/she the kind of person who follows how the illness has proceeded, or?

Iris: Yes. (I: something like?) He/she is extremely good...good, and (--) there at the memory association I have been, in that kind of groups, I was terribly surprised that it is not the same for all. I do not know why we have had it, like, twice a year a neurologist and twice a year comes our memory nurse here too. (I: Right) So that it is, it is, at least for now. Let's see how they...still the next year, does it continue. But...it seems to be very different in the city too (I: Right, in the same city, yes) Yes.

Ilpo's and his wife's interview is an example of how a multitude of actors from the private, public and third sector are portrayed as a part of their everyday lives and as contributing in different ways to their lives. Cleaning services were not provided by public care services, which was also mentioned. What is noteworthy in this interview is how the couple positioned themselves as recipients of support and 'excellent' care, and other actors (neurologist, health centre, memory nurse) as those who act and do things (the invitation comes twice a year, the memory nurse comes here) for the couple's wellbeing (for health check-ups). Another issue of note is that they portrayed their care arrangements as regular and as happening without their active involvement, which is rather rare in these interviews. In fact, Iris depicted her astonishment at realizing that, what for them was part of the 'normal' routine of care services, was not the case for all and people receive different levels of care.

6.1.2 Extract 2: Ilpo and Iris

I: Have you been happy with these, care arrangements what you have, do you feel that you need more help with something?

IRIS: No, not home-, if we think about homecare or this kind of health, health care, or what we might have, we are quite satisfied. We manage with what we got, three children and (--) at least, at least the one (in a hometown) living close by is available when needed, and that side... and then as said these control visits there (name of the hospital unit), so they are quite...and they make the memory test always again (Ilpo: And it is the same) the same, yes. Yes, and the thing that we have the girls with us every time, with us there, or we have been...And that has been (I: Has been good), we think it has been extremely good.

In the extract Iris positions herself and her spouse as a couple who are very satisfied with their home and health care services. Moreover, the hospital arranged regular memory tests and the couple were accompanied by their children every time they went for a test. The picture created by this piece of talk is that Ilpo and his wife's situation is under control, and they are supported by both public services and their children, who are available whenever needed.

6.1.3 Extract 3: Ilpo and Iris

I: Right yes, so you have no plans to move in the future.

Iris: No (Ilpo: No (--) no we have not, unless we) Unless we must go to a some place (Ilpo: Unless we must go to a nursing home (--)) [laughter]...nowadays there are so many with different names.

I: That was something I wanted to ask about, nowadays there is lot of talk about home being like the best place for a person till the end, so what do you think about that?

Iris: (--) that is my view (Ilpo: (--) very good (I: Right, yes, yes).

Ilpo: Yes, it is like that, but of course, if she for example dies before me, then it would be difficult for me to be alone here. But (..) even that I could manage for a little while at least. (I: Right, right, yes) There is one, lots of widows here, and they live alone, and they have (--) some problems (I: Right, yes). But their children and inheritors take care, as well as they can. But even today I met this lady with grey hair there, (laughter) walks and takes trash out, so we exchanged few words. So that is the problem, but it is in the whole society this kind of situation.

Iris: People live older and so, but I do not worry that yet, so that I, I (Ilpo: But) am of that opinion that we take it one day at a time, and if something comes up then, we make our own (I: Yes, right yes) own...and we have thought about our own old age so that we would be safe...safe then...

Ilpo: We have it even too well, with everything. We have it so, the society is around us (Iris: yes) so we have nothing to worry about.

Iris: Yes, as said, take one day at a time.

Most of the interviewees expressed ambiguous views regarding moving to a care home, which was most often described as an event that may take place but was not a particularly welcome option. In Ilpo's and Iris' interview, the couple's talk depicted the option of moving to a care home as an option that they might be forced to take (unless we must go) but did not wish to take. It was typical in these interviews that residential care was mainly seen as somewhere people must go or are sent to. In their talk, the couple used different names for residential care (care home, old age home, service housing, nursing home), but they were all categorized in the same category of 'some place', even though Iris remarked (today there are so many places with different names). Yet, overall, in this extract, moving to a care home was portrayed as unnecessary for either of them as the couple was 'safe' and had the whole of 'society' surrounding them. It was Ilpo who remarked that the ageing of the population was a problem facing society as a whole and particularly those living alone, such as widows. In contrast, as Ilpo said, 'everything is even too well' for him and his wife, and they had 'nothing to worry about'.

Ilpo's and his wife's talk evolved as a joint argument in which they portrayed their lives in relation to one another but also in relation to their children, health care services, a third-sector memory association, and other communities such as Ilpo's group of former work colleagues. Thus they portrayed a network of care that supported them and enabled them to take life day by day. However, this kind of positioning was rare, and next we discuss other, more common positionings.

6.2 You must look after yourself – Self-reliant couple

The analysis showed that the participants with memory illnesses did not position themselves purely as care recipients nor did their spouses position themselves solely as caregivers. Rather, the interviewees emphasized their abilities, skills and even the duties and responsibilities they took on to manage their daily lives. A recurrent pattern in talking about social and health care services and receiving support from public sector was the participants' emphasis of the need to act themselves and seek information about services and how to get them. In this kind of talk, the couples' positioned themselves as service users who needed to be active to receive support and services, while portraying public sector workers as distant, busy, difficult to reach or even indifferent to the needs of those seeking help.

6.2.1 Extract 4: Orvokki (wife with memory illness) and Olavi (husband)

I: Yes, yes, well I would ask about memory illness that is do you have the diagnosis?

Orvokki: Yes, I do have the diagnosis, and that was, three and a half year ago, diagnosed

I: Right, well when did you notice the first signs of the illness?

Orvokki: I, myself, I do not know if I really noticed, but, but I had anyway like a suspicion already, already two three years earlier I always offered myself that let's do tests (I: Right) But they did not show anything, and then, well three and a half year ago I went again, and then I got to the doctor, there it was found out, that (I: yes) mild.

When the interviewer asked the couple (in plural 'you noticed') about the first signs of illness, it was Orvokki who answered the questions. Orvokki positioned herself as a persistent seeker (always offered myself, went again) of access to memory tests until she got through to a doctor and her memory illness was detected.

6.2.2 Extract 5: Orvokki and Olavi

I: Right, yes. Well, do you feel that you have had enough information about memory illnesses in general? Have you been given enough information?

Orvokki: Well, not in my mind that has not been given that much, but I do not know in what way. I have not missed any information actually (I yeah, yeah)

Olavi: After that diagnosis, you joined the memory association right away and I joined couple years later. And in those memory café presentations, based on them we have looked for some detail from the internet. But in my mind, we have received quite enough. Of course, all this begins from your own activity. Public system does not offer them (I: Right, yes). So, I do not know in what way public system supports this memory association to make it possible to organize these activities.

Orvokki: We do have received, received information, information yes, and we, we do go to those, memory associations', if there are presentations or whatever program, we do go there (I: right) quite a lot.

At the beginning of the extract, the interviewer asked if the couple had received enough information about memory illnesses. Again, Orvokki replied first and denied having been given 'that much' information but downplayed the need for more information, thus emphasizing her own agentic role. Orvokki's husband joined in and reminded her that she was the one who had joined the memory association first. In this extract, both Orvokki and her husband turned the subject-object relation around by highlighting the actions they took to find information (joining the association, seeking information on the internet, attending 'memory café' presentations). The public sector's (public system) activities to support people were portrayed as non-existent (no public actor offers them), and the way the third sector delivered services remained unclear. Thus, the couple's own activeness in seeking information played a crucial role.

6.2.3 Extract 6: Orvokki and Olavi

I: Yes, yes. Well, what is the best place to live in old age, now that there is lot of talk that it is best for people to live at home, like in private home. So what do you think, that is that home always, like this kind of private home the best place to live or can it also be a service housing? Have you thought about that?

Orvokki: I do think that when I get to that state that I cannot function myself and cannot take care of myself then, then I go to somewhere (I: Yes, right). I do not, not, I, then it has to be a professional person, who looks after this and that. We are not, that, that kind of a couple. I can do things for him, but I do not, I do not want him to do things for me. It makes... (for both), no it, it will not do.

The interviewer asked about the couple's views on the best place to live in old age and equated home with a 'private home' and contrasted these with a 'care home'. Orvokki's reply shows that she interpreted the question to mean her future place to live. In many interviews, moving to a care home was described in the passive voice as 'being taken' or 'being placed', but Orvokki kept the active voice (I leave) portraying herself as the decision-maker in terms of moving and deciding what kind of help she wanted from her husband. To summarize the positions in this extract, being able to care for oneself and act independently was a requirement for living in a private home and when that was no longer possible it was time to move to a place with professional care workers. This process was depicted as inevitable once independent functioning was lost. In this positioning, the spouse was not a carer but a spouse, whose duty was not to provide intensive care. According to our interpretation, Orvokki's talk about herself being able and willing to care for her husband, but not wanting her husband to do the same for her, is an example of gender

positioning in which traditional gender roles explain this uneven division of care tasks (we are not that kind of couple). In short, they are still a wife and a husband.

In recent years, public social and health care services have been changed to meet the needs of people with memory illnesses, and new forms of service and information delivery have been created. These recent developments arose in the talk of the participants, as shown in the following extract.

6.2.4 Extract 7: Orvokki and Olavi

I: We, we have been talking about everyday life and social- and health care services, technology and housing and human relations and all that. I have no more topics to talk about, but do you have something you would like to talk about in connection to this?

Orvokki: I do not know. You talk, you are more talkative, so you talk.

Olavi: Well, there might be in connection to when a person receives memory illness diagnosis, or even in that stage when there is a suspicion, well you were written that certificate, medical certificate and there you were directed to that city's (Orvokki: Yes) they directed to this (name of the city) what it is now, home? something home, there is compound word, there (Orvokki: Main street) in connection to regional administration building is this kind of service centre.

I: Is it the civic centre (name of the centre)?

Olavi: yes, the civic centre. But in that connection, it would be good to...more detailed, would be good to find out about the person's environment and all that kind of things. I was left with the image that more inexperienced person digging up these things, is bound to be left to cope on their own. I do not criticize the work of the civic centre, hospital needs to focus on getting people well again, or as well as possible, but then these issues of the other side, so there, it is the city that in our system is responsible for them. So, in that point, might be a more detailed...like you see from Orvokki's task description, we know how to ask and search for a place, but certainly there is quite a big group, has not been involved in such matters at all, so it is difficult to find out about these things.

In this extract, Orvokki showed her agentic capability by giving the speech turn to her husband, explaining that he was more talkative than her, although they also completed each other's talk. They saw themselves as a couple, 'we', who know how to act with public services as opposed to people who are inexperienced in 'digging up' matters in the same way. The couple mentioned the social care innovation (civic centre) to offer citizens' a one-stop place to find information and receive advice on social care services, but they criticized its functioning. The public sector was positioned as an actor who was responsible for providing social services but failed in this duty, meaning that people needing had to be active themselves. In contrast to active people like the couple, many of the 'inexperienced' help-seekers were left without help.

6.3 We are in charge – Knowledgeable consumers

In contrast to the positionings discussed above, the spouses also portrayed themselves in relation to the illness itself and to public service providers as people who have knowledge, can weigh their options, and who make choices concerning care and in-service delivery according to their own needs and preferences. This position is more like that of a consumer or a client who is aware of their rights in relation to public services and is not afraid to demand services. Power relations were depicted as those of equal actors rather than the more common unequal positions of service recipient and provider.

6.3.1 Extract 8: Anja (wife with memory illness) and Aulis (husband)

I: Right. We are talking about memory illness first, so could you tell little bit what kind of memory illness you have and when it started?

Anja: It started, two thousand seventeen (2017) third day of October I received the diagnosis. Of course, there was earlier such things that I myself, I sought medical examination, and everyone was belittling it. But since I am a bookkeeper, a bank official, a financial manager, I have been involved with numbers, the whole forty years, so I am pedantic. And I noticed it myself that everything is not going ok now. And I almost pushed myself to see memory nurse. We asked is there nothing nowadays, after that she had to ask for a permission from a medical director if she is given the permission to send the referral to (name of specialist hospital, city in

East-Finland) (Aulis: (--)) (-) And then I got the referral, and they did these neuropsychological examinations and tests and then it started little by little. But it must have taken at least three years (Aulis: Couple of years) Two three years before they like believed that. They were thinking that it could be like momentary tiredness or something like that.

In this extract, Anja positioned herself as a professional whose work had involved dealing with numbers. Therefore, she was 'strict', and recognized her own memory problems and sought access to specialists, memory tests and neuropsychological examinations, even though ultimately, rather extreme actions were required (almost pushed myself) to get an appointment with the memory nurse. Public health care was portrayed as a rigid system, exemplified in the narration by how the memory nurse had to ask the chief physician for permission to refer her for further medical examinations. In Anja's narration, she is the one who managed to overcome the obstacles even though many years passed before the health care sector actors (they) believed her memory problems to be real. This kind of positioning continued throughout the interview, with Anja being the one demanding and evaluating the services received.

6.3.2 Extract 9: Anja and Aulis

Anja; Right, and then about these, in fact I am now trying to get to the, since I have been dropped out. I am sixty-two and..and sixty-five year olds get to the geriatrician, who would be best to evaluate these co-interactions of drugs. But I have been only once here (name of the hospital) to see the neurologist. That was worth nothing, even brought me down a little bit, "this is unfortunately advancing disease and unfortunately there is no medication for this". I said nice, thank you and goodbye. And I do not want to see him again and I have been to the doctor today, and I got myself to this good doctor who will send the referral (--)) (directly) to the geriatrician, even though in my age I am not yet their...but I want that because there is, my memory coordinator said, that they treat very well there. They take into account the whole person in holistic manner, and not like being in a conveyor belt.

In this extract, Anja again positioned herself as a person who actively sought a doctor's appointment to determine possible interactions of her medications, which also demonstrates that she had special knowledge of the potential harmful effects of drugs and of the rights to have medical examinations at a certain age. In addition, she evaluated the doctor's appointment useless. In contrast, thanks to information provided by 'her' memory coordinator, and 'a good doctor', she managed to arrange an appointment with another specialist in a geriatric clinic that treated people holistically.

6.3.3 Extract 10: Anja and Aulis

Aulis: Then it is her own activity that we have been active actors in Memory association.

Anja: Yes, I called (Aulis: So there) there, Memory association in Helsinki and asked them, and there I found out that memory association functions here.

Aulis: But I continue here (Anja: Yes) so, well, there was nothing, even though the diagnosis was received, and papers transferred here. Ordered everything (name of the health centre, hospital name) all the papers had come. For example, memory coordinator and memory nurse, nobody made any contact. I was of the opinion that let's wait for how long it takes (Anja: Right) but she called herself then and went (Anja: I could not wait any longer). She came by, was it the last week or week before that (Anja: ---) also some coordinator. So, these social and health care services, even though you have a diagnosis, and now (Anja) a disability pension, papers have been transferred here. So that was not much use. Of course, we are like more active than others, but how about then when a quite ordinary John Doe, knows nothing about these social and health care systems, nor these services, so he will be left totally (Anja: That is...) and they make the biggest part, we belong to (Anja: Yes) to that very small minor-, well that kind of minority which is active.

In recent years the public, private and third sector have developed different ways of supporting people with care needs and memory problems. These different forms of support were visible in this interview data, but the meaning given to the different actors offering and providing support varied. In the extract above, both spouses positioned themselves as keen participants in the memory association's activities but finding out about them was Anja's doing. She was positioned again as an actor who took the initiative. All in all, the couple positioned themselves as belonging to a 'very small minority' who were 'more active than other people' in contrast to the 'quite ordinary John Doe' who knows nothing about social and health care systems

and is 'left totally' without services and support. Their position also entailed a right to evaluate and criticize public services as having failed in their duties to contact and look after people and serve them all in an equal manner. Thus, service users had to be active and demand services to receive them.

The interviewees in this study represented young-old people whose parents were old-old, and it became evident in the data that although the couples were facing memory problems and other health problems in their own lives, many of them also had their own parents to look after. Thus, when the interviewees replied to the questions, they sometimes replied on behalf of two generations, as is the case in the following extract.

6.3.4 Extract 11: Anja and Aulis

I: What do you think about that when nowadays there is lot of talk about home being the best place to live in for an old person, as long as possible, so do you agree, or what thoughts it awakes in you?

Anja: Well, it awakes just that, for example my mother of whom I have spoken of, will turn eightysix not, at twentieth day if she reaches that. Hopefully she does, so she is so satisfied even though she lives alone in a block of flat, three stores and no elevator. And she is so satisfied, that there are all her own things, own routines and rhythms, and everything. She has lived there who knows for how long, ever since after retirement. And she has a nurse three times a day and food is brought three times a week. But, then I am of that opinion that if, if she struggles with coping there at home, so that she falls of the bed and falls over, and a fire comes or something...hurts herself or. So then, I think that she is no longer in good care when she is alone. (Unclear) his mother had, she fell from the bed, and could not get up herself, and alarm bell was at the night table. Could not get up herself. That is not, that is not anymore, like good care. Even though she was already in hospital then. But in my mind, it is that as long as you manage at home, I mean with the reservation that nothing happens.

(omitted talk about her mother's daily life)

Aulis: I think that the best place for a person is home so long you manage there (Anja: mmm) and I think that during our time there may become this kind of communal type of housing forms, in which supporting one another, and services are close in that same apartment. They do exist already, in England, United States has been even longer, and I believe there are in Finland too, in different parts.

(omitted talk about different locations)

Anja: Well and then, good that you now opened that topic, because I was thinking here, if he would have to give care to me. That would be terribly burdensome for him. But if there in the vicinity would be a helping hand who would assist both of us in a way, but particularly his wellbeing. So that would be quite ideal, so I would not have to, or that somebody, lie alone in a hospital, where somebody would come sometimes to visit. So, to be able to live with your spouse in the same, and then at the vicinity would be help. That would be a number one option absolutely.

When the interviewer asked about the best place to live in old age, they based their questions on their own views on a future place to live. Yet, Anja looked at the question of ageing in place in a private home from the perspective of the couple's parents, that is, for her, 'old people' were hers and her spouse's parents. As in the other interviews, home was portrayed the best place to live as long as one could manage independently or with home care help and had no major health problems. In these interviews, the interviewees talked about a rather new phenomenon in the senior housing sector (in Finland) that is 'collaborative senior housing complexes' around the country. Here the husband, Aulis, brought up collaborative senior housing as an alternative to an ordinary private home and assisted living facilities, which offered a 'homelike' environment with mutual support and services. Anja picked up the topic and presented collaborative senior housing as an 'ideal' 'number one' option, allowing spouses to live together while enabling the healthier spouse to escape overly burdensome care tasks. As stated earlier, although institutional care is recurrently described as the inevitable choice at a certain point when independent functioning has been lost, from the residents' perspective it also means places where people 'lie alone' and seldom receive visitors.

7. Discussion

The agency of people with memory illnesses is often doubted, and other people tend to speak on their behalf. The analysis in this study showed that people with memory disorders were able to participate in interviews, speak for themselves and express their goals and wishes for the future (cf. Sabat, 2005). In addition, people with dementia are often labelled as vulnerable, lacking cognitive skills and the ability to make rational decisions, and prone to behaving irrationally (Sabat, 2019). Our analysis showed that the positions of the participants with memory illnesses could not be described simply in terms of care recipient versus caregiver, dependent versus independent or agentic versus non-agentic positions. The participants had a whole range of positions, exemplifying diverse abilities, resources available to them and their spouse, and the actions and choices of other people. The result emphasizes that the agency of people with memory illnesses cannot be seen solely in terms of their illness nor in relation to their spouses' preferences and capabilities, but in relation to their whole living environment and national and regional policymaking (cf. Burkitt, 2016).

The interviews prepositioned the interviewees as people with memory problems and care recipients, and their spouses as a caregiver (cf. Harré et al., 2009). The interviewees adopted these positions, but in their speech gave themselves different, varying meanings. Being a person with a memory illness was an agentic position and was linked to taking action to find information about their illness and ways to cope with it. They also reflected and compared their situation to those of other older people facing different challenges and problems and saw themselves as 'doing better'. They also positioned themselves as another half of a couple, 'we', who acted and solved problems together. Speaking from the position of a person with dementia, they anticipated deteriorating health and increasing dependency and saw their future place to live in terms of their spouse's wellbeing. They also showed concern for their older parents, other older people living alone, and inexperienced users of social and health care services. The people with memory illnesses thus showed the ability to self-reflect, ponder their situation and make decisions and take actions in relation to their illness and their spouse's situation, but also to care for other people (cf. Boyle, 2014). The participants were evidently able to exercise agency and demonstrated their social self (Burkitt, 2016).

It should be noted that the participants selected for this study were people diagnosed with mild or moderate memory problems but had the ability to express themselves verbally in an interview. Other research methods that focus more on emotions, actions and non-verbal social interaction are needed to study the agentic or non-agentic positions of people with advanced dementia (Boyle, 2014; Sabat, 2005).

The second key argument we wish to make is that in relation to health and social care services, the interviewees adopted various positions, not only those of service users, or even patients. Different services and forms of support emerged in the interviews when the couples discussed their daily lives. In relation to social and health care actors, some couples positioned themselves as a couple tackling memory illness and its consequences with the aid of an array of helpers from different sectors. Thus, a person with a memory illness and their spouse were positioned as members of a network of several actors in their social network and the public, private and third sector, who all organized things for them, helped them access services and other support, and made them feel 'safe' (cf. Burkitt, 2016). These results show that public services play an important role in supporting ageing in place and the wellbeing of people with memory illnesses and their spouse carers (cf. Kröger & Bagnato, 2017). However, our analysis also concurs with the results of studies that argue that the services are not always sufficient or appropriate and do not meet the needs of all people and that there is a clear local variation in the access to and provision of services (Kröger, 2022; Rostgaard et al., 2022).

The third key result of the study was that the position of happy, satisfied service recipients was rather rare; it was much more common for both spouses to position themselves as 'active' citizens who sought information on memory illnesses and what support was available themselves, as the public sector was failing in its duty to offer this support and reach out to citizens needing it. Interestingly, the interviewees positioned themselves as more fortunate than older people living alone and the inexperienced service users who lacked knowledge of how to act in the current welfare system. While the interviewees had managed to navigate their way through the system and benefit from the current old-age and family care services, the inexperienced 'John Doe' was deemed to be left to manage on their own (cf. Kröger, 2022). These results concur with arguments that the Finnish welfare system is increasingly becoming a self-service system, forcing citizens to be active or needing family members to help them (Aaltonen et al., 2021; Anttonen & Karsio, 2017; Jolanki et al., 2013; Zechner & Valokivi, 2012). When a person is in a vulnerable position and

has multiple health and social problems, it is understandably difficult to ‘fight their own corner’ and this clearly goes against the whole idea of welfare services (Eskola et al., 2022; Halonen et al., 2021).

The marketization of the welfare system is a common trend in European countries, meaning that services are increasingly being commissioned by the public sector but provided by the private or third sector through complex arrangements of semi-private services. (Anttonen & Karsio, 2016; Kröger, 2022; Kröger & Bagnato, 2017). It is known that well-functioning co-operation between family carers and professional carers contributes to the wellbeing of families with care responsibilities (Sims-Gould & Martin-Matthews, 2010). This study’s findings are in line with those of earlier studies (Jolanki, 2016; Halonen, Van Aerschot & Oinas, 2021) that families sometimes need to really push to obtain the services and support to which they are entitled.

Interestingly, the analysis also showed that as a kind of extreme version of active citizen, some interviewees positioned themselves as knowledgeable and skilful actors who did not only know how to act in the current welfare system, but were aware of their rights, had knowledge of different services and benefits and were not afraid to demand what was rightfully theirs. In addition, the interviewees positioned themselves as equals to the actors in social and health services, and as having the right to evaluate the success and failure of these actors to provide citizens with appropriate information and support. This position comes close to what we understand as the consumer and client role in modern society and supports the argument that maybe new generations of citizens are not such docile service recipients, which is the point Anttonen and Karsio also ponder in their reflection of the future of the Nordic care model (2017). Future generations of family carers and even people with memory illnesses may begin to behave like consumers in a society that has put them in this position. Whether or not society is ready for this kind of conduct is another matter.

8. Conclusions

Family care has traditionally played an important role in elder care in many countries. With the current policy goals to support the ageing in place of older people and to invest in family care, family carers are expected to become even more important. The results of this study show Finland is dealing with similar issues and problems to those faced by family carers all over the world (Lindeza et al., 2020; Peel & Harding, 2014; Pinquart & Sörensen, 2003; Quinn et al., 2019; Tollhurst et al., 2019). Clearly the care of older people and their close ones is not yet at a sustainable level. There is a need to better support people with memory illness and live-in carers, and to continue developing high-quality residential care that is responsive to the needs of people with memory illnesses and their close ones so that they can feel ‘safe’ and looked after, and still retain their agentic positions.

This study showed that even though the agency of people with memory illnesses is often questioned by others, they have agentic capabilities and ability to express their views. Appropriate research methods such as detailed speech analysis used in this study are needed to unravel and contextualize their ‘message’ from fractured sentences or seemingly irrational remarks (Sabat, 2005; 2019). In line with Boyle (2014), we argue that to view people with dementia and their positions in relation to their spouses and other people only in terms of vulnerability, dependence, and lacking the ability to truthfully convey their own views and wishes ignores their agentic capability.

In addition, Boyle’s studies (2013; 2014) show that data on decision-making and the social actions of people with advanced dementia can be gathered when, in addition to interviews and spoken data, observational and visual data are used. Observations enable us to notice emotional expressions and habitual bodily gestures that convey preferences and aspirations, even if the person’s speech is impaired (Boyle, 2013). Recruiting people with memory illnesses to study their views on matters concerning their daily lives despite potential problems is an ethical challenge (Sabat, 2019) that researchers need to better meet in the future.

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Data availability statement

Data cannot be shared openly due to privacy/ethical restrictions. The data are, however, available from the authors upon reasonable request.

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Information in German

Deutscher Titel

Personen mit Demenzerkrankung und ihre Ehepartner als Akteure in hybriden Pflegeversorgungsmodellen

Zusammenfassung

Fragestellung: Die Studie analysiert, wie Personen mit Demenzerkrankung sich selbst und andere als Akteure des Alltagslebens positionieren, wie sie mit ihrer Erkrankung umgehen und welche Faktoren sie bei der Suche nach und dem Erhalt von Unterstützung im Alltag als wichtig erachten.

Hintergrund: Die familiäre Pflege spielt traditionell eine wichtige Rolle in der finnischen Altenpflege und wird im Rahmen der aktuellen sozialpolitische Ausrichtung Finnlands weiter gestärkt. Es gibt derzeit jedoch nur wenige Untersuchungen darüber, wie Menschen mit Demenzerkrankung ihre Pflegearrangements wahrnehmen und bewerten.

Methode: Die Studie stützte sich auf theoretische Ansätze der *relational agency* und des *positioning*. Die Daten stammen aus 10 qualitativen, halbstrukturierten Tiefeninterviews mit Personen, bei denen eine Demenzerkrankung diagnostiziert wurde, und ihren Ehepartner:innen. Diese Interviews wurden aufgezeichnet und transkribiert. Das Alter der Befragten lag zwischen 62 und 88 Jahren.

Ergebnisse: Die interviewten Personen positionierten sich zusammen mit ihren Ehepartner:innen als Paar, das umgeben von unterstützenden Personen ist und als zufriedene Leistungsempfänger:innen, aktive und sachkundige Leistungsnutzer:innen oder zum Teil auch als Konsument:innen, die Mängel sozialer und gesundheitlicher Pflegedienstleistungen kritisch einordnen und bewerteten können.

Schlussfolgerung: Personen mit Demenzerkrankung sind in der Lage, ihre Handlungsfähigkeit selbst-reflektiv zu beleuchten und auch andere Positionen einzunehmen als die einer erkrankten Person. Es besteht deutlicher Bedarf danach, Menschen mit Demenzerkrankungen stärker aktiv in die Forschung einzubeziehen und verschiedene Datenerhebungs- und Analysemethoden zu entwickeln, die es ihnen ermöglichen, ihre Ansichten zu vermitteln. In den heutigen alternden Gesellschaften sind unterschiedliche Formen der Unterstützung erforderlich, die auf die Heterogenität von Menschen mit Demenzerkrankungen und ihre Ehepartner:innen eingehen.

Schlagwörter: Demenzerkrankung, Familienpflege, qualitative Forschung, relational agency, Positionierungsanalyse

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