


ARTICLE

What is helpful in everyday living with dementia at home? Learning from families' diverse scenarios

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Abstract

As the population ages and the prevalence of dementia increases, caring for a relative living at home with dementia has become a reality for many families worldwide. Studies have shown that families are confronted with diverse difficulties as they try to address the challenges involved in providing care. By understanding how they manage daily life, formal service providers become better equipped to meet the diverse needs of these families. Learning how families live with memory loss and cognitive changes calls for an understanding of the shared context surrounding the person, including the collective of people, and their connections. With the research method of ethnographic case study, we followed eight families living at home with dementia for two years. All participants had been placed on a waiting list for a specialised dementia day care programme. The analysis presented here is based on three cases which reflect widely different experiences and situations. We describe how these families dealt with their daily living at home, if and how they made use of the formal support available and what approaches they found helpful for improving their lives. The results show how the persons living with dementia and their care-givers drew on the collective of their backgrounds, surroundings and available support. With diverse arrangements, families tried to find ways to make their daily lives work out. But constant re-arrangement was necessary. This knowledge could be a central learning point for formal service to build on. While systematic or routine procedures in service provision can be helpful, time and space must be provided for professionals to understand families' different practices, so that they can provide family-centred support.

Keywords: dementia; ethnography; case study; homecare; family care-givers; person-centredness; relational care

Introduction

Dementia is a blanket term used to refer to a wide range of cognitive changes that impact memory and thinking skills. With the growing prevalence of dementia, following demographic ageing, caring for a relative living at home has become a reality for many families worldwide (Prince *et al.*, 2015; Nichols *et al.*, 2019). Although a dementia diagnosis may be attached only to one person, its impact and consequences are shared by both families and the broader community (Taylor, 2008). Therefore, living with memory loss is a joint undertaking by the person experiencing cognitive changes and what surrounds and connects that person, including family and friends, community, their living spaces and their social connections (Moreira, 2010). Within these relations, families arrange care at home by drawing on their strengths, experiences and relationships (Schulz *et al.*, 2020).

Studies have also shown that families caring for a person living with dementia experience complex feelings and diverse difficulties as they try to manage the demands of daily life (Sutcliffe *et al.*, 2017; Lethin *et al.*, 2018; Reed *et al.*, 2020), especially when severe behavioural and psychological symptoms related to dementia emerge (Lethin *et al.*, 2018). Family carers are heterogenous, some feeling that they are coping well in daily life, while others become overwhelmed (McCabe *et al.*, 2016; Tatangelo *et al.*, 2018). Some experience anger, resistance, sadness, grief and powerlessness, while others show acceptance and acquiescence (Pozzebon *et al.*, 2016). These different reactions of family care-givers call for multiple modes of support, but authors who have studied the situation of families living with dementia have concluded that available formal support does not reflect their diverse needs, and may therefore not be helpful (Elmståhl *et al.*, 2018; Ceci *et al.*, 2019; Zwingmann *et al.*, 2020), in addition to coming in late in the dementia progress (Barbosa *et al.*, 2011). These authors have called for further research into how families can be supported in caring for the person living with dementia at home and managing daily life.

In this article we have drawn on authors who have articulated how daily life with dementia can be made as good as possible (Mol, 2006; Mol *et al.*, 2010; Moreira, 2010; Moser, 2011). These authors base their approach on a relational understanding of how people depend on each other in complex relations. Studies of families living at home with dementia have also reflected how they often try to organise daily life in the best way possible (Ceci *et al.*, 2019, 2020). They have shown how families constantly make new arrangements to continue daily activities, such as brushing teeth, maintaining fluid intake and keeping the person in need of care safe while going shopping. Using the term care collective, Ceci *et al.* (2019) described how such arrangements usually rely on diverse relations between people and things to hold things together, mobilising the participation of family and friends, as well as the formal health and social care systems. As they note, all participants in the collective need to be in tune and work towards a common aim. Similarly, Arthur Kleinman, in describing his experience of caring for his wife who was diagnosed with dementia, observed that everyday life becomes an ever-changing reality that requires constant adaptation. As he explained, the family care-giver must go along with the situation, trying out different care activities to find out what works and avoiding undesired outcomes (Kleinman, 2019).

The above understandings have much in common with ideas related to person-centredness that have been influential within dementia care and research for the last three decades (Kitwood, 1997). Person-centred care refers to care being tailored to each person's interests, abilities, history and personality, and in relation to the individual's place, self and social world (Kontos, 2005; Lann-Wolcott *et al.*, 2011; McCormack *et al.*, 2011). By drawing on ideas of person-centred approach, services can be developed to improve the support to people living at home with dementia (Brooker, 2003; Berglund *et al.*, 2019; Hennelly and O'Shea, 2022) by continually adapting activities in context with their everyday situation (Chung *et al.*, 2017).

Although this emerging literature related to how families go about living with dementia has made important contribution to improving their lives, more research is still needed in that field. There is also a need for a better understanding of what kind of formal support is helpful to families' everyday living. The aim of this article is therefore to explore how families go about their daily life at home with dementia, how they figure out ways to make life as good as possible and how to 'go on' to make the most out of their situations. Furthermore, the aim is to learn how formal care services have supported them in this undertaking. By learning how families manage their daily lives, we can begin to understand how they can be better supported in continuing their care-giving (Ceci and Purkis, 2021).

Method

The design of this research was a traditional ethnographic case study, using observations, interviews and document analysis (Hammersley and Atkinson, 2019). Ethnographic methods require investigators to observe people and objects 'in action' and, where possible, to participate in the practices of the study informants. The constant question for the ethnographer is: 'What is going on here?' (Sorensen, 2010). Ethnographic case study can also be thought of as a method of storytelling, or allegories, where the use of stories developed through case study methods can support a holistic understanding of situations. It can also draw attention to details that startle and interrupt the given picture in our minds, including assumptions about people and situations developed by the culture surrounding us (Tsing, 2015). Such interruption can help to develop and improve our thinking; it encourages us to open our eyes and learn from heterogeneity (Savransky and Stengers, 2018).

Eight families living at home with dementia participated in this study and were followed over a two-year period. These longitudinal observations allowed us to obtain an in-depth understanding of how families respond to the ever-changing situation of living with dementia at home (SmithBattle *et al.*, 2018). Expanding on Ceci *et al.*'s (2019) conceptualisation of life with dementia as collective, with an extended observational period, the intent of this fieldwork was to focus on what people do to sustain and improve their everyday lives at home when one member of the family has dementia and is on a waiting list for a specialised dementia day care programme. This required a closer look at the complex arrangements enacted to try to handle an increasing mismatch between the person living with dementia, the environment and the other family members, regardless of the specificities of the type or stage of dementia.

Setting, recruitment and participants

This study was conducted in the capital area of Iceland, a Nordic country with 387,800 inhabitants (Statistics Iceland, 2020) and a highly developed welfare service. Recently, the first national action plan on service for people with dementia in Iceland was released (Ministry of Health, 2020). It contains 48 action points in six different domains. Among those is an emphasis on the importance of increased support to families living with dementia at home. It focuses on earlier interventions such as open activity centres for newly diagnosed individuals and more flexible service hours in specialised dementia day care centres. The Icelandic nation is relatively young but ageing fast in the next few decades. People over 65 are now 14.5 per cent of the population but will be 20 per cent in 2037 (Statistics Iceland, 2020). Unfortunately, the national database on dementia is still in progress. Therefore, no information on the number of individuals diagnosed with dementia in Iceland currently exists. Still, according to British research, it is estimated that 7.1 per cent of those 65 years and older are living with dementia worldwide (Prince *et al.*, 2014). Thus, the number of people living with dementia in Iceland will likely rise from 3,600 in 2019 to 6,180 in 2040 (72% increase) (Ministry of Health, 2020).

At the time of this study's data collection, a diagnosis of dementia was primarily made by geriatricians of the Memory Clinic at the National Hospital in Iceland (Guðnadóttir *et al.*, 2021). When a diagnosis had been confirmed, families were expected to find their own approach to address issues that may come up. Their situation was assessed at biannual visits to the clinic and if difficulties seemed to have emerged, the person experiencing dementia was placed on a waiting list for a specialised dementia day care programme. This waiting list was where we decided to focus our recruitment. Being placed on the waiting list meant that dementia was already having a significant effect on the families' daily lives, and they were identified as in urgent need to access a day programme. An agreement was made with the staff at the Memory Clinic to introduce the study to families on the waiting list.

The research participants comprised eight older individuals ($N = 8$) living at home who had been diagnosed with dementia and their closest care-givers ($N = 13$), usually a spouse, a child or both. Each family placed on the waiting list was given a letter introducing the study. If they were willing to participate, the clinical nurse specialist managing the waiting list relayed their contact information to the first author.

Data collection

When a family had agreed to participate, the first author would call the home, introduce herself and ask for a convenient time to visit. This phone call was generally an important initial first step in the data collection process. The family care-givers, who in all cases answered the phone, were eager to share their experiences and said that they were thankful for the interest in their lives of living with dementia. The first visit was with the person diagnosed with dementia and his or her primary family care-giver, who was usually a spouse and/or an adult child.

Much of the data was generated at these meetings, mainly through informal interaction and observations, and in some cases formal interviews. Observations

took place mainly during home visits, where daily routines and activities at home were followed to see how the families found their ways in everyday living. We also observed social activities outside the home, including grocery shopping and doctor's appointments. Field notes were written during and after these visits, along with notes written in relation to other communication, such as telephone calls and emails. During the initial visits and again near the end of the data collection, members of each family were interviewed, both together and separately, using semi-structured interviews, which were recorded and transcribed directly.

The families were visited one to four times a month, with each visit lasting one to three hours, depending on their respective situations. When there were ongoing changes in their conditions or circumstances, the visits were longer and more frequent than in quiet times. Such an arrangement depended on close communication with the families, as they were to let the researcher know if there were some changes that had taken place, and that the researcher should check on them more regularly.

Each family was followed through their journey from being on a waiting list to receiving specialised day care. The duration of the data collection for each of the eight families varied from 13 to 24 months, and specifically from October 2017 to December 2019, therefore all before the COVID-19 pandemic. All data were collected by the first author in close collaboration with the last author.

Data analysis

The analysis of the data was conducted in line with the ethnographic tradition (Hammersley and Atkinson, 2019), and with the aim of obtaining a holistic understanding of the circumstances of families of persons with dementia living at home. A case study approach emphasised the significance of understanding various aspects of the families' situations, such as their communication modes, daily activities and practical issues of housekeeping. Exploring their ways of engaging in social activities, and multiple other methods to make the most out of their companionship with the one diagnosed with dementia, also supported the understanding of their everyday lives (Flyvbjerg, 2001, 2006; Stake, 2006; Yin, 2014).

In ethnographic studies, data analysis is a continuous process consisting of a constant comparative method, beginning in the pre-fieldwork phase, and continuing through observations and conversations in the field and between researchers (Hammersley and Atkinson, 2019). This practice was followed in this analysis, along with Hammersley and Atkinson's emphasis that researchers should go beyond the data, interpreting what is said or shown, to develop an understanding, and be prepared to move back and forth between ideas developed from the data. Field notes of observations and conversations were used, along with data from phone calls and semi-structured interviews, to portray multiple scenarios that would capture the complex situation of handling daily life in each family.

Continuous discussion within the research group during the analysis process provided opportunities to gain an in-depth understanding of the subject studied, which is an essential part of the ethnographic method (Hammersley and Atkinson, 2019). During this process, all data and emerging categories were considered and discussed by the researchers until consensus was reached.

Ethical considerations

This study was approved by the Icelandic Bioethics Committee. Participant families were given pseudonyms and particular care was taken to assure anonymity. A written consent form was collected from all participants with an emphasis on explaining the study to participants living with dementia. Though informed consent was obtained in writing during the first visit, the researcher started and ended every visit by ensuring that she was welcomed to their home; this involved listening to the participants’ use of language, facial expressions and body positions. The researcher was ready to draw back from her observations if signs of resistance appeared. In contrast, signs of appreciation, such as sentences like ‘thank you for the visit’, ‘it was nice to have you’ or ‘you are always welcome’, along with a sense of ease experienced during visits, strengthened the researcher’s certainty of continuing consent.

Findings

Every family had an important story to tell, but to give the space needed we present three cases in this article, families B, E and G. They were chosen as examples of widely different experiences and challenges of living with dementia and ways of responding. These three case studies demonstrate the complexity and heterogeneity of families living with dementia, how they manage daily life and make use of formal support. In Table 1, we provide an overview of marital status, time since diagnosis, time of observations and status at the end of the observations for all the participants.

The longitudinal design allowed us to observe how the situations of these families changed over time. Repeated visits and observations provided valuable insights into the different ways in which the families responded to such changes. In this article, as shown in Figure 1, we report on these three different family situations. In doing so, we demonstrate the care provided by each family and the multiple challenges they faced in their everyday lives. We then describe their diverse practices and different ways of reaching out for help.

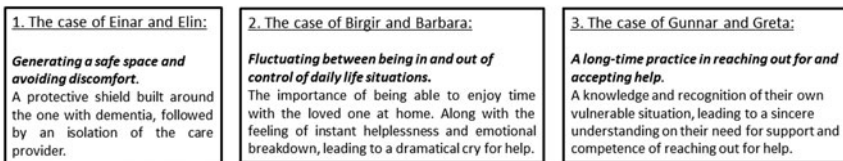


Figure 1. Overview of the three different case studies. The results show diversity in the ways the families attend to daily life with dementia.

Case study 1: Einar and Elin

Einar (80 years) had been taking care of his wife Elin (78 years) who was diagnosed with Alzheimer’s disease four years earlier at the Memory Clinic. They have had follow-up visits twice a year since then. Einar and Elin were retired and had four grown-up children living nearby. A close network of support was led by their oldest

Table 1. Overview of participants

Family identity	Gender of the person living with dementia	Age	Marital status	Time since diagnosis	Closest carer, first contact in research	Age of closest carer	Time length of research observation	Status at the end of observation
A	Female	86	Widow	3 months	Daughter	47	18 months	Dementia day care
B ¹	Male	76	Married	3 months	Wife	72	24 months	Dementia day care
C	Female	76	Married	4 years	Husband	76	24 months	At home
D	Male	74	Married	5 years	Wife	74	22 months	At home
E ¹	Female	78	Married	4 years	Husband	80	18 months	Dementia day care
F	Female	75	Widow	2 years	Daughter	36	18 months	At home
G ¹	Male	72	Married	3 years	Wife	71	20 months	Dementia day care
H	Male	76	Married	18 months	Wife	75	13 months	Dementia day care

Note: 1. The case study is presented in the article.

daughter, who helped with doctors' appointments and filling out the application for day care. She had also made it possible for her parents to travel abroad the year before the data collection, by accompanying them.

When Einar received an invitation to participate in this study, he was more than willing to provide some insight into their lives, but he was hesitant to have the researcher come to visit their home. As he explained, that might have increased Elin's discomfort. In fact, he also found it difficult to talk on the phone about their situation because Elin might hear him and become upset. This is an example of Einar's greeting when answering a phone call: 'Thank you for calling; it is nice to hear from you and good to know that someone is interested in our situation. Spare me a moment while I move into another room, as I can't really talk here' (Einar, phone call 01). He would say this while whispering and then hide in their bedroom. He said Elin got suspicious when he was on the phone and wanted to know who he was talking to and about what. 'I think it is better if we find another way of communicating. Could you maybe e-mail me?', he asked in the beginning of our conversations.

It took time to establish trust in the communication between Einar and the researcher, as this entry from the first author's research diary shows:

For six months, the communication was only by short phone calls and emails. Einar was sincere in what he shared but constantly aware of not disturbing his wife. After that time, I found that our connection had become stronger. He easily talked about their daily lives and shared his thoughts with me. Einar told me about the close relationship to their grown-up children but also about the diminishing connection with friends and old colleagues, which he missed. When I really felt that trust had been established, I asked for permission to come for a home visit, which he accepted, but he requested that the conversation not be directed at his wife's dementia diagnosis. Elin greeted me cheerfully on my arrival. She appeared to be an energetic and talkative person. 'How lovely to have a guest at our house. Welcome!' she said. Elin was a former teacher, and her face lit up when she told me about her students and teaching methods. 'I can't help it; I will always be a teacher, no matter what. Teaching is in my blood!' she said. (Researcher's diary, E-08)

In former communication with the researcher, Einar had described his wife as a cheerful and well-educated woman, who was devoted to her work and family, loved the outdoors and was never still. However, in the last five years, Elin had gradually experienced more symptoms of her dementia, with decreased strength in body movement and increasing lack of insight into her situation. Einar said she had no understanding of herself as having dementia, but it still seemed as if she had felt some changes. She would repeatedly ask him what was wrong with herself, but when he tried to explain the situation, she would become extremely angry and cry. Einar said he was concerned about his wife retaining her dignity and protecting her from any uncomfortable exposure in daily life. 'I find it extremely vital to keep our daily routine on a calm basis', he said. 'Stress and insecurity can turn everything inside-out! The day is so much more pleasant for both of us when she is happy and feels in charge of situations.' He described how important it was to never

mention dementia or memory decline; rather, he found it vital to create as many pleasant activities in their daily routine as possible:

Taking long walks, travelling abroad, going to concerts and attending the opera used to be our main pleasures. But Elin's diminishing ability to walk and insecurity among people's gatherings have affected our activities. Instead of walking, I now take Elin for a car ride occasionally; she likes that, and our music attendances are tangibly fewer. (Einar, visit 02)

In one of the follow-up visits at the Memory Clinic, Einar and Elin had been offered home help from the municipality, but he had declined. As Einar explained, he feared that having a stranger in their home, helping her with dressing and bathing, and doing household chores that Elin had always been in charge of, would upset her:

It is better that I do it, with help from her ... or, you see, she thinks she is doing house chores, but actually I do them when she is done. I am aware that my house-keeping skills are not admirable, but we manage well. (Einar, visit 03)

In these ways, Einar said he kept Elin active and preserved her role in their daily routines.

Over time, Einar and Elin had become more and more isolated in their home. Accordingly, his effort to minimise the impact of stimuli on his wife had taken a toll on his own social activity. He was no longer able to leave her alone at home because of her insecurity, and it was difficult to take her along to grocery stores. He only left her alone for a maximum of 30 minutes to get their necessities from the nearest store. Additionally, he had cancelled his weekly meetings with his old colleagues, and his outdoor activities were a part of history.

Generating a safe space and avoiding discomfort

Between Einar and Elin, dementia was not discussed openly because uncomfortable questions or comments evoked her anger or bad feelings and humiliation, which Einar wanted to protect her from. By avoiding situations that might have exposed Elin's declining cognitive ability, Einar was trying to prevent her from emotional disturbances. Moreira (2010) called this 'detaching' or re-directing focus to be able to stay in the present. Instead of a dominant view of forgetting, with a constant reminder of the cognitive decline, active forgetting (avoidance) can allow one to go on. This was evident in Einar's active method of letting his wife hold on to the feeling that she was in control. She remained a housewife as before and felt that she directed the household chores, although it was Einar who did all the work. Out of respect for her, it was important to him that she remained in charge. This involved rejecting formal support and service to limit any disturbance. Instead of going to big concerts and travelling far away, he narrowed the options down to short car trips and listening to music in their living room. By avoiding large gatherings and demanding conversations, he was able to prevent situations that may have been unpleasant for his wife or threatened her sense of self as a capable person.

Although Einar had rejected all formal support, he said he did this to protect Elin from having to confront the realities of living with dementia and her inability to handle daily living activities. The invitation to take part in this study seemed to give him an opportunity to express his experience and explore his own feelings regarding their reality. With use of e-mail conversations and listening to Einar whispering on a phone in the bedroom, a safe space was created for building up Einar's trust and comfort. Eventually, when Einar thought his wife was ready and was no longer afraid of disturbing her emotions, he invited the researcher to their home. In the end he felt that the visits had had a good effect on his wife. It gave her an opportunity to talk about all the good things she had accomplished through life, made her shine and lifted her dignity even more than before.

Case study 2: Birgir and Barbara

Barbara (72) was the wife of Birgir (76). They had been very close through their 35 years of companionship, as they lived an intertwined life because of their small company, which they both worked for. Just a few years before the initiation of the data collection, they had sold their company. Barbara said they were ready for a quieter time and had planned to enjoy their summerhouse and garden more. When we met, Birgir had just six months earlier received confirmation of his diagnosis of Alzheimer's disease. Barbara provided the following insight into their story:

We both worked long hours at our company. Birgir used to be so energetic in every way, and handy in mending things here at home. We never needed to hire any craftsmen for maintenance. He had a strong voice and was constantly ready for an argument. He used to be a bit of a harsh man, maybe even angry or at least did not sit quiet. But more and more, Birgir went into his shell, explaining himself to be lazy, and did not bother to do the things that needed to be done at the house. (Barbara, interview 01)

As Barbara explained:

I thought this was just normal, he was just tired because he had been working so much through the years ... I am not the type to sit around and wait for things to get done. When Birgir said he was lazy, I just stood up and took care of things myself. I would paint the window, drill in the wall, or whatever needed to be done. I did not notice the change in my husband, but our daughter encouraged me to take him to a doctor. (Barbara, interview 01)

In a visit to their primary health-care centre, the general practitioner (GP) referred them to the Memory Clinic for further evaluation. After an elaborate examination by a geriatrician, dementia was confirmed. Barbara said, 'For me, this process of diagnosis was difficult. I felt that I was being left hanging in the air, not knowing what was going on or what to do.' She went on:

The good thing was that Birgir was easy to be with; he was polite and even more cheerful than before. He did not get as angry as before. But he needed to be around

me all the time. That was onerous. He was like a child, always snuggling around me if he was not in his room piling up paper and organising something. (Barbara, interview 01)

After the verification of the diagnosis, Birgir received some medication to reinforce his memory function, along with antidepressants. 'We also got some information about the importance of nutrition and fluid intake. But that was all, and just like that, we were sent home and asked to come back after six months.' Barbara handed a business card with the telephone number of a nurse at the Memory Clinic and asked to call if anything was needed. Barbara described how annoyed she became by the kind of support offered:

Why should I call? What should I ask about? There was nothing offered, and I don't know what to ask for. Why should I call? They should be guiding us in advance, letting me know what the best thing to do is, to get through our days, but there is nothing. Nothing! There is no system taking care of us – just come back in six months... (Barbara, interview 01)

Life changed when their daughter, Bjork, announced she was having a child, their first grandchild, and moving back to the country with her husband. Barbara said her daughter's family gave them a new meaning of life and described the change they felt:

The feeling is tangible; this child is the absolute joy of our life. Birgir lightens up every time he sees the little one. The two of them have a special connection, have their own language ... When the child is around, I don't have to push Birgir up from the chair. He gets dressed quickly and comes straight down to the living room to play with the little one. Birgir seems more alive when the child is around. (Barbara, visit 03)

The young parents had been searching for day care, but with no success. Barbara gladly offered her assistance to take care of the little one while the parents were at work. At that time, Barbara and Birgir were participating in this study, and I visited them every month. The atmosphere in their home was pleasant and warm with the child on a playmat, the grandfather sitting nearby, giggling, and the grandmother bringing snacks and coffee to the table. Birgir enjoyed showing me and telling me about how he and the little one communicated:

I don't do much around here; I don't know much about small children. Barbara takes care of him, but I can play with him, and he seems to like it. I don't think I am doing any harm, sitting here and giggling with him. But Barbara does all the work. (Birgir, visit 05)

Barbara had another view of their situation. She said that she felt like she could not do this without her husband:

He plays with the child, sits with him and watches him carefully. Taking care of the grandchild is our common project; it would be more difficult for me to take care of

the child alone. Birgir does make a difference! I feel this role has brought my husband back; he has a responsibility, and I think it gives him a feeling of being important. (Barbara, visit 05)

As the months passed, there was a noticeable change in Birgir's behaviour, and the child became more of a handful. Barbara felt the days were becoming harder again. This seemed to be the rupture point of the thin line between being in or out of control. The child began moving around, and Birgir became more distant and less of a help in looking after him. Now, Barbara had them both to take care of. 'I feel like I am collapsing. I will not be able to go on like this', she said. She was angry at the total lack of formal service provided both to her husband and her grandchild:

Where is the system? What kind of welfare system do we have? There is no help for young parents in need of day care, and there is no help for persons living at home with dementia. I am stuck here with the two of them because the system is not working. I am not sure how long I can survive; I think I am going crazy... (Barbara, visit 07)

In her despair, she started calling the offices of the municipality repeatedly, shouting out for help, and trying to get day care for her grandchild and a placement in a specialised dementia day care programme for her husband:

It goes the same for both; they are on a waiting list for day care, and the only thing I can do is make a phone call, again and again, in a weak hope that my shouting will get them higher on the list. I love them both, my husband and my grandchild, but this is too much for me. I cannot go on like this! As much as I love my husband, I cannot go on like this! (Barbara, visit 07)

Over time Barbara and Birgir have altered their arrangements to meet their situation, adjusting and readjusting as Birgir's condition changes. But now, the failure of the system to respond to her requests for help leaves Barbara feeling overwhelmed and abandoned.

Fluctuating between being in and out of control of daily life situations

Their journey with dementia had been an ever-changing up- and downhill road, like a roller-coaster, forcing Barbara to be constantly on the lookout for new ways of making their daily life enjoyable. She said the diagnosis of dementia confirmed to her that she was trapped in a demanding role of carer, which she did not ask for and that was her biggest shock. Instead of companionship in their retirement, Birgir had to be taken care of like a child, which Barbara thought was diminishing. In studies of a caring relationship between couples living at home with Alzheimer's disease, it has been pointed out that conceiving a spouse as a child can enable the processes of continued care (Seaman, 2020). By building on the already-existing relational ties, Seaman (2020) shows how deep connections allow for an ongoing recognition of a spouse's love, who is no longer a spouse-like relation, to uphold personhood for the one living with dementia.

Such approach had not been helpful for Barbara in the beginning. But taking care of their grandchild together united them again and created a meaningful role for Birgir; as Barbara said, it 'brought him back to life'. Suddenly he got dressed again in the mornings without being prompted to do so and actively took part in the babysitting. Good care has been pointed out to be about sustaining the person, but that involves a continuous process of trying out different care, and in this ongoing process of care, tensions and conflicts are a noticeable part (Thygesen and Moser, 2010). The tension was visible in Barbara's everyday reality, the joy of seeing Birgir active and helpful with their grandchild but at the same time the sorrow of experiencing him as a child himself, with deteriorating capacity in daily living, and feeling frustrated by the lack of formal support.

Barbara was longing for proactive professional support that could provide guidance in her attempts to get through their days at home and lighten her burden. But such support was not offered by the Memory Clinic. Rather the focus there has been on evaluating the progress of dementia symptoms on a prescheduled basis with additional open support-line for families on their demand (Gudnadottir *et al.*, 2021). Families were offered to call if they had any problems, but that approach did not meet Barbara's needs. She was insecure about when and what to ask for at the support-line, what was significant enough to bring up with the professionals. On the other hand, if the clinical nurse specialist had rung her up and asked some outline questions and offered support in advance, Barbara might have realised her needs and wishes.

Case study 3: Gunnar and Greta

Gunnar (72) and Greta (71) had been married for 50 years. Life had given them four children and eight grandchildren, and they described their family as helpful, beautiful and unified. Nevertheless, they had had their share of trauma in life. Their son had been severely and chronically ill for a long time, leading the couple to become more aware of how they could support each other and their family:

You can say that we have been practising through the years – to talk to each other in sincerity and be aware of the small but important things in life ... Through the emotional difficulties surrounding our son's illness, it has been most helpful for us to face every change and challenge in our life instead of hiding under a blanket or pretending that nothing is wrong. (Gunnar, interview 01)

Gunnar and Greta described how they had pushed themselves to watch out for new possibilities and to seek assistance both from their children and formal support.

Their journey with dementia began when Gunnar had discovered changes in his own memory three years prior. Without his wife's knowledge, he had made an appointment with his GP regarding memory decline. It was not until they received a call for a visit to the Memory Clinic that Greta became aware of her husband's actions and concerns. After the Alzheimer's diagnosis was confirmed, Gunnar concentrated on reading everything he could about the process of dementia and the resulting changes in brain function:

I want to know as much as I can about the function of the brain and how this diagnosis will affect my life, and I don't want to hide away our situation. It is important for me to speak openly about our feelings and walk this pathway along with my wife and our family ... There is so much support available, and we can reach out for it if we care to. (Gunnar, interview 01)

Gunnar and Greta attended monthly social meetings at the Alzheimer Café, as well as educational meetings at the Alzheimer Association. They also attended biweekly sing-along sessions that their municipality offered. Gunnar loved to sing and found it very liberating. As his wife described, 'It is wonderful to take Gunnar along to the singing sessions; he enjoys it so much. His body moves naturally and unconsciously with the music and in these moments, he looks free and healthy' (Greta, interview 01).

When we met for the first time, Gunnar's memory had been rapidly declining, and his complications with speech had been increasing, despite all his attempts to slow the development of the illness. In our second interview, without her husband present, Greta described how Gunnar kept asking the same questions repeatedly and making a mess of simple things; she said that she had to bite her tongue and re-gather her patience every day:

He no longer knows how to work the remote control for the television, and he is constantly making some mess on his computer in his daily search for new knowledge ... This is extremely tiring, and I don't know where I would be without my daughters. They are my prime support and my buffer for my daily concerns. I also attend bimonthly support groups for family care-givers, and these are essential for me to be able to speak up about my difficulties and the distress I experience in my daily life. (Greta, interview 02)

Though she was tired and frustrated by their situation, it was important to Greta to do everything she could to support her husband and make their life enjoyable:

Sometimes I get frustrated towards him, especially when I am tired, and then I say something inappropriate to him, like, 'What have you done? Do you always have to have your fingers messing with the remote control?' Then I feel bad about my behaviour, because I know he can't do anything about it ... It is important for me to say that I'm sorry and apologise to him, and we talk about our feelings and frustrations regarding our situation; that is so important! (Greta, interview 02)

Greta said that their ability to express painful emotions had evolved through their deep love for each other and a long life together. However, it was also the fruit of their work dealing with various life dilemmas.

A long-term practice of reaching out for and accepting help

Living with dementia was a challenge for Gunnar and Greta, but the family had been able to build up their common understanding and approach towards Gunnar's dementia. Whether it was of inherent nature or built from their previous

experience of dealing with family difficulties, due to their son's severe chronic illness, the family had a kind of a head start in terms of seeking help at the time of Gunnar's dementia diagnosis. They already had knowledge and emotional strength to be able to talk about mental discomfort with sincerity. These important elements of Gunnar, Greta and their family is in conclusive line with the fundamentals of the VIPS framework which was designed to turn Kitwood's philosophy on person-centred care into practice. VIPS emphasises how people living with dementia and their carers must be 'Valued', treated as 'Individuals', attended to their 'Perspective' and their 'Social environment' (Brooker and Latham, 2015).

Throughout their lifecourse, Gunnar and Greta had practised trusting and valuing each other, expressing their emotions, confiding in professionals, as well as working together to build a collective understanding of their situation. These are, according to Brooker and Latham's (2015) definition of VIPS, important elements for persons living with or caring for others with dementia. Despite that ability, Greta described how she would easily get angry with her husband and have a hard time controlling herself. But, with regular attending and use of support groups along with the support of their daughters, Greta could get through these difficult moments.

Gunnar and Greta are willing and able to reach out for peer support groups, psychological treatment and social gatherings that the formal support system has to offer. Their living with dementia does influence their daily life and feelings, but because of their active communication and collective understanding between the couple, the health-care system needs to put out a minor effort in guiding them to a relevant solution.

Discussion

Our findings reflect the complex nature of living with dementia at home. All three families described above were attempting to manage the varying issues of living with dementia as best they could. Similar to Moreira's (2010) findings, the family care-givers had learned step-by-step how to address the challenges in their everyday lives by focusing on their understanding of circumstances and experimenting with constant adjustments: Einar by avoiding all mention of Elin's dementia (case 1), Barbara by engaging Birgir in activities and later by asking for more support (case 2), and Gunnar and Greta by taking advantage of the support and services available (case 3). Employing diverse approaches, these families drew on their own experiences, knowledge and strengths, and their ability or lack of ability to make use of the assistance available.

In our previous publication, drawing on interviews with health and social care professionals working with families living with dementia, we found that with suspicions of dementia symptoms, the focus of formal services was on diagnosing and following exacerbations of the condition (Gudnadottir *et al.*, 2021). That analysis also showed that there was limited emphasis on the family's care needs even though health-care professionals were aware of family care-giver burdens, which were confirmed in the case studies presented here.

In cases 1 and 2, we saw how Einar and Barbara, two very different spouses of individuals diagnosed with dementia, lacked formal support in maintaining their

own physical and mental wellbeing. Einar focused on *generating a safe space and avoiding discomfort* but doing so resulted in isolation. His approach is in line with the experience of Kleinman (2019), who also described the delicate path of accompanying a loved one through their dementia. Kleinman learned that dementia would lead the way and that his role was to be present, to act on his wife's needs for comfort. The fact that Elin, Einar's wife, got upset and emotional whenever dementia was mentioned encouraged him to avoid all contact that could trigger such feelings. This avoidance led him to become more socially isolated and physically inactive. As Einar said, 'When she is happy, the days are more pleasant.' However, through his actions, he ended up managing the entire burden of care, and his own self-care was neglected.

Barbara was *fluctuating between being in and out of control of daily life situations*, trying to manage each day by relying on pride and persistence. Studies have shown that preserving personal roles and dignity throughout the process of dementia is of utter importance (Tranvåg *et al.*, 2013; Eriksen *et al.*, 2016), just like Birgir pointed out how he felt he made a difference, having the role of sitting near the little boy and playing with him. This change had an equally positive effect on Barbara; she felt she had regained the former connection with her husband. She eagerly celebrated the fact that her husband was significant and indispensable in their collective role of babysitting.

In the third case, of Gunnar and Greta, we saw *a long-term practice of reaching out for and accepting help*. Their previous experience had taught them the importance of sincere communication and the support of family members. They described how living with dementia is complicated, but they tried to make the best out of their time together. As in line with the emphasis of the VIPS model (Brooker and Snaedal, 2016), Greta had learned it was important to read into the nuances of her husband's feelings and react to changes before they devastated them. Brooker and Latham (2015) point out the importance of being proactive but also prepared, taking steps back and forth in the search for a relevant support. This is what Greta did, she sought help in all kinds of recreational and supportive opportunities such as singalong get-togethers, outdoor walks, appointments with a psychologist and peer support group meetings. For her it was important to try them all out, to see what fitted them best.

When looking at common practices of the health-care professionals in dementia care, one might think the formal support system is built around families like Gunnar's and Greta's. In our previous article, the key informants of dementia care informed that the support system assumes families need time to find their own way in living with dementia to figure out both what kind of service they need and when they will need it (Guðnadóttir *et al.*, 2021). Thus, the formal care system seeks to provide families space to be in control of their process, protecting their independence. However, this also means that families must be on the lookout for the available service and be aware of what kind of support they should reach out for. That brings our attention to how families like Barbara's and Birgir's, or Einar's and Elin's, are fitting into such a service model.

Systematic reviews of practices among families living at home with dementia reflect great diversity in how families try to balance their life and why they do or do not seek help with dementia (Bjørkløf *et al.*, 2019; Parker *et al.*, 2020). Other

studies have shown that families' unmet needs and self-sufficiency in the situation of living with dementia are related to each family's background and collective surrounding (Zwingmann *et al.*, 2020). The collective thereby refers not only to how families work with their situations but also how professionals offer open conversations and services aimed at practical and emotional support (Ceci and Purkis, 2021). Thus, the concept of collectivity emphasises the importance of addressing complicated emotions, reading into the multiple aspects of families living with dementia, and stepping out to provide support in managing their roles as caregivers (Swallow, 2017; Swallow and Hillman, 2019). It was such proactive support that Barbara, the wife in case 2, so clearly said she was longing for. But formal care providers have revealed the constraints that lack of resources and time pose to such support (Hennelly and O'Shea, 2022). Berglund *et al.* (2019) also argue that there is a lack of research on how a holistic view of the family can be considered in providing person-centred care for people living with dementia at home. A focus on the 'collective' could be of help in acquiring relevant knowledge given the emphasis on connections and links between people, surroundings and practices (Ceci *et al.*, 2020).

It is important that services be provided in accordance with best practice, but even good service can go wrong if individuals or clients do not accept the assistance or do not know how to act towards it (Moreira, 2010). As we saw in the case of Barbara, formal service had every step laid out. The treatment had been initiated, instructions and education were offered to support the symptoms and the disease's pathway, and a follow-up appointment was booked with an additional option of earlier contact if needed. Nevertheless, Barbara still felt insecure and alone in this project. What Barbara was longing for was proactive support and someone who could guide her through it and show an interest in taking the path with her. Helping her to see and understand that 'Although everything may fit and seem to work well for a time, it may well slip again' (Thygesen and Moser, 2010). This could have built the trust she needed to go on with her life, taking care of her husband and learning to live with dementia along the way.

Conclusion

The three case studies presented here provide important insights by highlighting that families are indeed different, and that their ways of dealing with the circumstances of their daily lives emerged out of the collective of their backgrounds, surroundings and available support. Within diverse arrangements, families continuously found ways to make their daily lives work out. When they no longer did, re-arrangement was necessary. This could be a central learning point for formal service to build on in their support for families living at home with dementia in order to understand the needs of families that may not have the strength or knowledge to seek adequate support.

Implications for practice and policy

Deep appreciation and understanding of the heterogeneity of families' situations suggests that tailored support for families living with dementia will be most helpful

to them. However, understanding the specific situations of families requires that formal care providers have the time to learn from families what would best support them. For policy makers, this means formal care providers require greater proximity to people's homes, increasing opportunities for being present when troubles arise. These providers must be empowered to exercise local knowledge and discretion to engage in help that supports and extends the efforts of families. Policy should be informed by values that assert the centrality of care: the practices and flow of everyday life at home must be respected and supported. Thus, the role of policy is to create a workplace environment that enables frontline practitioners to gain proximity to families providing care, and use local knowledge and discernment in responding to the care issues of the moment.

Strengths and limitations

A longitudinal observational study allows a more in-depth understanding of slowly changing processes such as living with dementia. Case studies are not generalisable, but they give essential insight into the cases reported and add valuable information on the complexity of families' lives at home with dementia. The researcher inevitably affects the scenario when they are placed in observational settings and is in contact with the participants. However, as in this study, regular visiting over a long period allows for trust to be created between the researcher and the participants.

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