Improving care at home for people living with dementia and family support

Margrét Guðnadóttir

Thesis for the degree of Philosophiae Doctor

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School of Health Sciences

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Ágrip

Samfara breyttri aldurssamsetningu þjóða, þar sem fjölgun er mest meðal eldri aldurshópa, eykst fjöldi þeirra einstaklinga sem greinast með heilabilun. Fjölskyldur um allan heim þurfa því að takast á við áskoranir sem tengjast umönnun einstaklinga með heilabilun heima fyrir. Í þessu umönnunarhlutverki upplifa fjölskyldur jafnan flækjur og hjálparleysi, en bæði einstaklingarnir sem greindir hafa verið með heilabilun og þeirra nánustu fjölskyldumeðlimir geta fundið fyrir einangrun og upplifað sig ekki lengur sem hluta af því samfélagi sem þeir búa í. Rannsóknir sýna að fjölskyldur telja heilbrigðisyfirvöld bregðast skyldum sínum hvað varðar umönnun fólks með heilabilun og stuðning við fjölskyldur, en aðstandendur upplifa sig oft gleymda eða yfirgefna í því samhengi. Þessar niðurstöður hafa aukið áhuga vísindamanna og stjórnvalda á að skilja hvernig bæta megi stuðning við þessar fjölskyldur.

Í þessari doktorsritgerð er leitast við að varpa nýju ljósi á það hvernig styðja megi við fjölskyldur einstaklinga með heilabilun í þeirra daglega amstri og stuðla að því að gera líf þeirra og aðstæður eins góðar og völ er á. Fjölskyldum var fylgt eftir í þeirra umhverfi þar sem daglegt líf var kannað og hvernig tekist var á við atburði. Doktorsverkefnið var mótað innan hugmyndafræði um tengsl og samhengi einstaklinga og aðstæðna þeirra. Sú hugmyndafræði snýr að skilningi á því að umönnun á sér stað og kristallast í samhengi við þá einstaklinga sem um ræðir hverju sinni og tengsl þeirra á milli (e. care collective). Rannsóknin byggir á þremur vísindagreinum (greinar I-III) sem leggja upp með að auka þekkingu á þeim áskorunum sem fjölskyldur mæta í heimilislífi sínu þegar fjölskyldumeðlimur hefur greinst með heilabilunarsjúkdóm. Þá fjalla greinarnar einnig um það hvernig fjölskyldur takast á við mismunandi áskoranir því tengdu og finna sér farveg í sínu daglega lífi. Vonast er til þess að niðurstöðurnar geti nýst við þróun og betrumbætur á þeim formlega stuðningi sem hið opinbera stuðningskerfi veitir einstaklingum með heilabilun og þeim aðstandendum sem sinna umönnun heima fyrir.

Doktorsverkefni þetta byggir á tveimur rannsóknum þar sem notast var við eigindlegar aðferðir; viðtalsrannsókn við lykilstarfsmenn (grein I) og langtímavettvangsrannsókn með tilfellasniði (grein II og III). Í rannsókn I var rætt við 20 lykilstarfsmenn í margvíslegri formlegri þjónustu vegna heilabilunar. Auk viðtala var unnið með vettvangsathuganir á vinnustöðum þeirra og rýni á opinberum gögnum um þjónustu og umönnun vegna heilabilunar. Gagnasöfnun í rannsókn I fór fram á árunum 2016 og 2017. Við gagnagreiningu var stuðst við þematengda rammaaðferð (e. framework method). Rannsókn II, vettvangsrannsókn með tilfellasniði, var gerð á átta fjölskyldum þar sem einstaklingur hafði greinst með heilabilun. Gagnasöfnun vettvangsrannsóknarinnar stóð yfir tveggja ára tímabil, frá 2017 til 2019. Allir þátttakendur voru tengdir minnismóttöku

Landspítala og voru á biðlista fyrir sérhæfða dagþjálfun vegna heilabilunar. Hverri fjölskyldu var fylgt eftir í gegnum tímabil þeirra á biðlista, þar til boð um pláss í sérhæfðri dagþjálfun bauðst og í allt að sex mánuði eftir það.

Niðurstöður viðtalsrannsóknar við lykilstarfsmenn í formlegri þjónustu sýndu að aðstæður fjölskyldna sem sinna umönnun vegna heilabilunar á Íslandi eru að mörgu leyti sambærilegar við aðstæður fjölskyldna í nágrannalöndum. Áherslur í formlegri þjónustu eru á mat og nákvæma greiningu á undirliggjandi orsökum heilabilunar en minni áhersla er lögð á áhrif aðstæðnanna á fjölskyldumeðlimi þess sem er með heilabilun. Þeir lykilstarfsmenn sem rætt var við sögðust meðvitaðir um álagið sem oft lægi á fjölskyldum og að þær þyrftu meiri stuðning. En þeir töldu jafnframt að slíkur stuðningur væri ekki hluti af þeirra megináherslu í starfi. Lítil tengsl voru á rannsóknartímanum á milli minnismóttöku, heilsugæslu og heimaþjónustu. Almennt höfðu heilsugæsla og heimaþjónusta ekki lagt áherslu á þróun vinnulags eða sérfræðinálgunar í sinni þjónustu við fólk með heilabilun og aðstandendur þeirra. Þó höfðu sérhæfðar dagþjálfanir verið sérstaklega þróaðar með tilliti til þjónustu vegna heilabilunar og voru nátengdar minnismóttöku Landspítala. Vankantar þeirrar þjónustu voru langir biðlistar eftir því að komast að. Fjölskyldur höfðu því yfirleitt ekki aðgang að þeim stuðningi fyrr en aðstæður heima fyrir voru orðnar mjög erfiðar vegna þróunar heilabilunarsjúkdómsins. Til að bregðast við því ástandi hafa Alzheimersamtökin á Íslandi, sjálfstæð stofnun utan opinberrar þjónustu, boðið upp á stuðning sem skortir hjá hinu opinbera stuðningskerfi. Sá stuðningur felst m.a. í einstaklingsráðgjöf og stuðningshópum fyrir aðstandendur, auk þess sem samtökin reka sérhæfðar dagþjálfanir.

Tilfellin sem fjallað var um í grein II vörpuðu ljósi á ýmsa þá vankanta sem fjölskyldur fundu fyrir í þjónustu. Þau gáfu til kynna þær fjölbreyttu aðferðir fjölskyldna í að finna sér sinn eigin farveg til að komast í gegnum dagana heima með heilabiluninni, á meðan beðið var eftir því að komast að hjá formlegum stuðningi sérhæfðrar dagþjálfunar. Allar fjölskyldurnar í rannsókninni áttu það sameiginlegt að finna þörf fyrir aukinn stuðning formlega kerfisins og að fagfólk sýndi aðstæðum þeirra áhuga.

Samkvæmt viðmælendum rannsóknar á minnismóttöku Landspítala liggur áhersla formlegs stuðningskerfis á Íslandi í að veita fjölskyldum sem annast einstaklinga með heilabilun svigrúm til að vera sjálfar við stjórnvölinn í aðstæðum sínum og auka þannig sjálfstæði þeirra og sjálfræði. Slíkt aukið andrými felur þó í sér að fjölskyldur verða sjálfar að vera meðvitaðar um hvers konar stuðningi er þörf á, vera sjálfar vakandi fyrir því hvað er í boði og sækja sér þá þjónustu sem möguleg er. Það er ekki öllum fjölskyldum gefið að hafa slíka yfirsýn. Í grein III var fjallað um þann tíma þegar boð um dagþjálfun barst og þá hvort eða hvernig slíkt boð studdi við fjölskyldulíf. Niðurstöður bentu áfram til mikils fjölbreytileika í aðstæðum og reynslu fjölskyldna. Sú vitneskja rennir stoðum undir þá ályktun að ólíkar þarfir kalli á fjölbreytileika í veittri þjónustu. Ekki falla allar fjölskyldur inn í þann ramma sem opinber þjónusta hefur byggt þjónustuframboð sitt á. Sumir einstaklingar öðluðust aukinn lífsþrótt og lífsfyllingu með þeim stuðningi sem veittur var

í sérhæfðri dagþjálfun á meðan aðrir voru minntir á sársaukafullan hátt á breyttar aðstæður sem höfðu áhrif á sjálfsmyndina. Sú reynsla gat valdið vonbrigðatilfinningu og jafnvel það mikilli þjáningu að fjölskyldan sagði upp plássi sínu í dagþjálfuninni, þó að það væri eini formlegi stuðningurinn sem í boði væri. Tilfinningar eins og ótti og reiði kraumuðu innra með fólki, þær blönduðust stolti og snertu við grunngildum í hugum fjölskyldumeðlima. Slíkt gat líka hindrað þau í að þiggja boð um sérhæfða dagþjálfun.

Heilbrigðisyfirvöld hafa lagt áherslu á sérhæfða dagþjálfun sem lykilinn í þjónustufarvegi vegna heilabilunar. En til þess að mæta megi flóknum og ólíkum þörfum einstaklinga sem greindir hafa verið með heilabilun og fjölskyldna þeirra, verður hið opinbera stuðningskerfi að efla slíka nálgun innan heilsugæslu og heimaþjónustu. Það er mikilvægt að skapa tíma og rými fyrir fagfólk að öðlast skilning á, lesa í og læra af mismunandi aðferðum fjölskyldna í daglegum áskorunum sínum með heilabilun. Þjónusta við fjölskyldur og einstaklinga sem lifa með heilabilun verður að vera hönnuð með það fyrir augum að svigrúm sé til að þróa og laga þjónustuna að þörfum hverrar fjölskyldu. Það að hlusta og læra af fjölskyldum, hvernig þær takast á við sitt daglega líf og þær áskoranir sem heilabilun felur í sér, gefur fagfólki einmitt tækifæri til að þróa þjónustu sína svo að hún geti betur mætt ólíkum og breytilegum þörfum hverrar fjölskyldu.

Lykilorð:

Umönnun vegna heilabilunar, fjölskylduumönnun, umönnun í heimahúsi, hugmyndafræði tengsla og samhengis, sérhæfð dagþjálfun vegna heilabilunar.

Abstract

As the global population ages, the prevalence of dementia is on the rise, making it a reality for many families worldwide to care for a relative living with dementia at home. It is generally acknowledged globally that providing care for a person living with dementia at home comes with various challenges. While trying to address these challenges, families are often confronted with difficulties and helplessness related to their caregiving. People diagnosed with dementia and their family caregivers may experience isolation and a feeling of no longer belonging to their social circles. Studies have shown that families often feel forgotten and abandoned by the healthcare authorities in their caregiving responsibilities. This has increased researchers' and policymakers' interest in how formal services can better support these families.

By exploring how families manage their daily lives with dementia, this PhD thesis aims to enhance our knowledge of how they can be assisted in making life as good as possible. This study is conducted within a relational understanding of life and the shared context surrounding a person identified as the care collective of people and their connections. This research is based on three scientific papers (Articles I-III) that provide knowledge about the challenges faced by families where a member has been diagnosed with dementia and the arrangements they make. The idea for the future is to use these findings to develop community-based services for individuals living with dementia at home and their family caregivers.

This doctoral project comprised two studies using qualitative designs: an interview study with key informants (Article I) and a longitudinal ethnographic case study (Articles II and III). Study I involved interviews with 20 professionals who were key informants, field observations of their work settings and reviews of public documents on dementia caregiving. In Study I, data collection was made in the years 2016 and 2017 and analysed using the framework method. Study II, an ethnographic case study, was conducted with eight families, each with a member who had been diagnosed with dementia over a two-year period. All participants were on a waiting list for a placement in a specialised day programme for dementia care. Each family was followed through the waiting period, while receiving an offer of a placement in such a programme and for up to six months afterwards. The ethnographic data were collected from 2017 to 2019.

The findings of the interview study with the key informants reflect the reality faced by family caregivers of persons living with dementia in their local community in Iceland, in many ways comparable to the situation in neighbouring countries. As the key informants described, if signs of cognitive difficulties emerged, the person would be referred to the Memory Clinic for assessment, which focused on making an accurate diagnosis of an

underlying illness, while exploring the condition's impact on family members was not emphasised. Participants recognised that families were often stressed and required more support but did not consider such support their primary responsibility. The connection between the Memory Clinic and primary and home care services was limited, and community services, in general, had not emphasised the development of expertise and work methods in relation to dementia care. The specialised day programmes were exceptions, with strong ties to the Memory Clinic. The drawback was the late delivery of such services, so families had limited access to support until their situations reached a severe level. Alzheimer Iceland, a nongovernmental organisation, provided individual consultations and organised support groups for relatives and specialised day programmes.

The case studies presented in Article II reflected some of the shortcomings of this situation. They depicted families' diverse experiences in finding ways to live with dementia at home while on a waiting list for formal support. They made multifaceted arrangements to make their daily lives work, but all longed for more guidance and for professionals to be interested in their situations.

According to professionals at the Memory Clinic, the current formal care system in Iceland seeks to provide families with space to be in control of their own process of living with dementia and protect their independence. However, this space also means that families must be on the lookout for the available services and be aware of what kind of support they should reach out for, but not all families have the capability to take on such a role. In Article III, we learned from the cases regarding how or whether an offer to attend a day programme supported families in living better at home. Again, the variety of situations and experiences brings to our attention the fact that families do not all fit into the formal service model provided. While some individuals living with dementia could be more engaged in daily life with the new energy they gained from the support at the specialised day programme, others were painfully reminded of their lost identity, which caused disappointment, distress and eventual withdrawal from the programme. Fear and anger rooted in the family members' pride could also prevent them from accepting a placement.

Health authorities have stressed the importance of creating a service trajectory for dementia that prioritises access to specialised day programmes. However, to meet the complex needs of individuals living with dementia and their family caregivers, the formal service providers must enhance their approach to primary care and home care. Time and space should be provided for professionals to understand families' different practices so that the former can offer family-centred support to the latter. Services for families of persons living with dementia must be designed to have the capacity to improvise and be adaptable. Learning from families about how they find their way in their daily lives with the challenges of cognitive changes enables formal service providers to better meet each family's varied and specific needs.

Keywords:

dementia care, family caregiving, community care, relational understanding, dementia day programme

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I am very grateful to the members of my doctoral committee for fulfilling the obligations that come with it and carrying out their responsibilities with dignity. Christine Ceci, whose work this research relies heavily on. Her wealth of knowledge and experience in this field was invaluable in this project. Marit Kirkevold brought both her wisdom and connections to this project. She introduced me to the Norwegian specialists at Aldring og Helse, which opened new dimensions in my mind regarding the development of formal care for people living with dementia in home settings. And how fortunate I was to have Jón Snædal on board. With his genuine interest in improving the lives of people living with dementia and his special talent for making everyone feel valued in conversations. Jón is our greatest expert in building up services regarding dementia in Iceland and proved to be very important in connecting me with all standpoints of that sector.

I would like to bring my deepest gratitude to the participants in the study themselves, whom I cannot name individually due to the nature of the study. These are people who were diagnosed with dementia, their spouses, daughters and sons, and other close relatives. They showed me great trust by allowing me into their lives and homes and sharing with me their reality: challenges, hopes, expectations, disappointments, and concerns. I am also deeply thankful to the healthcare professionals and other experts I spoke to in relation to data collection and the research work itself.

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I extend my gratitude to all those who supported the project financially and provided me with facilities. Their interest and positivity towards the research were extremely motivating and gave me hope that it is possible to do more and better for families dealing with dementia. Here, I would like to mention the Icelandic Gerontological Research Center (RHLÖ), the Icelandic Nurses' Association, the Research Fund of Ingibjörg R. Magnúsdóttir, the Memorial Fund of Helga Jónsdóttir and Sigurliði Kristjánsson, the Memorial Fund of Kristín Thoroddsen, Landsbankinn, and the Icelandic Gerontological Society.

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List of Abbreviations

EVIDEM-ED	Evidence and Value: Impact on DEcision-Making—EDucational intervention
GP	General Practicioner
OECD	The Organisation for Economic Cooperation and Development
RHLÖ	Rannsóknarstofa Háskóla Íslands og Landspítala í öldrunarfræðum
	(e. Icelandic Gerontological Research Center)
UK	United Kingdom
VIPS	Values people, Individual needs, the Perspective of a service user, the Social environment
WHO	World Health Organisation

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List of Original Papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I, II, and III):

I. Gudnadottir, M., Ceci, C., Kirkevold, M. and Bjornsdottir, K. (2021). Community based dementia care re-defined: Lessons from Iceland. *Health & Social Care in the Community, 29*(4), 1091-1099. https://doi.org/10.1111/hsc.13143

II. Guðnadóttir, M., Ceci, C., Kirkevold, M., Snædal, J., & Björnsdóttir, K. (2023). What is helpful in everyday living with dementia at home? Learning from families' diverse scenarios. *Ageing & Society*, 1-21. https://doi.org/10.1017/S0144686X23000636

III. Guðnadóttir, M., Ceci, C., Kirkevold, M., Snædal, J., & Björnsdóttir, K. (2024). When a space opens up: Families' experiences of specialised dementia day programme placements. (Manuscript in review)

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Declaration of Contribution

The doctoral candidate, Margrét Guðnadóttir (MG), wrote this doctoral thesis under the guidance of Kristín Björnsdóttir, her supervisor, and other members of the doctoral committee: Christine Ceci, Marit Kirkevold and Jón Snædal. The three-year scholar grant from RHLÖ was applied for by Kristín Björnsdóttir. Other grants were applied for by MG with guidance from Kristín Björnsdóttir.

Paper I: All authors contributed to the study design (Margrét Guðnadóttir, Kristín Björnsdóttir, Christine Ceci and Marit Kirkevold). Kristín Björnsdóttir started the data collection in 2016. In 2017, MG took over the data collection and finished conducting the interviews and data analysis in close collaboration with Kristín Björnsdóttir. All authors critically revised the manuscript.

Paper II: All authors contributed to the study design (Margrét Guðnadóttir, Kristín Björnsdóttir, Christine Ceci, Marit Kirkevold, and Jón Snædal). MG and Kristín Björnsdóttir collaborated on the data analysis and drafting of the manuscript. All authors critically revised the manuscript.

Paper III: All authors contributed to the study design (Margrét Guðnadóttir, Kristín Björnsdóttir, Christine Ceci, Marit Kirkevold, and Jón Snædal). MG and Kristín Björnsdóttir collaborated on the data analysis and drafting of the manuscript. All authors critically revised the manuscript.

1 Introduction

In this dissertation, I aim to enhance our knowledge and understanding of the challenges in the daily lives of persons diagnosed with dementia and their families living at home. In this study, I explored how families find their way to live with dementia as well as possible. Additionally, I focused on how the formal health- and social care system met these families' needs. Much of the research on families living with dementia has focused on the burden they experience. However, I followed authors who have suggested a turn to exploring daily life at home and how these families can be assisted in making life as good as it can be (Ceci & Purkis, 2014; Lily et al., 2012). Ceci and Purkis (2022) have recommended that rather than focusing on each individual – the person diagnosed with dementia, the family caregiver or the healthcare worker – researchers could study how care is delivered in the contexts in which it occurs by exploring the participation of different actors in a web of relations.

Learning from families' everyday living can help us, healthcare providers, to understand where and how we can strengthen our formal care system and support families living with dementia at home. In my experience as a clinical nurse specialist in home care, I have noticed some limitations in formal services in the context of dementia care at home. Repeatedly, I have observed that our healthcare system does not fully respond to the needs of families living with dementia. As a daughter reflected publicly:

> When my father was diagnosed with incurable prostate cancer, it was a shock for us, but it also brought out heartwarming feelings about how well the system worked when he received such a diagnosis. Suddenly, a team of specialists surrounded us with support, treatment and follow-up. We were told that his disease was incurable, but still, we felt this warm understanding and support from the healthcare system and society. Then, four years ago, my father was diagnosed with Lewy Body, a dementia disease, which was also incurable, like his prostate cancer. However, the dementia diagnosis did not trigger the support of any team of healthcare specialists, and we had no follow-up in the healthcare system. The resources are few and restrictive, and we continuously lack understanding and knowledge from the formal care system (Alzheimer Iceland, 2021).

The reality of this daughter and many other family caregivers I have met in my work and studies has been the driving force for my PhD journey, highlighting the importance of creating more helpful support for families living with dementia.

By studying how families make arrangements at home, the resources they activate and the various types of formal assistance they access to make their everyday lives as good as possible, I tried to provide insights into their daily lives. My research involved observing how people living with dementia and their family caregivers understood and responded to the difficulties that emerged in their daily lives over an extensive period. I hope that this study can contribute to the development of home care and outpatient services for persons living with dementia and their families. It is tailored to the Icelandic situation but will undoubtedly be relevant to other nations confronting similar challenges.

2 Background

2.1 Living with dementia

Dementia is a general term that describes various cognitive changes affecting memory and thinking skills. With demographic ageing, living with dementia at home is an increasingly common reality worldwide (Nichols et al., 2019; Prince et al., 2015). Memory loss is a complex issue that calls for a shared responsibility between the person experiencing cognitive changes and those around the individual, including one's family, friends, community, living environment and social connections (Moreira, 2010). Although one person receives the dementia diagnosis, its impact and consequences are felt by both the family and the community (Taylor, 2008). The role of families in providing care to individuals with cognitive decline is often significant, drawing on their unique strengths, experiences and relationships to provide support (Schulz et al., 2020).

Studies have shown that individuals living with dementia often experience a sense of isolation and a lack of stimulation (Gjöra et al., 2021; Prince et al., 2013; Stall et al., 2019). They may feel like their world is shrinking, with walls closing in on them; as a result, they often need help from their family caregivers to stay engaged in and connected to the world around them (Biglieri & Dean, 2021; Førsund et al., 2018; van Wijngaarden et al., 2019). Living in a familiar and caring environment at home can increase their feelings of security and prolong the possibility of living well at home (Grobosch et al., 2023). Therefore, creating an environment that supports individual needs and promotes social interaction, physical activity and mental stimulation is essential. By doing so, we can help people living with dementia enhance their abilities to maintain a good life (Pols, 2023).

2.2 Influence of family caregiving

Most people living with dementia are cared for by family members or other unpaid caregivers without any additional support. According to the World Health Organization (WHO, 2022), 65–75% of individuals living with dementia are cared for at home by family members, including spouses and adult children. Caring for a family member diagnosed with dementia at home can lead to health-related and financial difficulties (Eurostat, 2019; OECD, 2018; WHO, 2015). Studies have found that these family caregivers may experience frustration and exhaustion from their responsibilities around the clock (Dempsey et al., 2018; Safavi et al., 2018). These challenges are particularly pronounced when the individual living with dementia exhibits significant behavioural and

psychological symptoms (Lethin et al., 2018). It is essential to acknowledge that in such challenges, many families feel forgotten and alone (Lilly et al., 2012).

Numerous studies conducted in various countries have shed light on how family caregivers deal with caregiving's emotional, logistic and practical demands. While some caregivers feel that they are managing their responsibilities well, others report feeling overwhelmed and disempowered and experiencing negative emotions such as anger, sadness and grief (Kraijo et al., 2012; McCabe et al., 2016; Pozzebon et al., 2016; Tatangelo et al., 2018). For this reason, family caregivers need multiple modes of support that address their individual needs. However, the authors who have studied the situation of families living with dementia have noted that the available formal support does not reflect their diverse needs and may not be helpful (Ceci et al., 2018; Elmståhl et al., 2018; Zwingmann et al., 2020), particularly when offered late in the progression of dementia (Barbosa et al., 2011). Many relatives also struggle with guilt and self-blame when taking breaks (de la Cuesta-Benjumea, 2010) or passing on caregiving responsibilities to nursing homes (Graneheim et al., 2014). These findings imply that further research is needed to determine how families can be supported in caring for the person living with dementia at home while managing daily life. Healthcare professionals have been urged to acknowledge the intricate realities of families living with dementia and provide assistance according to their specific needs and circumstances (Ceci & Purkis, 2021).

2.3 Care collective and arrangements made by families

The thoughts and observations presented here are based on understanding people's interdependence in complex relations (Mol, 2006; Mol et al., 2010; Moreira, 2010; Moser, 2011). This approach recognises the importance of relational ordering or collectivisation practices, which refer to how people living with dementia depend on their support systems. It highlights the significance of building and maintaining relationships for a good quality of life instead of solely focusing on cognitive decline and therapeutic interventions (Moreira, 2010; Moser, 2011) because dementia's impact extends beyond the individual and affects families, communities and healthcare workers (Taylor, 2008). Researchers have tended to focus only on the caregiver-care-recipient dyad (Ceci et al., 2020). Thus, broadening the research gaze was necessary to understand the relations among people and things and institutional practices to discover what makes life easier or more difficult.

Studies on families living at home with dementia have shown how they often try to organise their daily lives in the best way possible (Ceci et al., 2020; Ceci et al., 2018), and researchers have reflected on how families make new arrangements to continue daily activities. Arthur Kleinman (2019) wrote in "The Soul of Care" about caring for his wife, who was diagnosed with dementia. He described their everyday life as a constantly changing reality that demanded flexibility and trying different care practices to find what

worked. Kleinman emphasised that family caregivers must adapt to the changing needs of the one living with dementia. Ceci et al. (2018) coined the term "care collective" to describe arrangements that rely on relationships between people and things. These arrangements involve the participation of family and friends, as well as formal healthcare and social care systems.

Relational interactions are vital for individuals living with dementia to maintain a meaningful social connection with the world (Tranvåg et al., 2015). Such interactions create a sense of connectedness, recognition and dignity, thus strengthening an individual's self (Clark et al., 2020). Relationships involve a complex exchange whereby individuals affect their surroundings while being influenced by those with whom they interact (Brown Wilson, 2007). However, it is easier to maintain an active and meaningful relationship in one-on-one interactions than in larger gatherings (Fakoya et al., 2021). Inclusive and acknowledging relations have been found to strengthen the identity, sense of belonging and dignity of people living with dementia (Tranvåg et al., 2022). Such interactions confirm an individual's value as a human being and contribute to cognitive stimulation and public value. Losing such interpersonal contact can negatively impact an individual's dignity or sense of self-worth, so it is essential to promote meaningful interactions with individuals living with dementia (Hennelly et al., 2021; Tranvåg et al., 2015).

2.4 Dignity

The concept of dignity in the context of dementia refers to acknowledging and respecting the personhood of those affected by the condition. This means recognising their unique characteristics and needs and ensuring that their care is tailored to support their quality of life and maintain their sense of self (Gastmans, 2012).

Dignity is a multifaceted concept that encompasses different aspects of a person's feelings and experiences as a human being (Clancy et al., 2021; Lundberg, 2018). It refers to a sense of respect and recognition, which is crucial for an individual's well-being. Autonomy and independence are highly valued in societies, whereas frailty and dependence on care are often perceived as weaknesses that can quickly diminish a person's dignity (Pols et al., 2018). Therefore, cognitive decline can adversely affect an individual's self-respect and sense of dignity (Tranvåg et al., 2022; van der Geugten & Goossensen, 2020). Recent studies have shown that for people diagnosed with dementia, their threatened dignity can lead to their withdrawal from social interactions, particularly with larger groups of people (e.g., Ren et al., 2023). It is essential to note that individuals' dignity plays a vital role in interacting with their families, healthcare professionals and the community. How individuals experience their dignity affects their overall well-being, including their physical and emotional health. Therefore, it is crucial to understand and acknowledge the importance of dignity in the lives of individuals experiencing cognitive decline (Pols, 2013; Pols et al., 2018; van Gennip et al., 2016).

Because dignity is a relational concept, though it may be violated within some relations, it can be preserved by keeping families in relation to their social contexts and helping them be true to themselves (Pols, 2023; Pols et al., 2018).

As individuals living with dementia progress through the stages of their illness, they require increasing levels of external care. Therefore, it is vital to implement dementia care that preserves their dignity, which in turn is essential for addressing the complex healthcare challenges that arise (Manthorpe et al., 2010; Torossian, 2021). Research has suggested that families often perceive the trajectory of life with dementia as robbing them of their dignity and thus dehumanising, which can be distressing for both the individuals living with dementia and their family caregivers (Palmer, 2013; van der Geugten & Goossensen, 2020).

2.5 Person-centred care

The idea of person-centredness has been influential in dementia care and research for the past 30 years and shares many similarities with the concepts mentioned earlier related to dignity (Kitwood, 1997). Person-centred care means customising care to individual interests, abilities, histories, personalities, and social worlds rather than focusing mainly on the disease diagnosis (Kontos, 2005; Lann-Wolcott et al., 2011; McCormack et al., 2011). Drawing on these concepts, services can be developed to improve support for people living with dementia at home (Berglund et al., 2019; Brooker, 2003; Hennelly & O'Shea, 2022) by continuously adapting activities to their everyday situations (Chung et al., 2017).

In the late 1980s and throughout the 1990s, Tom Kitwood, a British psychologist, wrote several articles advocating for a change in how people living with dementia were viewed. He rejected what he named the "neuropathic ideology" and called for a recognition of people living with dementia as individuals (Kitwood, 1997). In short, he described the neuropathic ideology of dementia as the perception of it solely as a neurological disease, requiring little attention as long as no cure is available. He claimed that this understanding led to the dehumanisation of people living with dementia, depriving them of their personhood. Since the publication of his influential book, Dementia Reconsidered – the Person Comes First (Kitwood, 1997), the emphasis on personhood and person-centred care has gained a strong foothold. As a result, various conceptualisations and care models for dementia have emerged, building on Kitwood's philosophy of person-centred care (Fazio et al., 2018; McCormack & McCance, 2021). Among these conceptualisations, the VIPS model has gained wide recognition. VIPS is an acronym for valuing persons living with dementia and their caregivers, treating them as individuals, looking at the world from their perspective and enriching their social environment (Brooker & Latham, 2015).

2.6 Formal support

The increasing prevalence of families caring for persons with cognitive decline at home has emphasised the importance of supporting the former in their role of helping the latter live longer and better at home. However, Stephan et al. (2018) pointed out that family caregivers perceive the formal service as starting too late and not acting on each family's complex needs and situations. When building up formal support, healthcare professionals need to recognise the complex lived realities of families dealing with dementia and take action to address the latter's diverse situations and support needs (Ceci & Purkis, 2021).

In response to the WHO's (2017) call for the extended residence of persons living with dementia in their homes, many countries have developed action plans to outline services in support of these individuals and their families (Arthurton et al., 2022; Hennelly & O'Shea, 2019; Icelandic Ministry of Health, 2020; Norwegian Ministry of Health and Care, 2020; OECD, 2018). The existing literature demonstrates a range of situations among individuals living with dementia, their family members and the formal services available to them. Significant similarities exist despite cultural differences and variations in welfare service structures and family relationships across countries. The RightTimePlaceCare study (Bökberg et al., 2015) and the Actifcare study (Kerpershoek et al., 2019) were conducted in eight diverse European nations. They described the services available to persons living with dementia and their families. The findings from these studies revealed that general services were underutilised across all countries, leading to the speculation that the services provided were insufficient and that individually adjusted care and support for families was lacking.

In relatively recent years, primary care has been increasingly recognised as well-suited to provide comprehensive healthcare that centres on individuals in the context of their complex lives (Fiscella & McDaniel, 2018; Khanassov & Vedel, 2016). However, primary care worldwide needs improvement for coordinating services and interdisciplinary integration to provide holistic and long-term person-centred care, despite the good intentions of healthcare authorities (Hone et al., 2018; Rao & Pilot, 2014).

Poor coordination of services for persons diagnosed with dementia has called for increased efforts to enhance the linkage across services such as Memory Clinics, day programmes for dementia care and home care, identified as dementia networks (Stephan et al., 2018). However, as observed in the RightTimePlaceCare study, along with research in other countries, such as Canada (Ceci et al., 2018; Ward-Griffin et al., 2012) and Australia (Lloyd & Stirling, 2011), the affected families' access to services is difficult, or people frequently do not view them as helpful. Therefore, it may be argued that the evidence base remains minimal, requiring further research on how families living with dementia at home can receive the best support (Røsvik et al., 2019). The leading aspect of formal support and often the first touchpoint of formal care provided to families at home is the specialised dementia day programmes.

2.7 Specialised day programmes for dementia care

Specialised day programmes for dementia care are regarded as highly beneficial for persons diagnosed with dementia and their families, offering them opportunities for socialisation and engagement in meaningful activities that promote wellbeing (Orellana et al., 2020; Rokstad et al., 2022).

Although attending such programmes has not been proven to delay institutionalisation (Rokstad et al., 2018; Vandepitte et al., 2016), studies have shown that they are beneficial in addressing the multidimensional needs and demands of persons living with dementia and their family caregivers (Maffioletti et al., 2019).

Various specialised day programmes are available in municipal settings during working hours, all focusing on providing respite for family caregivers, as well as activities (e.g., sports, crafts, and cognitively stimulating games) and proper nutrition for persons living with dementia (Strandenæs et al., 2019; Symonds-Brown & Ceci, 2022). Research has shown that these programmes can increase families' sense of security and improve the quality of their lives (Lindeza et al., 2020; Zarit et al., 2011). Such programmes may also help reduce caregivers' exposure to stressors, such as behavioural issues, wandering and emotional outbursts experienced by persons living with dementia (Laparidou et al., 2019; Reinar et al., 2018; Tamayo-Morales et al., 2021). However, the various service settings, their accessibility, activities, opening hours and the different support models offered to caregivers have made it challenging to determine their benefits to families (Orellana et al., 2020; Zarit, 2018). A study conducted in Norway found that family caregivers of people living with dementia wished for the day programmes to be adjusted to the individuals attending them. Adapting the programmes to individuals' backgrounds or functional levels could avoid making them feel insecure and uncomfortable (Tretteteig et al., 2017).

It is becoming increasingly understood that specialised day programmes for people living with dementia and their family caregivers can provide valuable support to home care and enhance family caregivers' feelings of safety and relief (Rokstad et al., 2019; Tretteteig et al., 2016). These programmes have also been shown to improve the quality of life of people diagnosed with dementia by giving them opportunities for social connection in a safe environment outside their homes (Rokstad et al., 2017; Strandenæs et al., 2018). However, some caregivers feel guilty or hesitant to accept an offer for their family member diagnosed with dementia to attend these programmes, especially if the person living with dementia shows resistance or refuses to do so. This can put extra pressure on caregivers already dealing with a heavy emotional load (Huang et al., 2017; Nogales-Gonzalez et al., 2014; Tretteteig et al., 2017). Some families even avoid formal care altogether because they believe that it threatens the independence of those living with dementia (Stephan et al., 2018).

Studies have indicated that attending day programmes, regardless of the type, can

improve emotional well-being through increased social interaction and engagement in social activities (e.g., Maffioletti et al., 2019). However, there is a need for flexible and tailored approaches in day programmes for dementia care to address the complex needs of people living with dementia at home (Finnanger-Garshol et al., 2022). For instance, day programmes with flexible opening hours during evenings and weekends can be crucial for some individuals (Tretteteig et al., 2017).

An innovative type of day programme for dementia care that has gained attention is the farm-based service, structured and organised like regular day centres but established on farms in various countries. The farm setting and resources are utilised as part of the service, providing personalised care tailored to individuals' unique needs. Such service offers more person-centred care than standard day programmes for dementia care. Promising results have been observed from such programmes established in Norway, the Netherlands, the United Kingdom and Japan (de Bruin et al., 2020; Ellingsen-Dalskau et al., 2021; Ibsen et al., 2018; Marshall, 2020; Ura et al., 2021).

According to a study conducted in Norway, the participants living with dementia described themselves as being at ease and active in their various tasks at the farm and enjoying spending all this time outdoors. They also emphasised that it was good to be able to work and feel useful. They thought they contributed to the farm, which gave meaning to their lives (Ibsen & Eriksen, 2021). This result resonates with the notion of how meaningful activities can affect the well-being of a person living with dementia.

In a meta-synthesis conducted by Førsund and her colleagues (2018), they discovered that the physical space and environment can play a crucial role in providing essential support to individuals. They conceptualised this support as a secure feeling of being at home or in place. Their study also revealed that the experience of belonging and contributing to society can be a key factor in living a good and meaningful life with dementia. The reason is that it increases an individual's feeling of security and autonomy, which is essential for maintaining a sense of well-being and quality of life. These findings highlight the importance of creating dementia-friendly environments that promote social engagement, community participation and a sense of belonging.

2.8 Icelandic setting

Iceland´s culture is part of the Nordic welfare tradition, meaning that the state is perceived as responsible for providing comprehensive services to citizens in need (Björnsdóttir, 2002). Therefore, with the increasing prevalence of dementia diagnosis in Iceland, as in other parts of the world, due to the ageing population, the need for formal services has risen. This situation has pushed Icelandic authorities to rethink how the healthcare system can provide the service and support needed in relation to dementia diagnosis, prevention, and care. At the same time, Alzheimer Iceland, a nonprofit organisation established originally by relatives of persons living with dementia, has raised and publicised the voices of family caregivers and people living with dementia. This

initiative has resulted in increased public awareness of the importance of doing more and better for families living with dementia in Iceland.

As a recent policy document reflects, the Icelandic government emphasises enhancing the structure of formal dementia care and improving the quality of life of individuals living with dementia and their family caregivers (Ministry of Health, 2020). The first Icelandic national action plan for service for people diagnosed with dementia, released in 2020, contains 48 action points divided into six categories. Similar to other nations, this plan was created based on international clinical pathways and guidelines that have been developed for persons living with dementia (Dementia Policy Team, 2016; National Institute for Health and Care Excellence, 2018; Winblad et al., 2016; WHO, 2018). A key focus is supporting families caring for individuals living with dementia at home. To achieve this aim, the document recommends earlier interventions, such as opening activity centres for newly diagnosed individuals and offering more flexible service hours in specialised day programmes for dementia care (Ministry of Health, 2020).

2.8.1 Dementia care trajectory for home-dwelling people in Iceland

When individuals begin to display symptoms of memory impairment, such as forgetfulness or confusion, their general practitioners (GPs) commonly refer them to the Memory Clinic at the National University Hospital of Iceland for a comprehensive assessment. The Memory Clinic is a specialised facility focusing on accurately diagnosing dementia and initiating appropriate treatment plans. Established in 1995, it has served as a central coordinating unit for specialised dementia healthcare services nationwide.

Individuals who receive a dementia diagnosis are referred back to primary health care except those in need of more specialised treatment and care. Those in regular follow-up at the Memory Clinic meet with the primary team, a geriatrician and a nurse who evaluates the progression of the disease, identifies any requirements for managing different symptoms, and assesses the situation of their families. The extended team of psychologist, occupational therapist and speech therapist are available if a family is experiencing severe distress. In such cases, they are referred to the hospital's psychologist for further assistance (Landspitali, 2017).

When dementia symptoms increase with fewer opportunities at home for various activities and in cases when a family's daily life shows signs of unease and exhaustion, an application is made for a specialised day programme for dementia care. When the application is received, the individual is placed on a waiting list, stored and updated in a central database and handled by the specialists at the Memory Clinic. The Memory Clinic staff and the day programme directors manage the waiting list at bi-monthly meetings by prioritising the persons experiencing the most difficulties at home. After a person enrols in a specialised day programme, the Memory Clinic hands over the responsibility of coordinating all services to the day programme directors. Nevertheless, physicians from the Memory Clinic continue to monitor treatments by making weekly visits

to each day program. Most persons attend a specialised day programme all weekdays. Figure 1, originally published in Article I (Guðnadóttir et al., 2021), shows a diagram of the service trajectory of dementia care in Iceland.

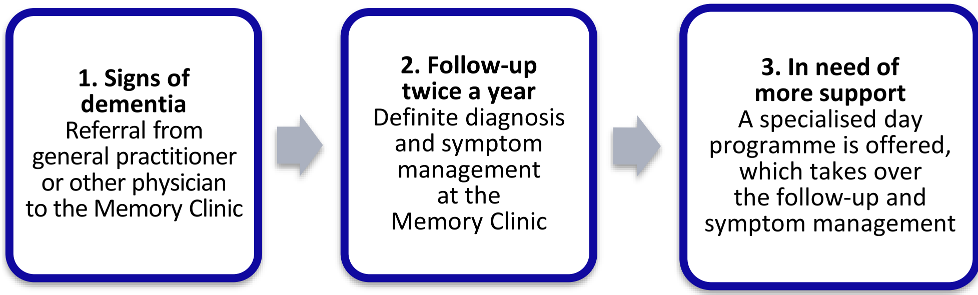

Figure 1. The common trajectory of dementia care in Iceland at the time of Study II

Home care in Iceland for people living with dementia is often added very late in the illness process or not at all. Similar to the reality of other nations, home care is usually not organised as general family support (Granbo et al., 2019). Instead, home care services are primarily provided when assistance with physical tasks or medication support is needed. This task-oriented support has been better suited to help persons without dementia than those who are living with dementia and their families. The growing awareness of the lack of formal support and the challenges faced by families in their daily living with dementia highlights the need for a thorough analysis and effective action towards providing support to families to enhance their ability to live a better life at home with dementia.

3 Aims

In this PhD dissertation, my overall objective is to gain deeper insights into the difficulties faced by individuals diagnosed with dementia who live at home, as well as their family caregivers. In the study, I also aim to identify the helpful services and support offered and to understand how families manage the challenges of everyday life with dementia. The underlying idea is to use these findings to develop community-based services for individuals living with dementia. As Figure 2 shows, the overall research was divided into Study I and Study II, which resulted in the publication of three scientific papers.

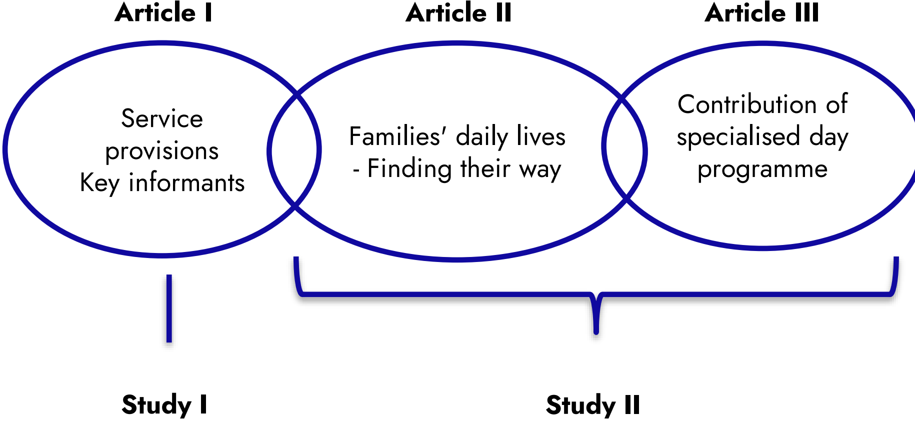

Figure 2. Division of this PhD research

Table 1 presents an overview of the division between the two studies and the research questions in each article. The articles covered one aim each:

1. Map what kind of service or assistance is provided to older people who experience cognitive decline in the metropolitan area of Iceland. This was done by examining the policy and practice context of formal dementia care, as well as exploring how professionals and formal care providers understand and manage the situations and needs of families living with dementia and the thresholds for service provisions (Article I).

2. Understand and describe how families lead their daily lives at home with dementia, figure out ways to make life as good as possible, and continue to make the most of their situations (Article II).

3. Learn how formal care services, such as specialised day programmes for dementia care, have supported families in this undertaking (Article III).

Table 1. Overview of studies and articles included in this PhD dissertation.

Study	Article title	Research question
I Key informant interviews Policy and practice context in Iceland	I Community-based dementia care redefined: Lessons from Iceland	1 What are the conditions and care needs, and what kind of assistance is provided to older people who experience cognitive decline and receive home care services in the metropolitan area of Iceland?
II Longitudinal case studies on families with a member living with dementia	II What makes a difference in living with dementia at home: Learning from families' diverse scenarios	2 How do people living with dementia, their primary caregivers and extended family members make arrangements, mobilise resources and access formal assistance to make everyday life as good as possible?
	III When a space opens up: Families' experiences of specialised dementia day programme placements	3 What meets individuals living at home with dementia and their family caregivers when offered a placement in a specialised day programme for dementia care?

In this dissertation, I connect the three articles to explore the various aspects of dementia care within the community. I focus on the formal support provided, family arrangements in daily life and the specific support offered by day programmes for dementia care. Through that lens, my dissertation sheds light on the experiences of families living at home with dementia. I examine how they manage their daily challenges, what support systems work for them and what areas require further improvement to enable families to live at home as comfortably as possible.

4 Materials and Methods

This qualitative study focuses on families living at home where one member has been diagnosed with dementia, as well as on the assistance they receive to make life as good as it can be. The methods comprised interviews with key informants, who were all professionals working in the formal geriatric service system (Study I, Article I), and longitudinal ethnographic case studies designed around eight families, focusing on their experiences of daily living at home with dementia, the available support and whether it was helpful for them (Study II, Articles II and III). The study was conducted in collaboration with the staff at the Memory Clinic at the National Hospital and the Welfare Department in the City of Reykjavik.

4.1 Settings of studies

This research was carried out in Reykjavik, the capital of Iceland, a Nordic country with a population of 383,700 people (Statistics Iceland, 2024) and a highly developed welfare service. Iceland is a relatively young nation, but its population is ageing rapidly. Currently, people over the age of 65 make up 14.5% of the population, but this is expected to increase to 20% by 2037 (Statistics Iceland, 2020). At present, there is no available information on the number of individuals diagnosed with dementia in Iceland, but a national database on dementia is under construction. However, based on information provided by WHO, an estimated 6,9% of individuals aged 65 and above are thought to live with dementia worldwide (WHO, 2021). According to the Ministry of Health (2020), the number of people living with dementia in Iceland is projected to increase by 72% from 3600 in 2019 to 6180 in 2040.

4.2 Study I – Article I: Interviews with key informants

Semi-structured interviews were conducted with 20 key informants who were healthcare professionals, both managers and practitioners, with a large part of their work as clinical. We asked them to describe their understanding of dementia care and support, their priorities in organising dementia care and what they identified as most helpful in supporting families caring for their relatives living with dementia at home.

4.2.1 Sampling and data collection

The study focused on managers and practitioners who were responsible for providing formal services to individuals diagnosed with dementia in the community. The selected participants were key informants with extensive experience in organising and delivering services to people living with dementia. Some of them also played a role in developing

policies related to dementia care. A purposeful sampling strategy and snowballing technique were used to identify and select 20 participants for the study. By doing so, we were able to gain insights from different institutions providing care to people living with dementia and their families. This approach helped to capture diverse perspectives and understandings of the services offered, resulting in a more comprehensive and varied pool of participants.

The 20 key informants (see Table 2, originally published in Article I (Guðnadóttir et al., 2021)) participated in semi-structured interviews (see the interview guide in Subsection 4.2.2), which were transcribed by a professional secretary. The participants were asked to describe the available services, their understanding of what was helpful to families and how the services might be improved. All participants provided their written informed consent.

The key informant interview data collection started in 2016 and ended in 2018. The participants took the researchers on rounds of their facility and described its main activities. After each visit, the researchers noted their observations in field notes. In addition to the interviews and field notes, they also examined written documents, such as policy statements, printed materials aimed at families, and information posted on websites for the general public.

Table 2. Participants of Study I.

Key informants	**Number**
Nurses and geriatricians at the National Hospital's Memory Clinic	6
Nurse specialists at day programmes for dementia care	4
Nurses and general practitioners at the Community Health Clinic	3
Managers in charge of nursing and social home care services	5
Managers at the Alzheimer Iceland	2
Total	**20**

4.2.2 Interview guide for key informants

The interview guide for key informants was originally published in Article I (Guðnadóttir et al., 2021).

1. Tell me about your role and experience in providing service to families living at home with dementia.

2. What do you think are the most important issues to look into for family members taking care of a person living with dementia at home?

3. Where do family members seek support, and how do you think it works for them?

4. What is most helpful in your service that supports families living at home with dementia?

5. What could be done differently in your service to provide more support to these families?

6. What do you think is of utmost importance to people living with dementia and their families?

7. Can you give me an example of a family for whom the service was doing well, in your opinion?

8. Can you give me an example of a family whose received service was not doing well enough?

9. Who would you recommend I could talk to for further insights into these matters?

4.2.3 Data analysis

To analyse the data in this study, we utilised the framework method, a systematic and adaptable approach that is well-suited for qualitative research and data analysis in health sciences (Gale et al., 2013). The data are labelled, sorted and interpreted thematically (Spencer et al., 2014). As a PhD candidate, I worked with my main supervisor (Kristín Björnsdóttir) to categorise, sort and organise the data collected from the interviews. We created themes that were based on the journeys of families through the diagnosis and support system. During the analysis process, we used both deductive and inductive approaches, which involved understanding the various ways of providing dementia care as outlined in the introduction and being receptive to new data. As themes relating to the families' journeys emerged, in partnership with my doctoral committee, we re-read the interviews for comparison before reaching a final consensus (see Table 5 for an overview of the themes in Study I).

4.3 Study II – Articles II and III: Longitudinal ethnographic case study

According to Hammersley and Atkinson (2019), traditional ethnographic methods, such as observations, interviews, and document analyses, can provide valuable insights into people's daily routines and reliance on them. Ethnography is particularly useful for identifying helpful practices due to the rich contextual data it offers.

By adopting an ethnographic case study approach, researchers can gain a more comprehensive understanding of a family's situation and its challenges in their day-to-day lives (Flyvbjerg, 2001, 2006; Stake, 2006; Ying, 2014). Ethnographic case study methods require researchers to engage in the activities of the study participants and observe them in their natural settings. This approach encourages researchers to ask questions, such as "What is going on here?" (Sorensen, 2010), and in our case, "What is shaping the experiences of home care for persons living with dementia and their families?"

An ethnographic case study is a way of telling stories or allegories using its specific methods to understand situations comprehensively. It can bring to light details that might surprise us or challenge our assumptions about people and conditions, often shaped by our culture. This approach can positively interrupt our thinking by exposing us to heterogeneity and encouraging us to learn (Savransky & Stengers, 2018; Tsing, 2015).

In terms of theory (as introduced in Chapter 2, Section 2.3), Study II is located within the traditions of care practices and relational logic (Law & Mol, 2008; Mol et al., 2010; Moser, 2010; Thygesen & Moser, 2010). We focus on studying how individuals and objects coexist in relation to each other. These relations are dynamic and reciprocal, where each entity affects and is influenced by the other. According to Law and Mol (2008), such interactions cannot be determined by a single factor or element but are shaped by multiple enactments, events and situations, which produce specific and complex practices.

4.3.1 Sampling and data collection

In Study II, we recruited eight families from a waiting list for specialised day programmes for dementia care. We followed the families as they transitioned from being on a waiting list to receiving an offer of a placement in a specialised day programme, along with the trial period of accepting or rejecting that offer. Being added to the waiting list indicated that dementia was already having a significant impact on the families' daily lives, and professionals considered them in urgent need of access to support from a day programme.

Led by the main goal of the data collection – that is, to gain insights into the daily routines of families living with dementia – we examined how they managed their daily lives and

the available resources. In that way, we could improve our understanding of providing better support to families in their caregiving roles (Ceci et al., 2018). The data collection for each family varied in duration from 13 to 24 months within the period from October 2017 to December 2019, before the outbreak of the COVID-19 pandemic. I collected all data in close collaboration with my main supervisor.

I made an arrangement with the staff at the Memory Clinic to introduce the study to families on their waiting list. The study involved eight older individuals who had been diagnosed with dementia and were living at home along with their closest caregivers, usually their spouse, child, or both. Each family was sent an introductory letter about the study. If they were willing to participate, the clinical nurse specialist in charge of the waiting list provided me with their contact information.

Once a family agreed to participate in the study, I contacted them by phone and introduced myself. I asked them for a convenient time to visit. This phone call was a crucial first step in the data collection process. The family caregivers, who always answered the phone, were happy to share their experiences and were appreciative of the fact that someone was interested in their lives with dementia. During the first visit, I met with the person diagnosed with dementia and the primary family caregiver. Both of them signed an informed consent for participation in the research, agreeing for me to be in regular contact and visits.

A significant amount of data was obtained during the meetings, both formally through interviews and informally during visits, through observations and interactions. I primarily observed family caregivers and individuals living with dementia during their daily routines and activities at home, as well as outside activities, such as grocery shopping and doctor's appointments. I wrote field notes during and after these visits and made notes on other forms of communication, such as phone calls and emails. At the beginning and the end of the data collection, I conducted semi-structured interviews with each primary family caregiver and the person living with dementia, both individually and together, which were recorded and transcribed directly.

I visited the families 1–4 times a month. The duration of each visit varied between 1 and 3 hours, depending on the family's situation. When there were significant changes in the families' circumstances, I increased the frequency and length of the visits. This arrangement relied heavily on open communication between the families and me. If there were any changes in the family's situation, they were required to inform me, and I would then increase my visits. Table 3 and Table 4 provide an overview of the participants and the data collection in Study II. These tables were originally published as one table in Article II (Guðnadóttir et al., 2023).

Table 3. Participants of Study II – part 1

Family identity	Gender of the person living with dementia	Age at the onset of data collection	Marital status	Time since diagnosis at the onset of data collection
A	Female	86	Widow	3 months
B	Male	76	Married	3 months
C	Female	76	Married	4 years
D	Male	74	Married	5 years
E	Female	78	Married	4 years
F	Female	75	Widow	2 years
G	Male	72	Married	3 years
H	Male	76	Married	18 months

Table 4. Participants of Study II – part 2

Family identity	Closest caregiver, first contact in research	Age of closest caregiver at the onset of data collection	Duration of observations (months)	Status at the end of data collection
A	Daughter	47	18	Day programme
B	Wife	72	24	Day programme
C	Husband	76	24	At home
D	Wife	74	22	At home
E	Husband	80	18	Day programme
F	Daughter	36	18	At home
G	Wife	71	20	Day programme
H	Wife	75	13	Day programme

4.3.2 Guide for interviews with family caregivers and a person diagnosed with dementia

1. How did the process of dementia start?
2. Who noticed the first symptoms?
3. What were the first symptoms?
4. How have the symptoms developed?
5. What is your typical day like?
6. What do you do during the day?
7. What helps you the most during the day?
8. How is the connection between you at home?
9. Do you use music, radio or television as support?
10. Do you receive help – if so, then from whom?
11. What helps you to rest/rejuvenate?
12. What supports or strengthens you?
13. What could help you more?
14. Are you in contact with the Memory Clinic? How often? Do you call or vice versa?
15. What does your home mean to you?
16. Do you experience complex problems or behaviours related to dementia?
17. How do you deal with complex problems, such as yelling or agitation?
18. How do you/your family see your situation?
19. What matters to you in your daily life?

4.3.3 Observational framework

During observations and fieldwork in the homes of persons living with dementia and their families, these were the primary aspects in mind:

1. Observe communication, body language and triggers.
2. How do they find their way in everyday living?
3. How is the formal support?
4. What is lacking?

4.3.4 Data analysis

The data analysis followed the ethnographic tradition, which aimed to create a holistic understanding of the situations of families living at home with persons diagnosed with dementia (Hammersley & Atkinson, 2019). The case study approach helped highlight the importance of understanding different aspects of a family's situation when living with dementia. These included their communication modes, daily activities and practical issues related to housekeeping. Studying their ways of engaging in social activities and using various other methods to maximise companionship with the person diagnosed with dementia also helped them comprehend their daily lives (Flyvbjerg, 2001, 2006; Stake, 2006; Yin, 2014).

In ethnographic studies, data analysis involves a constant comparative method that begins in the pre-fieldwork phase and continues throughout the fieldwork, observations, and conversations among researchers. (Hammersley & Atkinson, 2019). In the data analysis, we followed the practice of interpreting not only what was said or shown but also going beyond the data by connecting the collective of people´s words and body language, their environment and their situation to develop a comprehensive understanding. We also followed Hammersley and Atkinson's emphasis on being prepared to move back and forth between the ideas developed from the data. To better understand how families managed their daily lives, we relied on a variety of sources, such as our field notes, phone calls, and interviews, to describe the multiple scenarios. By analysing this data and having ongoing discussions within our research group, we were able to gain a deep understanding of the subject. This process involved carefully considering all data and emerging categories, and we reached a consensus through discussion, which is a crucial aspect of the ethnographic method (Hammersley & Atkinson, 2019).

4.4 Ethical considerations

This study received approval from the Icelandic Bioethics Committee (VSNb2015020005/03.07). The participants' identities were kept anonymous through the use of pseudonyms. Due to the small population of formal service providers, some

participants in the interview study relieved the researcher of the responsibility of maintaining complete anonymity and invisibility in the result data. All participants gave their written consent, with particular attention to those living with dementia, to ensure that they understood the study.

Ascertaining informed consent from persons living with dementia can be a complex and challenging procedure. The usual way of obtaining informed consent about the participants' understanding of the research is by having each sign a consent form. Such written consent grants the researcher the right to use the information given by the participant (Wynn & Israel, 2018). However, in cases of the participants' cognitive impairment, a one-point informed consent is not a reliable confirmation of their understanding from one meeting to another. Therefore, when including cognitively impaired older people in research, the emphasis should be on the process of consent (McKeown et al., 2010), which is an ongoing procedure of ensuring that each participant understands the purpose of the research and joins it voluntarily.

To maintain continuous consent in this project, I began and ended each visit by ensuring the participants welcomed me into their homes, paying attention to their language, facial expressions, and body language. I withdrew from making observations if I noticed any sign of resistance. Signs of appreciation – such as "Thank you for the visit" or "It was nice having you" – along with a sense of ease during the visits strengthened my certainty of continuing consent. This approach both recognises the importance of preserving the acknowledgement of the will of a person diagnosed with dementia and follows the heart of ethnography, which usually involves a long-term and in-depth involvement in people's lives (Banks, 2018). Its foundation is based on the researcher's obligation to build the participants' trust; therefore, the latter's consent is a continuous process of negotiation throughout the research (Wynn & Israel, 2018).

5 Results

This chapter presents a summary of the results. The detailed results can be found in the respective publications (Articles I, II, and III).

5.1 Article I

Table 5 presents an overview of the themes that emerged from the data analysis in Study I. According to the findings, formal services and support for individuals living with dementia were mainly organised and delivered by the Memory Clinic at the National Hospital. When a person attended a specialised day programme, the formal support and symptoms evaluation were transferred to the doctors and nurses at the day programme.

The emphasis in formal dementia care has been chiefly on diagnosing, evaluating the progress of the disease and treating its symptoms. Taking care of practical daily life issues was viewed as the family's responsibility. However, our key informants emphasised the importance of making specialised day programmes available at the later stages of dementia. They said these programmes offered rehabilitation for individuals living with dementia and support to their family caregivers to help them cope with their daily life struggles.

It was evident that providers of primary care, community-based healthcare, and home care services thought they were often ill-equipped to support these families. Although professionals in the field acknowledged that the families were frequently under significant stress and might require additional assistance earlier in the illness, the professionals admitted feeling they were not able to offer adequate support to the home environment.

This service gap was being addressed by the formal service providers. Towards the end of the data collection period, services were being redesigned to prioritise primary care. The study results highlighted that dementia care in Iceland primarily focuses on accurate diagnosis and treatment, with little emphasis on supporting families with daily life issues. It seems that supporting families is often considered a private matter for each individual family.

Table 5. Overview of emerging themes in Study I.

Themes in Study I – Article I	Content of themes
1. Importance of accurate diagnosis and follow-up	The Memory Clinic has been the key sector in providing guidance and support after dementia diagnosis.
2. When life at home becomes difficult	Daily issues of living with dementia were viewed as the family's responsibility. Specialised day programmes came in at later stages.
3. Dementia care redefined: Enhanced participation of primary care	The increased waiting time for Memory Clinic appointments has pushed the emphasis on dementia diagnosis and support towards community services.
4. Help from the voluntary sector	Alzheimer Iceland, a nongovernmental organisation, has contributed to areas where the formal system has fallen short.

5.1.1 Importance of accurate diagnosis and follow-up

In interviews with the professionals at the Memory Clinic, participants highlighted their roles in obtaining a diagnosis and accessing formal services for families dealing with memory-related conditions. They used the metaphor of "reaching the shore", which meant that families should learn to let go of their previous expectations and find new meanings in life while adapting to the course of the disease. As one nurse at the Memory Clinic described:

> Families often require an anchor, a professional who can provide guidance and support. However, it is essential to understand that no one can control the progress of dementia. Instead, families must learn to adapt to the changes and find new meaning in everyday life. (KI05 – Memory Clinic)

However, some interviewees expressed doubts about the healthcare system's ability to meet all the essential support needs of the families. They questioned whether the system possessed the capacity to provide services to family members who were not identified as clients.

5.1.2 When life at home becomes difficult

Taking care of practical daily life issues was considered the family's responsibility. Nonetheless, placement in a specialised day programme was perceived as providing

important support to families and rehabilitation for persons living with dementia. A considerable part of the data collection occurred in relation to the introduction of placement in a specialised day programme. I met with several professionals working in this area. Through fieldwork and interviews, I learned that the main objective of day programmes was to provide person-centred support based on the circumstances and requirements of each individual and one's family.

Professionals in the field recognised that for persons living with dementia, joining a day programme could be a difficult and stressful experience for their families. They developed several valuable practices to help address this issue and ensure a smooth transition. Nurses who worked in day programmes for dementia care emphasised the importance of focusing on the individuals' strengths and creating a joyful routine to help them adjust and participate in activities:

> It is essential to identify and foster the unique strengths of every individual and support their ability in every possible way. Our approach emphasises daily activities that bring joy and fulfilment. However, achieving this requires developing trust and providing enough space for individuals to adjust to new situations. (KI11 – Specialised Day Programme)

The nurses we interviewed also spent significant time building relationships with patients' families and offering emotional and practical support. They provided formal and informal discussion opportunities, including family meetings, to help families share experiences and learn from one another.

Although everyone agreed that day programmes were important, there was an issue with their inflexibility. The programmes were operated from 8 a.m. to 4 p.m., which was an unsuitable schedule for persons living with dementia who preferred to sleep in and start their day slowly or for relatives who needed time after work to shop or exercise. This inflexibility could create difficulties for individuals and their families, and the nurses believed that a more flexible approach could make a significant difference in the quality of care they provided.

5.1.3 Dementia care redefined: Enhanced participation of primary care

At the time of the research data collection, the waiting time for Memory Clinic appointments had increased over the past few years due to the growing awareness of cognitive difficulties and dementia diagnoses in Icelandic society. As a result, the role of primary healthcare services in dementia care was being reconsidered and described as an important step towards a more holistic approach, as one key informant described: "The family physician has a broader overview than specialists, making primary care advantageous for dementia care at home. However, the discussion of dementia care at home has not yet sufficiently emphasised this" (KI20 – Primary Health Care).

Our key informants expressed their concerns about poorly coordinated and fragmented community services for individuals living with dementia. In their minds, inadequate communication between service providers was one of the main issues.

The participants reported weak teamwork and limited connection between primary healthcare and home care services for individuals living with dementia. For example, the home care nurses mentioned that most of their referrals came from the acute care hospital rather than the community health centres.

5.1.4 Help from the voluntary sector

The voluntary sector can play a pivotal role in supporting families living with dementia. One such organisation that provides invaluable assistance is Alzheimer Iceland. However, it is important to note that accessing this support is entirely up to the families since it falls outside the formal dementia care trajectory. However, no established pathway currently directs families towards this type of service.

One key informant from Alzheimer Iceland highlighted the importance of greater collaboration between service sectors to reach out to families needing support:

> Alzheimer Iceland is a voluntary organisation that offers support to families who are living with dementia, outside of the formal dementia pathway. Our current connection is mainly with the Memory Clinic, but we need to improve our collaboration with primary health care and social services to better assist families in need. (KI08 – Alzheimer Iceland)

Thus, Article I guided us to the important notion that the gap between service sectors posed a significant obstacle to providing practical support to those families who needed it most.

5.2 Article II

At the time of our data collection, a dementia diagnosis was primarily made by geriatricians at the Memory Clinic at the National Hospital in Iceland (Guðnadóttir et al., 2021). Once a dementia diagnosis had been confirmed, the family was responsible for finding ways to address any issues that might arise. The family's situation was evaluated during biannual visits to the clinic. If issues arose, the person diagnosed with dementia was put on a waiting list for a specialised day programme.

In Article II, the focus was on families who were waiting for a placement in a specialised day programme for dementia care. The ethnographic research participants comprised eight older individuals living with dementia at home, along with their closest family caregivers, usually a spouse, a child or both. These families were perceived as being in urgent need of access to a day programme because placement on the waiting list meant that dementia had already started to have a significantly negative effect on their daily

lives. Although each family had a unique story, the analysis in Article II was based on three cases: families E, B, and G. These cases were chosen as examples of experiences and challenges commonly faced by families living with dementia and how they responded to these circumstances. Table 6 shows an overview of the results of the case studies in Article II. Table 6 was originally published in Article II (Guðnadóttir et al., 2023).

In the following sections, I give a short insight into the situation of everyday living for families E, B, and G. Article II provides a more thorough description of the cases (Guðnadóttir et al., 2023). In the case study results, we described how the three families managed their daily lives at home and made use of the available formal support. The results showed how families developed their own approaches to improving their lives, drawing upon their backgrounds, surroundings, and available support. Despite different living arrangements, all families had to constantly re-arrange their lives to make it work.

Table 6. Overview of case studies in Study II – Article II.

Case 1: Elin and Einar	**Case 2: Barbara and Birgir**	**Case 3: Gunnar and Greta**
Generating a Safe Space and Avoiding Discomfort	**Fluctuating Between Being In and Out of Control of Daily Life Situations**	**A Long-Term Practice of Reaching Out for and Accepting Help**
When a protective shield is built around the person living with dementia, it can be followed by an isolation of the family caregiver.	The ability to enjoy time with a person living with dementia at home is important but often overshadowed by feelings of helplessness and emotional burnout, leading to a cry for help.	Acknowledging their own vulnerability led to a sincere understanding of the need for support and competence in seeking help.

5.2.1 Family E: Generating a safe space and avoiding discomfort

Due to the fear of making Elin angry and humiliated, Einar felt uncomfortable discussing dementia with her. He was afraid that any mention of her declining cognitive ability could trigger her negative emotions and distress. Elin was genuinely a joyful person who enjoyed music and laughter, but her dementia symptoms had increased her insecurity in crowded spaces. When Elin lost control, she got more confused and started crying. Therefore, Einar avoided situations that could expose Elin's condition, hoping to protect her from emotional disturbances. Despite her condition, his main aim was to preserve

her dignity and well-being. As Einar described: "Elin's reduced mobility and insecurity in crowds have impacted our activities. We now take car rides instead of walking and no longer attend music events" (Einar, visit 02).

Einar used an active approach to ensure that his wife felt in control. At home, he let Elin believe she directed the household chores, although he did all the work. With a rag in her hand, Elin wiped the dust off tables and told her husband the necessity of doing it properly. He thanked her for her contribution, and when she did not notice, he wiped the table again. Einar respected his wife's feelings and believed that it was vital that she remained in charge. He had avoided formal support and services to limit any disturbance and prevented unpleasant situations that might threaten her sense of self as a capable person. This strategy involved avoiding large gatherings and demanding conversations. Instead, he opted for short car trips and listening to music in their living room, which he said made Elin´s eyes sparkle and bring a smile to her face. Einar created by this, a safe space for Elin to help her get through her days. However, at the same time, he isolated himself at home with his wife, distancing himself from the companionship of old friends and cultural events that had always been an important part of his life.

5.2.2 Family B: Fluctuating between being in and out of control of daily life situations

Barbara's life with her partner Birgir, who was diagnosed with dementia, had been a constantly changing journey. It was like a roller-coaster ride, and Barbara must continually find new ways to make their daily life enjoyable. When Birgir was diagnosed with dementia, Barbara realised that she had to assume the role of a caregiver, which was demanding and not what she had asked for. This was the biggest shock for her. Instead of spending their retirement as companions, Birgir now needed to be cared for like a child, which Barbara found to be degrading for both of them.

During the research observations, Birgir was always polite and quiet, sitting in his chair in the living room. He seemed at ease and comfortable and only spoke in short sentences about unspecific matters when asked. Barbara shared that Birgir was a diligent and passionate person in his younger days. She loved having conversations and working together with him at that time. However, now, as his dementia progressed, she felt like he was gradually slipping away. He seemed disinterested in life and was unresponsive most of the time, which was the most challenging thing for Barbara to endure. She said she was lost in how to proceed with their life without support and compared it with the situation of their grandchild who needed a daycare:

> I am struggling to manage my responsibilities as a caregiver for the young parents and my husband, who is living with dementia. Unfortunately, there doesn't seem to be any adequate support system in place to help me. It's

> becoming overwhelming, and I'm not sure how much longer I can handle it… (Barbara, visit 07)

She said she had wished for proactive professional support that could guide her in coping with daily life at home and ease her burden. However, the Memory Clinic did not provide such support. Instead, the professionals there focused on assessing the progression of Birgir's dementia symptoms on a scheduled basis, although they offered an open support line for families on demand. Barbara was unsatisfied with the approach of seeking support via a helpline. On the one hand, she felt unsure about when and what to ask for and what issues were significant enough to bring up with the professionals. On the other hand, if the clinical nurse specialist had proactively contacted her and asked specific questions while offering support, Barbara might have gained a better understanding of her needs and wishes.

5.2.3 Family G: A long-term practice of reaching out for and accepting help

Life with dementia was a challenge for Gunnar and Greta, but they had developed a mutual understanding and approach to Gunnar's condition. It's not clear what led to this capacity, whether it was due to their previous experience in dealing with their son's mental disorder or their inherent personality traits. The family was well prepared to seek help when Gunnar was diagnosed with dementia. They said it was because they already had the emotional strength and knowledge required to discuss mental discomfort with honesty. Gunnar and Greta trusted and valued each other, expressed their emotions, confided in professionals and worked together to understand their situation.

> We have practised sincere communication in our marriage, and we are mindful of life's small yet important things. This has helped us to confront the emotional difficulties surrounding our son's illness, and we have been able to build upon that experience. (Gunnar, interview 01)

These findings point out that although living with dementia does affect families' daily lives and emotions, if families are able to practice active communication and have a mutual understanding, it can, in some cases, make it easier for the healthcare system to guide families towards a suitable solution with minimal effort.

5.3 Article III

In Article III, we followed up on the longitudinal ethnographic case study described in Article II. This time, we focused on the reality of families finally being offered a placement in a specialised day programme for dementia care after a long waiting period. Again, we presented three cases, those of families E, D and C.

All families shared stories about their challenges when offered a placement in the

specialised day programme. To illustrate the diverse experiences of those attending the programme, these three case studies were selected for Article III. For an overview of the case studies' results discussed in Article III, see Table 7. The first case is a positive account where the day programme proved to be a lifesaver for the family. The second case portrays a failed attempt despite the family's persistence. The third case highlights a family that was unwilling to try out the programme due to the resistance and antagonism of the person living with dementia.

Table 7. Overview of case studies in Study II – Article III.

Case 1: Elin and Einar	**Case 2: Diana and David**	**Case 3: Carol and Carl**
Finding inner peace	**A constant reminder of identity loss**	**Struggling with family honour**
After a difficult time finding the courage to accept a day programme and alleviate the isolation that had built up at home, they both found the soothing relief of new energy and comfort.	The service let them down, and they found the day programme distressing because it reminded them of David's limitations. They eventually cancelled their participation in the programme.	The day programme never became an option. Extreme changes in personality, alcohol misuse, fear and anger stood in the way of accepting the offer. No other support option was available, and the family felt left without support.

5.3.1 Family E: Finding inner peace

Einar described his journey with Elin and dementia as very emotional and stressful. He said that they had both been insecure, and Elin had shown signs of depression and emotional distress. It had been difficult to see how his joyful and socially active wife had disappeared and been taken over by her anxiety. However, she returned to her upbeat attitude towards life after entering the day programme. Einar said that Elin had become talkative and happy again and was even eager to go for a drive or a short walk with him, as he describes so well:

> The most important thing is for me to see that Elin is comfortable, and she is that today. At this point in her disease, she is unaware of her disability. She seems to believe that nothing is wrong with her – and seeing her in that way is good. Though I need to help her with everything, getting

> dressed, bathing, mealtimes and medication, it does not seem to bother her at all needing this help. I am aware that her disease will only get worse. However, I am focusing on enjoying the moment while it lasts. Elin is happy, and life is good at the moment. (Einar, interview 03)

5.3.2 Family D: A constant reminder of identity loss

Diana observed that despite David's cognitive decline, he appeared to have a greater understanding of his situation than his family thought possible. She mentioned that David sometimes became acutely aware of his changed abilities, which could cause him to feel humiliated.

> He experiences frustration, anger and sadness when he cannot do things he used to enjoy. These emotions come and go, and he does not remember much from day to day. As a result, what made him angry one day may be forgotten the next day until the next episode of frustration begins. (Diana, interview 01)

5.3.3 Family C: Struggling with family honour

Connie, the older daughter, described how the family dealt with her mother's dementia and her parents' pride:

> From as far back as I can remember, my parents have always been reluctant to acknowledge or discuss mental health issues. In their view, revealing such vulnerabilities is a sign of weakness, and they believe it is best to keep them hidden within the confines of one's home. They view seeking help or placement due to cognitive disorders as degrading and humiliating and consider it inappropriate to reveal any weaknesses, such as memory loss, depression, alcohol misuse or other disorders. In their eyes, it's important to maintain a façade of perfection and avoid any blemishes on one's surface. (Connie, interview 02)

6 Discussion

In this dissertation, my overall objective was to gain a deeper understanding of the challenges faced by individuals living with dementia in their own homes and by their family caregivers. My aim was to understand how families manage everyday life with dementia as well as identify services and support that can help them. Theoretically, the study was framed within a relational understanding of everyday life as collaborative, where people support one another. In this understanding, the collective influence of individuals and the environment, such as the home, social surroundings and formal services, is explored. In such studies, the focus is on how things are done, or the enactments, to make the situation as good as possible. The main results of both Studies I and II are discussed in relation to the following four sections: 1. The complex nature of families living with dementia at home, 2. Recognition and support of formal dementia services, 3. The support of specialised day programmes, and 4. Creating a better patchwork of everyday care.

6.1 Complex nature of families living with dementia at home

This study reflects the situation of families of persons living with dementia at home. It shows how life at home can be fragile, where the person diagnosed may have limited insight. The three case studies presented in article two reflected different situations: Elin, who was not able to face her declining cognitive ability; Birgir, who had moments of being able to cope with life when taking care of his grandson; and Gunnar, who took initiative in having his condition diagnosed and entered into an open dialogue with his wife.

Family caregivers play a critical role in the lives of persons living with dementia. However, they may deal with various challenges in their daily lives while taking care of a family member diagnosed with dementia (Moreira, 2010). Our results indicated that family caregivers had to learn how to read into the situation each day and find ways through improvisation and adjustment. They had to rely on their understanding of the circumstances and experiment with constant adjustments to their caregiving routine. In this process, family caregivers had to be patient and persistent. They had to be willing to try different strategies and approaches until they found those that worked best for them and the person living with dementia.

Through the analysis in Article I, I detected that when healthcare professionals suspected symptoms of dementia, their formal services tended to focus on diagnosing and managing the exacerbations of the condition rather than attending to the care needs of the family, despite being aware of the challenges faced by the family caregivers. This

finding was further confirmed through the case studies presented in Study II (Articles II and III). These results highlight the need to consider the impact of dementia on the family and caregivers and to provide adequate support to address their care needs.

Two spouses of individuals diagnosed with dementia faced the challenge of maintaining their own physical and mental well-being without formal support. Einar prioritised creating a safe space and avoiding discomfort but became isolated as a result. In his experience, Kleinman (2019) learned the delicate balance of accompanying a loved one through the process of dementia. He realised that the disease would guide the way, and his role was to be present while acting on his wife's need for security. These experiences highlight the importance of prioritising a family caregiver's physical and mental well-being while accompanying the family member through dementia. Maintaining a balance between being present and taking care of oneself is crucial. When observing Einar and his wife, Elin, I witnessed how Elin became visibly upset when the topic of dementia was brought up, causing Einar to become isolated and inactive. He took care of Elin alone, leaving little time for his own needs. As the story of Kleinman (2019) emphasised, Einar's reality highlighted the importance of finding a balance between caring for others and self-care.

Barbara was struggling to maintain control of her daily life as she dealt with the effects of Birgir's dementia symptoms on their daily life. Despite her challenges, she was determined to manage each day with pride and persistence. Studies have shown that maintaining a sense of personal identity and dignity is crucial for individuals living with dementia (Eriksen et al., 2016; Tranvåg et al., 2013). As Birgir's caregiver, Barbara understood this concept well. She recognised the importance of personal roles and how these could have an impact on a person's quality of life. It made a significant difference in Birgir's life to have a role in taking care of their grandson by sitting near the little boy and playing with him. This seemingly small change had a positive effect on Birgir. Barbara felt that she had regained her former connection with her husband and eagerly celebrated the fact that he was still significant and indispensable in their collective babysitting role. By recognising the importance of personal roles and relationships, as this case shows, caregivers can make a substantial difference in the lives of persons dealing with dementia.

The third case involved Gunnar and Greta, who had a long-term practice of seeking and accepting help from others. They had learned from their past experiences that honest communication and the support of their family members were crucial for them. Their journey of living with dementia was not easy, but they tried to make the most of their time together. The key attributes of Gunnar, Greta and their family perfectly aligned with the core principles of the VIPS framework, which was developed to put Kitwood's (2007) person-centred care philosophy into action. The VIPS approach stresses the importance of valuing persons living with dementia and their family caregivers, treating them as individuals, attending to their perspective and enriching their social environment by

regarding them with respect and appreciation, acknowledging their unique perspectives and considering their social surroundings (Brooker & Latham, 2015; Brooker & Snaedal, 2016).

As emphasised by the VIPS model, Greta realised the significance of understanding her husband's moods and emotions and responding to any changes before these could negatively impact their lives. Furthermore, Brooker and Latham (2015) emphasised the importance of being proactive and prepared while searching for relevant support. Greta had taken a similar approach; she tried to explore different recreational and supportive opportunities with Gunnar, such as sing-along get-togethers, outdoor walks, appointments with a psychologist and peer support group meetings. She believed that it was essential to try different methods to see which one suited them best. As described in Article II, Greta's approach to seeking support for herself and her husband showed her strength and competence in making use of the support system. She understood that it was not just about being proactive but also about being prepared for any situation (Guðnadóttir et al., 2023). She took steps back and forth in her quest for relevant and helpful support to Gunnar, and her efforts paid off. Greta's story shed light on how sincere communication, family support and a proactive and prepared approach to seeking help in challenging times can, for some families, be the key to a more pleasant living at home with dementia.

In the realm of dementia care, healthcare professionals' standard practices might lead people to believe that the formal support system is built around families such as Gunnar and Greta. The findings in Article I indicate that the key informants in dementia care believe that families require time to adjust to living with dementia; they also need time to determine what kind of assistance they need and when it may be required. Therefore, the formal care system strives to give families enough space to be in charge of their process and maintain their independence. However, this approach necessitates that families must actively search for the available services and be mindful of the support they need. It calls attention to how families, such as Barbara and Birgir or Einar and Elin, fit into such a service model. This critical question needs to be answered to ensure that all families receive the support and care they require when living with dementia.

Systematic reviews of studies focusing on how families cope with life when a member has been diagnosed with dementia, based on their knowledge and adjustability to their situation, reflect many variations (Bjørkløf et al., 2019; Parker et al., 2020). Other studies have also demonstrated that a family's ability to meet the demands of caring for someone living with dementia is influenced by their background and overall support structure (Zwingmann et al., 2020). The idea of collective care has been used to describe how families and professionals work together to provide practical and emotional support (Ceci & Purkis, 2021). This approach emphasises the importance of recognising the complex emotions and practical challenges that families face when caring for someone living with dementia, as well as providing them with the support they need to manage their caregiver

roles (Swallow, 2017; Swallow & Hillman, 2019).

As Berglund et al. (2019) noted, there is a need for more research on how to implement a holistic approach to family care to provide person-centred care for those living with dementia at home. Caring for a person diagnosed with dementia can pose significant challenges to families, mainly due to the lack of proactive support and resources from formal care providers (Hennelly & O'Shea, 2022). Therefore, it is crucial to explore ways to offer better support and resources to families caring for persons living with dementia.

By focusing on the collective approach, healthcare authorities and practitioners may acquire the relevant knowledge necessary to address the connections and links among people, their surroundings and their practices (Ceci et al., 2020). In conclusion, understanding the complex needs of families living with dementia requires a collective, holistic approach that recognises the importance of practical and emotional support and seeks to build connections between families and professionals. Care can be ineffective if individuals reject or lack knowledge on how to receive the offered assistance. Good care involves sustaining the person but requires a continuous process of trying out different care methods, and tensions and conflicts form a noticeable part of that ongoing process of care (Thygesen & Moser, 2010).

As we observed in the case of Birgir and Barbara, formal services were offered and provided to Barbara and her husband, with every step laid out and the treatment initiated. Birgir was at ease at home with the support of his wife 24/7, but Barbara felt trapped, insecure and alone in their reality. Healthcare providers had offered guidance and education on Birgir's dementia. A follow-up appointment was booked, but Barbara wanted more proactive support to guide her through the process. She needed help understanding that though things may work well for a while, they might slip again (Thygesen & Moser, 2010). With the right support, she could have found the strength to continue caring for her husband and to live life with dementia.

6.2 The role of formal dementia services

Our research shows that primary healthcare services, including those of GPs and community health nurses, as well as home care services, have limited involvement in providing care for individuals living with dementia. In other countries, such services have been described as ill-equipped and poorly coordinated in meeting the needs of these families (Moreira, 2010; Moser, 2011). However, in Iceland, a policy shift has begun to transfer the responsibility of providing dementia-related services to primary care, particularly at the early stages of the illness, to ensure that individuals diagnosed with dementia receive adequate care and support. This move aims to redefine these services by placing the family at the centre of care. When addressing dementia in families, it is essential to understand how or whether different individuals with varying backgrounds can contribute to caregiving. By recognising this issue, the focus shifts from one sole caregiver to a collective effort that involves the person experiencing dementia, the

relatives and other caregivers. This joint project brings together various actors who work jointly to make the life of the person living with dementia as comfortable and fulfilling as possible. By sharing the responsibility of care, everyone involved can offer their unique skills and knowledge to provide the best possible care for the person living with dementia.

Dementia services have primarily focused on the individual experiencing cognitive decline and on the illness. However, the key informants also expressed their recognition of the challenging situations faced by the families. They acknowledged the complexity of dealing with dementia and the impacts it can have on the lives of not only the individuals diagnosed with dementia but also their family caregivers. However, they were uncertain about how public services could or should provide adequate assistance.

Alzheimer Iceland stands outside the formal dementia care trajectory in the country, but it has been an essential contributor in areas where the formal system has come short. One of their significant contributions has been the development of a comprehensive and accessible website that provides information and assistance to individuals and families dealing with Alzheimer's and other dementia diseases. Alzheimer Iceland also offers personalised consultations to individuals and families, support groups for relatives and specialised day programmes that cater to the specific needs of people living with dementia.

Dementia can be a confusing and unpredictable condition that requires intervention and support. According to Gjødsbøl and Svendsen (2018), it is a complex and multifaceted condition with many variables that can affect its development and progression. In response, families often develop arrangements to help their members diagnosed with dementia manage the symptoms and maintain their quality of life at home. Ceci et al. (2018) have called for the service providers' greater understanding and support of the families' arrangements. In some cases, relatives may attempt to isolate the person diagnosed with dementia to prevent moments of confusion and disorientation (Berry, 2014). This strategy may involve creating a quiet and calm environment with minimal stimulation or distractions. Other families may prioritise activities that the person diagnosed with dementia valued in the past (Le Galès & Bungener, 2019). This approach may involve maintaining a daily routine and engaging in activities that provide the person with a sense of familiarity and comfort.

Our key informants had extensive knowledge and experience of the differences in the care of individuals living with dementia. These informants had developed care practices to respond to such differences. The professionals at dementia day programmes emphasised that they focused on individual strengths and felt they were actively involved in guiding families. They were in close contact with the Memory Clinic and home care staff, which allowed them to act on their assessment of the illness's behaviour through their daily evaluations. These findings align with earlier studies on day programmes in Iceland. (Gústafsdóttir, 2014, 2011), which suggests that day programmes can bring

contentment and structure to families by strengthening the ties among their members and with the service providers and easing the impact of dementia. However, it is important to note that specialised day programmes only become available late in the process, and families need support earlier in the illness trajectory.

Research has found that families value customised and flexible respite and home care services (e.g., Kampanellou et al., 2017). Primary care, including home care, may be well-suited to provide comprehensive and family-centred services, given its holistic approach. The Icelandic Ministry of Health's published Action Plan for dementia care (2020) emphasises this idea, calling for integration between the Memory Clinic and primary care. The plan also suggests transferring the initial diagnosis and monitoring responsibilities to primary healthcare, with the aim of providing early support to families in the illness trajectory. This could result in better outcomes for individuals living with dementia and their families.

The process of transitioning to an integrated healthcare system is complex, as evidenced by experiences from other countries. The UK's EVIDEM-ED and Better Care Fund projects have shown that simply providing focused education and formal planning to staff is insufficient (Harlock et al., 2019; Wilcock et al., 2013). In order to create a comprehensive and effective healthcare system, it is important to achieve integration of services and a collective emphasis. This requires a long-term commitment that involves a shared vision, strong leadership, funding, and educational focus. To achieve this, it is crucial to enhance the participation and management of primary care, community-based physicians, nurses, and home care services. This objective can be achieved by bringing together different healthcare providers and services to work cohesively towards a common goal. It is important to note that this process does not occur instinctively but requires a concerted effort from all involved parties. By collaborating and implementing the necessary changes, they can create a more helpful, fair, and safe healthcare system for all (Fæø et al., 2020).

6.3 Support from specialised day programmes

Specialised day programmes for dementia care have been acknowledged as among the most effective support systems for individuals living with dementia and their families (Tretteteig et al., 2016). In many countries, including Iceland, a placement is offered on a waiting list for such programmes when symptoms of dementia have become overwhelming and have started to cause complications at home (Rokstad et al., 2022). It is crucial to examine how these programmes cater to families' needs. In this study, I have presented various cases demonstrating how families respond differently to offers made by day programmes. Thus, my study provides valuable insights into the efficacy of day programmes for dementia care and how these can be improved to better serve individuals and their families.

In line with previous studies (Tretteteig et al., 2016; Rokstad et al., 2022), the day

programme proved to be a turning point for Einar and Elin, who were struggling with fatigue and isolation due to Elin's dementia. The programme gave Einar a break from caregiving, allowing him to rest and reconnect with friends. And Elin, who felt disheartened, found her enthusiasm and joy as a teacher again in the programme. Engaging in social interactions helped her regain a sense of purpose and self-worth, and it gave Einar hope that his wife could still find joy despite her condition. However, in the second scenario, Diana was hopeful about the day programme for her partner David, but it turned out to be unsatisfactory. David felt resentful and restless attending the programme, and it was emotionally draining for Diana to see him miserable. David no longer enjoyed crafting as it reminded him of what he had lost. Despite her efforts, the programme was not beneficial for David and proved to be a challenging situation for Diana, and they eventually withdrew from the programme.

The experiences of David, Diana, Carol and Carl demonstrate how the loss of personal dignity can significantly adversely impact individuals' interactions with their community. David's humiliation during the programme activities and Carol's resentment towards attending such a programme resulted in their depressed feelings and withdrawal from participation. This finding is consistent with those of other studies, which have shown that individuals facing cognitive decline are at risk of losing their self-respect and dignity, leading to social withdrawal, particularly from larger groups (Ren et al., 2023; Tranvåg et al., 2022; van der Geugten & Goossensen, 2020). Moreover, the presented case studies highlight the often-fragile relationship between formal support providers and family caregivers. For Diana, the burden of her husband's misery at the day programme was even more exhausting than caring for him at home, emphasising the challenges that families face when engaging with formal services (Stephan et al., 2018). These case studies, in line with recent research (Lindwall & Lohne, 2021), demonstrate that the loss of personal dignity can have a devastating impact on individuals' well-being and social interactions. Therefore, it is essential to provide support and care that respects and values the dignity of individuals, especially those facing cognitive decline.

To achieve the aim of preserving individuals' dignity, it is necessary to analyse the reality of the families' daily lives and understand the foundation of dignity. Since dignity is a relational concept, it can be preserved by keeping families in relation to their social context and helping them embrace their true selves (Pols, 2023; Pols et al., 2018). David and Diana's shared experience is an excellent example of how the loss of dignity can negatively impact people's lives. They both struggled to cope with the effects of dementia, and Diana felt like she was in a constant battle with the system. She did not receive the necessary support to help her husband; instead, the support system tried to fit them into a predefined structure. The professionals should lead in finding alternative means of support and acknowledging the diverse needs of the families they serve. It is crucial to say, "I see you – the path we have been taking is not helpful, so together, we need to find a new patchwork to make your life as good as possible." By doing so, the support professionals can empower the families and help maintain their dignity.

6.4 Creating a better patchwork of everyday care

As Ceci and Purkis (2023) observed, services designed to support families living with dementia usually follow a prescriptive approach, which involves a set of predetermined steps for care. However, the case studies presented here reveal a stark contrast between the streamlined approach of formal care and the complex and unpredictable reality of families' diverse needs and situations. Families often resort to tightly weaving together a patchwork of care that fits into their everyday lives with dementia, improvising and constantly making adjustments along the way. This reality is far from simple and demands a more nuanced approach by the formal support system to meet the individual needs of families living with dementia.

Carol's and Carl's experiences have brought to light an important issue. In cases where day programmes and other formal support systems fail to meet the needs of family caregivers, what are the alternatives for those who do not fit the designed support? It is important to examine how the formal support system can better address the needs of family caregivers and provide more tailored assistance for those who require it.

It is widely acknowledged that individuals diagnosed with dementia, just like any other person, need to feel that their lives still have a purpose and that they remain an integral part of society (Huizenga et al., 2023). The same holds true for their family caregivers (Hammar et al., 2019). To address this issue, many countries have introduced the role of dementia care navigators, which has been found helpful in providing personalised and effective support to people living with dementia and their families (Giebel et al., 2023).

A dementia care navigator is a trained professional who guides people living with dementia and their families through the healthcare system and helps them access the appropriate care and services they need (Jelley et al., 2021). The navigator serves as a key point of contact for families, offering emotional support and encouragement to individuals, helping them build on their strengths and feel more secure in their daily lives at home (Stephan et al., 2018). By providing personalised and customised support, dementia care navigators can help individuals feel more connected to their community and build a sense of purpose and belonging, which are essential for their well-being (Gjøra et al., 2021; Prince et al., 2013; Stall et al., 2019).

Day programmes can serve as excellent sources of support and guidance for family caregivers to better understand the challenges of caring for someone living with dementia (Symonds-Brown et al., 2021). However, if the design of day programmes is not integrated into families' daily lives, their effectiveness can be of limited support in how families carry on their living at home with dementia. Therefore, care providers should focus on creating programmes tailored to the unique needs of individuals and their family caregivers and seamlessly integrated into their home environments.

6.5 Strengths and limitations

This thesis and its data collection process have strengths and limitations. A few points will be drawn concerning the overall methodology used in the study design and data collection of both Study I and Study II. However, further methodological considerations have been described in more detail in each article (Articles I, II, and III).

Study I comprised semi-structured interviews with 20 key informants from five different settings of formal services provided to individuals diagnosed with dementia and their family caregivers. The emphasis was on capturing different voices reflecting diverse perspectives and understanding of the professionals in each service setting. The data collection was restricted to the greater metropolitan area in Iceland and, therefore, does not capture the situation of the service provided outside the country's capital area. However, the variety of professionals and service settings strengthened the overall view and understanding of the formal service provided.

The data collection of Study I was performed by me, the doctoral candidate, and my main supervisor, who founded the overall study and started the data collection in 2016. In 2017, when the PhD study was funded by a grant from The Icelandic Gerontological Research Institute (RHLÖ), I took the data collection over with guidance from my supervisor. As was described above, an interview guide was used, and we met frequently to discuss the progress of the interviews. This collaboration created a dynamic and fruitful discussion about the variety of voices and viewpoints of participants. The findings were based on our collective analysis of transcribed interviews.

The recruitment process of participants in Study II was made in collaboration with experienced professionals at the Memory Clinic, who initially contacted the families and informed them about the study. This neutral participation offer helped secure the eight families' free, willing participation. The ethnographic and longitudinal design of study II allowed for a deep insight into the everyday life of families living with dementia. During repeated contacts and visits, I came to understand the intricacies of daily life and how each family made arrangements and adopted new practices to cope. The longitudinal design was very beneficial in light of the long waiting time for a specialised dementia day programme. At first, the idea of data collection was set up as a 12-month observation. However, when it became clear that 12 months would not give the possibility to follow families through the long transitional phase: a) being on a waiting list, b) eventually receiving an offer of a placement at a day programme, and then c) following up on how or if that offer was of support to individuals and family caregivers. We decided to prolong the observational phase to 24 months. The prolonged time had both positive and negative effects on the study. It extended the data collection process twofold, but it also gave the researcher more time to connect with the families.

A longitudinal observational case study thoroughly explains slowly changing processes, such as living with dementia (Schoch, 2020). While case studies cannot be generalised,

they offer valuable insights into specific cases (Yin, 2014) and, in this study, turned out to add essential information about the complexities of living with dementia at home. The researcher inevitably influences the scenario when placed in observational settings and interacting with the participants (Hammersley & Atkinson, 2019). However, in this study, the researcher paid regular visits to each family, conducting both interviews and observations over an extended period. Each meeting involved the observer guaranteeing that she was welcome and using the opportunity to confirm her understanding of each family´s situation. This close and repeated contact increased the possibility of trust being established between the researcher and the participants.

6.5.1 Trustworthiness

Although there is no universal agreement on how to judge the quality of qualitative research studies, both transparency and reflexivity are considered highly important (Moen & Middelthon, 2015; Polit & Beck, 2012). Reflexivity requires researchers to be continuously aware of their personal biases and preconceptions that can influence the research process (Polit & Beck, 2012). In their much-cited guide to assure quality, Lincoln and Guba (1985) coined trustworthiness as a key concept. Following their guideline, to assess the trustworthiness of this dissertation, I apply the criteria of credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985; Nowell et al., 2017).

Credibility is an essential aspect of qualitative research. It refers to our confidence in the data's accuracy and interpretations (Lincoln & Guba, 1985). Using multiple data sources and methods, known as triangulation, is recommended to enhance study credibility (Polit & Beck, 2012). To better understand the care and support given to people with dementia who live at home and their family caregivers, I used triangulation methods. This involved combining observation, interviews, and data from policy documents. Using participant observation and interviews allowed for a comprehensive understanding of the complexity of the trajectories through detailed accounts of real life with dementia (Flyvbjerg, 2006; Hyett et al., 2014). An additional method of data triangulation is person triangulation. Person triangulation is a way to validate data from multiple perspectives on each case (Polit & Beck, 2012). Using that method was a strength of the study, as it helped shed light on the different aspects and interactions between different actors, including the ones diagnosed with dementia, their family caregivers, and healthcare professionals.

Dependability refers to the stability of data over time and conditions. It can be contrasted with transferability, which refers to whether study results can be applied to other settings (Lincoln & Guba, 1985). One technique to ensure that data is dependable is to perform member checking. This involves sharing the researcher's interpretation of the data with the participants and obtaining their feedback. The goal is to confirm that the researcher's interpretation accurately reflects the participants' experiences. Member checking can be performed during the data collection process or after the analysis. (Polit & Beck, 2012).

For my study, I conducted multiple interviews with participants in Study II over time. This allowed me to follow up on their previous responses and gain further insights. Additionally, the information gathered during the interviews complemented my observations, field notes, and interpretations.

Confirmability refers to the neutrality of research results, shaped by participants instead of researchers' motivation (Lincoln & Guba, 1985). In the analysis process, I had this in mind, and I emphasised reflecting on myself as a researcher and how I possibly affected the data collection, analysis, and interpretations. One challenge I faced, as described in the method section, was related to the researcher's potential impact on and susceptibility to influence during the observations (Sporrong et al., 2022). A continuous reflection and discussion with my main supervisor throughout all phases of the research process was very helpful.

The concept of transferability pertains to the degree of generalizability of research findings to other contexts or populations. In other words, it refers to how research outcomes can be applied to different settings or groups beyond the original study (Lincoln & Guba, 1985). Here, the study has its apparent limitations. A longitudinal case study comprised of eight families is in no way generalisable to the context of the population living at home with dementia. The cases observed were though of wide variability, emphasising the heterogeneity of the situations of families living at home with dementia.

Data collection was finished in December 2019, shortly before the outburst of the COVID-19 pandemic. That was convenient for the sequence of the study observations. The world and reality of families living with dementia at home did alter during the pandemic, with decreased support outside of the home and increased possibility of isolation of persons living with dementia and their family caregivers. However, fortunately, an end has been declared to the pandemic, and we seem to have found our way back to a more normal situation of service and communication. This gives the results of this study weight in our continuous work and debate on how families living with dementia can be better supported.

6.6 Implications for practice and future research

To provide tailored support to families living with dementia, it is essential to comprehend and value families´ diverse situations. However, to understand the specific requirements of families, formal care providers need enough time to interact with them and learn about their needs. To achieve this, policymakers must ensure that formal care providers are situated closer to people's homes, thereby increasing the probability of being available when needed. Additionally, these providers should be empowered to utilise their local knowledge and judgment to offer assistance that complements and enhances the efforts made by families.

As I discussed at the beginning of this thesis, I hope this study will contribute to the development of home care and outpatient services for persons living with dementia and their families. Therefore, I long to take future steps in bringing forward care practices in more supportive home care for persons living with dementia and their family caregivers, a movement that would enhance the knowledge and practice of formal care providers from both health and social care.

My supervisor and I have already drafted a design for participatory action research that would be done in partnership with key stakeholders: people living with dementia, their family caregivers, health and social care staff of home care, and professionals from primary care and the Memory Clinic. An emphasis would be placed on workgroups to develop services and educational materials. The project would aim to transfer and integrate knowledge between all these stakeholders, drawing on literature related to integrated care and fundamental care.

7 Conclusions

This study's results emphasise the importance of providing varied and flexible support for individuals living with dementia. Health and social care professionals should have the skills to understand and distinguish family connections in the daily lives of individuals living with dementia so they can provide the necessary assistance and guidance.

The case studies demonstrate that a person-centred approach is crucial when dealing with behavioural problems in a day programme. The relationship between formal support providers and family caregivers in addressing issues that emerge in daily life as a result of cognitive changes is complex. Health authorities and care providers have focused on creating standardised programmes to evaluate symptoms and provide daily care. However, this one-size-fits-all approach may not address family caregivers' unique needs and circumstances. By acknowledging the heterogeneity of families and providing them with tailored support, the challenges of daily living with dementia can be better addressed. The case studies also highlight families' different ways of coping with daily life with dementia that stem from their backgrounds, surroundings, and available support. When their approach no longer works, re-arrangement is necessary. This is an important lesson for formal service providers to understand the needs of families who may lack the strength or knowledge to seek adequate support.

It is important to customise support for families living with dementia based on their specific situations because every family's experience is unique. However, to understand these situations, formal care providers need time to learn from families about what support they need. As Ceci and Purkis (2023) emphasise, this means that policymakers should ensure that care providers are located close to people's homes so they can be present when needed. These providers should also be empowered to use their local knowledge and discretion to offer support that complements the families' efforts. Policies should prioritise care and respect everyday life at home. To achieve this aim, policymakers need to create a workplace environment that enables frontline practitioners to work closely with families, using local knowledge to respond to their needs at the present moment. Integrating services and adopting a collective approach requires a shared vision and strong leadership, as well as funding and educational resources. Therefore, involving primary care, health and social care professionals, and home care services in a more holistic approach can enhance the quality of dementia care at home.

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Paper I

Paper I

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Community-based dementia care re-defined: Lessons from Iceland

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Abstract

Studies of families caring for persons with dementia living at home often reflect feelings of being forgotten and abandoned by the authorities to shoulder the responsibility for care-giving. This has increased interest in how formal services can better support these families. This article analyses how health and social care professionals envision the needs of families of persons with dementia living in the community. It also describes the contributions of the formal care system to these families. The study design was qualitative. It involved interviews with professionals ($N = 20$), field observations from the settings where they worked, and public documents addressing care-giving for people with dementia. Data were analysed using the framework method. The findings reflected how those providing services to persons experiencing cognitive changes mainly understood the services as specialised. They focused on the diagnosis and treatment of the individual with dementia. They considered other aspects of care, such as attending to practical issues of daily life, to be a private matter, for which the family was responsible. In later stages of dementia, specialised day programs become available, offering rehabilitation to motivate positive daily living—for both the person experiencing dementia and family-centred supporters. Professionals in the field described primary care, community-based healthcare and home care services as poorly equipped to support these families. Participants acknowledged that families were often under a lot of stress and might need more support earlier in the illness. However, they saw themselves as powerless. Towards the end of the data collection, services were being re-designed to emphasise the role of primary care. In light of its holistic and family-centred approach, primary care may be well placed to integrate relational understanding of living with dementia and specialised knowledge of dementia treatment.

KEYWORDS

community care, dementia care, family care-giving, relational understanding

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What is known about this topic

- Older persons with dementia living at home and their families need more formal support.
- Studies in many countries have described formal support as fragmented and available too late.
- The nature of appropriate and helpful support for families of people with dementia needs clarification.

What the paper adds

- Formal dementia care in Iceland has mainly been defined as specialised services, focusing on accurate diagnoses and treatment of the disease.
- Specialised day programs, available at advanced stages, emphasise collective responsibility for well-being and family support.
- Given the holistic approach promoted in primary care, emphasis on community care may foster a relational approach and promote interdisciplinary collaboration.

1 | INTRODUCTION

Caring for a person living with dementia at home has become a common reality for families worldwide, leading to both financial and health-related difficulties, (Eurostat, 2019; OECD, 2018; WHO, 2015). Families may experience challenges, such as anger towards the disease, grieving the loss of the relative's personality and mental exhaustion related to around-the-clock care responsibilities (Dempsey, Dowling, Larkin, & Murphy, 2018; Safavi, Berry, & Wearden, 2018). Many families feel forgotten and alone (Lilly, Robinson, Holtzman, & Bottorff, 2012). This seems to reflect their lack of knowledge and understanding of how formal services may best assist them (Ceci, Symonds Brown, & Purkis, 2018; Purkis & Ceci, 2015). Our article focuses on how health and social care professionals understand the situation of families of persons with dementia living in the community and the nature of the formal services provided. This article describes how they see the impact of dementia and the possibilities available to the families seeking assistance.

Dementia has been described as an incurable disease that runs its own trajectory. This understanding of dementia represents it as changes in the individual's memory and functioning, captured in diagnostic techniques and the classifications of dementia's different forms (Moreira, 2010). Attention has mainly focused on the person diagnosed with dementia. Efforts and funds are primarily directed at prevention and finding a cure, while acknowledgement of the family members' complex and invisible work is limited (Seaman, 2018).

An alternative way of portraying and responding to dementia has emerged in recent years. Researchers refer to it as *relational ordering* (Moser, 2011) or *collectivisation practices* (Moreira, 2010). This framing seeks to recognise connections holding people living with dementia in relation, making them part of a collective. When people start experiencing symptoms of dementia, the care others provide matters more. This suggests that relational aspects of a good life are important to understand. Memory loss is not only a 'symptom' of dementia. It also affects the person's surroundings (both people and things). There is neither a sole focus on cognitive decline nor a goal of a therapeutic solution. Rather, attention focuses on how to handle and support daily life (Moreira, 2010). Although dementia resides in one person, the family, community, healthcare workers and society at large share and interact with its impact and consequences (Taylor, 2008). These different understandings of the impact of dementia informed our analysis in this article.

1.1 | How are families supported?

Studies from different countries have shown how family members try to manage the demands, feelings and logistics involved in caregiving. These studies reflect considerable heterogeneity among family members. Some are overwhelmed, while others feel that they are coping (Kraijo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2012). The studies have also revealed complex feelings accompanying caregiving, such as resistance, anger, sadness, powerlessness, feelings of loss and grief, acceptance and acquiescence (Gillies, 2012; Kraijo et al., 2012). Many relatives feel guilt and self-blame for taking respite (de la Cuesta-Benjumea, 2010) or handing the person in their care over to a nursing home (Graneheim, Johansson, & Lindgren, 2014).

The emerging literature shows varied situations between persons with dementia, their family members and the formal services available. Although countries differ in culture, the structure of welfare services and family relations, there are important similarities. A European study, RightTimePlaceCare in eight countries in diverse areas, described services available to persons living with dementia and their families. It showed that general services in all the countries were under-utilised. The finding led the authors to speculate that emphasis on individually adjusted care plans for families was lacking (Bökberg et al., 2015). Many parties in the field view primary care as being well-positioned to provide holistic, continuous family-oriented healthcare, focused on individuals in their complex context of living (Fiscella & McDaniel, 2018; Khanassov & Vedel, 2016). Despite good intentions, however, primary care remains inadequate, and authorities have tended to overlook its potential for co-ordinating services and interdisciplinary integration to increase holistic long-term person-centred care (Hone, Macinko, & Millett, 2018; Rao & Pilot, 2014).

Stephan et al. (2018) described how poor co-ordination of services in Germany for persons living with dementia led to enhanced linkage between services identified as *dementia networks*. Yet, as the RightTimePlaceCare study observed, along with studies in other countries, such as Canada (Ceci et al., 2018; Ward-Griffin et al., 2012) and Australia (Lloyd & Stirling, 2011), these families' access to services is difficult, or people frequently do not view them as helpful, and the evidence base is still very limited (Røsvik et al., 2020).

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Studies have explored the needs of caregivers (McCabe, You, & Tatangelo, 2016) and the intersection between their care and formal services (Singh, Hussain, Khan, Irwin, & Foskey, 2014). These findings call for further exploration of how those responsible for services understand the nature and aims of services designed for families of persons with dementia in the community. This study's guiding research questions were: How do key informants (KI), working in dementia care, envision the needs of the families of persons living with dementia in the community and how do they describe the contribution of formal services to assist these families?

2 | METHODS

The findings presented in this article were part of a larger ethnographic study. It focused on how families living with dementia make arrangements to live as well as they can, and what support may be helpful. In this first part of our project, we focused on how professionals understand the formal care system contributes to meeting the needs of these families.

2.1 | Setting and participants

The data collection took place in the Reykjavik Greater Metropolitan Area in Iceland. Two of the authors collected the data. One has extensive experience in doing ethnographic research, and the other is a doctoral student with experience in qualitative work in addition to 10 years of clinical experience as a team leader in home care nursing. Both are keenly interested in developing knowledge on how to best support persons diagnosed with dementia living in the community and their families. The data were collected in Iceland with the approval of the National Bioethics Committee (VSNb2015020005/03.07).

We decided to approach managers and practitioners in different settings directly involved in organising and providing formal services to people living with dementia in the community. A purposeful sampling strategy and snowballing generated a sample of 20 participants. This approach allowed for good variation in sampling from different organisations providing care to persons with dementia living in the community and their families. These varied voices reflected diverse perspectives and understandings of the services provided. The participants were identified as KI (see Table 1). They participated in semi-structured interviews (see interview guide, Table 2). The interviewers asked participants to describe the services available, their understanding of what is helpful to families, and how services might be improved. All participants provided written informed consent.

The data collection started in 2016 and ended in 2018. Participants took the researcher on a round of each facility and described its main activities. The researchers wrote field notes after each visit. All KIs had extensive experience in organising and working with persons with dementia, and some of them also had a role in policy development. In addition to the typewritten interviews and field notes, we reviewed written documents like policy statements, printed information, and material posted on websites intended for the general public.

2.2 | Analysis

We chose the framework method for data analysis, a systematic and flexible approach well suited for research in the health sciences (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The framework yields a theme-based analysis by labelling and sorting the data and interpreting the main findings (Spencer, Ritchie, O'Connor, Morrel, & Barnard, 2014). After individually categorising, sorting and organising the data, the first and last authors together developed themes that all the authors then discussed. Attention focused on the families' trajectory through the system of diagnosis and support. The process involved both deductive analysis of the different ways of understanding dementia care presented in the introduction and inductive analysis, which called for openness towards the data. As themes related to the families' trajectory through services started to emerge, the interviews were re-read for comparison until we reached a final consensus.

3 | FINDINGS

We begin by describing the organisation of dementia care in Iceland and the trajectory of patients through the system (see Figure 1). We

TABLE 1 Number and role of participants

Number of participants	Professional role of Key informants
6	Nurses and geriatricians at the memory clinic at the National University Hospital of Iceland
4	Nursing managers (RNs) at specialised dementia day programs
3	Nurses and general practitioners in primary care
5	Managers of nursing and social service in public home care services
2	Managers at Alzheimer Iceland
20	Total

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then turn to our KIs understanding of the needs of the families and how they envision the services meeting those needs. We have organised the findings around service trajectories, from diagnosis at the memory clinic and to the specialised day programs. In addition, we discuss the contributions of primary healthcare and the voluntary sector at different points.

3.1 | Trajectory of dementia care in Iceland

When a person starts showing signs of memory difficulties, a physician, often a General Practitioner (GP), refers him or her to the memory clinic at the National University Hospital of Iceland. The clinic's focus has been on developing an accurate diagnosis of dementia and initiating the treatment. The memory clinic has served as a co-ordinating unit for specialised dementia healthcare services nationwide since its establishment in 1995 (Landspitali, 2017). Upon receiving a diagnosis of dementia, persons are offered regular follow-up at the clinic every 6 months. There they meet with a geriatrician and a nurse who assess how the disease has progressed, any needs for managing different symptoms and their families' resiliency. In cases of distress, the family is referred to the hospital's psychologist.

When the family's daily life shows signs of uneasiness and exhaustion, the service provider advises the family to apply for placement in a specialised dementia day program. Collective bimonthly meetings of the staff from the memory clinic and the directors of the programs manage the waiting list for the program. As the person starts a day program, the responsibility for co-ordinating all services shifts from the memory clinic to the directors of the day programs, while the physicians from the memory clinic continue to monitor treatments through weekly visits to each day program. Home care is usually added very late, or not at all, in the dementia process and has not been organised as general family support. Rather, they primarily provide that service when physical assistance is needed or medication support.

TABLE 2 Research interview guide

1. Participant asked to describe their current work.
2. Tell me about your experience with providing service to families of persons living with dementia at home.
3. What do you think are the most important issues to address regarding family members who are taking care of a loved one living with dementia at home?
4. Where do family members seek support, and how do you think that is working for them?
5. What, in your opinion, is most helpful in your service in supporting families of persons living with dementia at home?
6. What in your service do you think could be done differently to provide more support to these families?
7. What do you think is most important to people living with dementia and their families?
8. Can you give me an example of a family where you thought the service was doing well?
9. Can you give me an example of a family where the service was not doing well enough?
10. Who would you recommend I talk to for further insight into these matters?

3.2 | The importance of accurate diagnosis and follow-up

The memory clinic has focused on developing an accurate diagnosis of dementia and initiating the right treatment. Here is how one participant summed this up:

> We will do the assessments and the tests needed to arrive at a diagnosis, and then we will start the treatment and manage the follow-up. If everything runs smoothly and no difficult side effects show up, the person might be sent back to the family physician for further monitoring. Later, often around two years later, difficulties have started to emerge. Usually this leads to an application to a specialised day program
> (KI03 – Memory Clinic).

He continued describing how various medications were used to address symptoms like anxiety or agitation. As he noted, this may lead to more sedation, calling for more prompting and guidance from family members.

According to the nurses at the memory clinic, getting a diagnosis of the underlying condition is important to the families and often brings them relief. As they explained, knowing the nature of the situation is important as well as having access to formal services. One of the nurses used the expression *reaching shore* to capture both what families are dealing with and how to proceed: 'It is important for them to have an anchor, a professional on the other end of the line for guidance and support.' Part of reaching the shore was also for the family to be able to *let go*, meeting each day as it comes. 'They need to understand that no one can steer the progress of the illness… it is important for them to go with the flow of the dementia and find new meaning for the little things in life.' As she explained:

1. Signs of dementia: Referral from GP or other doctors to the memory clinic

2. Follow-up twice a year: Definite diagnosis and symptom management at the memory clinic

3. In need of more support: Specialised day program offered, which takes over the follow-up and symptom management

FIGURE 1 The formal dementia trajectory in Iceland

COLOUR online, B&W in print

> Families are diverse and deal with the diagnosis and dementia's pathways in different ways. Some relatives experience a major shock after the diagnosis of their loved one's dementia, but others develop more insight into the situation. It is important for us, the nurses at the memory clinic, to read the families and provide the right support to help them adjust to their new reality
> (KI05 – Memory Clinic).

Both the nurses at the memory clinic and the physicians regarded the nurses' purview to entail support of and consultation on daily life. As families leave the clinic at the end of each visit, the nurses hand out their card and encourage them to call. In exceptional cases, they also initiate contact to find out how the situation at home has developed. Although this support was considered helpful, our KIs also stated that families needed to find their own way, stand on their own feet without interference of outsiders or professionals. In collaboration with a psychologist at the clinic, the nurses had previously established support groups for family caregivers. Such activities, however, were erratic and had faded out. As one of the physicians explained, 'The focus of the memory clinic has been on the medical perspective, but we have also been trying to develop the nursing focus. However, it tends to fade out, and we have to start again' (KI03 – Memory Clinic). Regular follow-up every 6 months after diagnosis aims at monitoring changes in cognitive ability. Although KIs all agreed that the families of persons with dementia often found things difficult, many families seemed unsure about the roles of the formal health and social care systems in supporting families. Many of them described important support but acknowledged the limits of the system in meeting such needs. Some of them also questioned the capacity of the system to provide services that do not target the person experiencing cognitive difficulties, but rather family members who, strictly speaking, are not clients of the healthcare system. As one participant observed, 'being a family means that people have some obligation to one another' (KI05 – Memory Clinic). This indicated that the role of the healthcare system was to provide information and guidance to families so that they can better cope with difficult situations.

3.3 | When things at home get difficult: Focus on the family

Key informants discussed how many families start experiencing difficulties as the illness progresses. The person living with dementia may not be able to stay at home alone while the carer goes shopping or to work. The carer may need a break as his or her loved one becomes agitated in certain situations. As signs of family stress and exhaustion emerge, the person living with dementia is placed on a waiting list for a specialised day program.

The day programs are based on a relational understanding of the families' situation, emphasising meeting the needs of the persons in the context of their connections and surroundings. That all involved parties are part of a caring chain of the family. The KIs from the programs discussed how entering a day program can be a difficult time for families, and how they had tried to develop helpful practices to facilitate the transition. They explained how the services reflect Kitwood's (1997) philosophy of person-centred care, using life stories to design meaningful activities for each person. As the KIs noted, some individuals are very reluctant to spend time at day programs and need a gentle approach. Once they settle in, most of them start to relax. As one KI put it:

> It is important to concentrate on the strengths of each individual and stimulate his ability in every way. We focus on activity and joyful routine each day. But this requires building up trust and giving space for adjustment to a new situation
> (KI11 – Specialised Day Care).

The nurses described how much of their time is devoted to the family, providing opportunities for informal discussion of issues they are struggling with, complex emotions and possibilities for support from home care or temporary respite. In many cases, they organise family meetings and try to include all family members in the conversation. Although all KIs see the day programs as very important, they also see organisational inflexibility as an impediment. The day programs were open from 8 a.m. to 4 p.m., which many participants saw as restrictive for the persons living with dementia, who often like to sleep in and start the day slowly, and for relatives, who need time after work to shop and exercise.

3.4 | Dementia care re-defined: Enhanced participation of primary care

Although participants appreciated the work of the memory clinic and the special day programs, both the general public and professionals in dementia care have repeatedly voiced their concerns in the Icelandic media related to available support for families of persons living with dementia. A number of participants noted, that with increased incidence of cognitive difficulties, the waiting time for an appointment with the memory clinic had increased. These trends have provoked discussions about changes in work methods, turning the attention to primary healthcare services. They had not been part of the closely knit system of the memory clinic and specialised day programs. All persons showing signs of cognitive difficulty had been referred to the memory clinic for diagnosis and treatment. As an interviewed GP said:

> If I see a patient who is experiencing memory decline, I will make an appointment at the memory clinic. It has been my understanding that family physicians do not diagnose dementia or prescribe memory-enhancing medications
> (KI20 – Primary Health Care).

As this quote reflects, primary healthcare's purview of dementia care has been limited. Many KIs also described community services

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for people living with dementia as underdeveloped, poorly co-ordinated, highly fragmented and ill equipped to address the issues facing the families of persons living with dementia. In addition to the lack of communication between services, participants described the teamwork at the community healthcare centres as weak and the connection with home care services limited. The home care nurses noted that most of their referrals came from the acute care hospital, not from the community health centres.

On the other hand, home care nursing and social services were often described by others as overly task-oriented, i.e. provided in an 'in-and-out' style. This fact was related to the rigid schedule for care. In care plans, services are outlined in circumscribed assignments of designated tasks, providing limited opportunity for a person-centred approach. In general, participants agreed that the organisation of home care services meant that they were not designed to sufficiently meet the needs of persons with dementia. Time for extended visits to help with dressing and eating at a slower pace, for example, was not provided. Demands for cost containment had pressured the staff to get things done fast. This poorly fits persons living with dementia.

As participants from primary healthcare noted, GPs, community health nurses and home care nurses are well equipped to care for people in the early stages of dementia. They may have followed families for decades, know their strengths and weaknesses and have good insight into what may be helpful to the family to keep going at home. As a GP observed:

> The advantage of primary care is the broad overview the family physician has, more than the specialist. The discussion of dementia care at home has not sufficiently emphasised this
>
> (KI20 – Primary Health Care).

A community health nurse noted: 'We in primary health care are the first service the family contacts regarding dementia. Worried relatives often call us seeking advice' (KI19 – Primary Health Care). She described how developing trust is extremely important in the initial phase of dementia, but when the person is referred to the memory clinic, primary healthcare often loses contact with the person. Towards the end of data collection, this began to change. The annual report for primary healthcare in the Reykjavik Metropolitan Area told of the enhanced integration between services at the National University Hospital and the community healthcare centres. The report stated that the diagnosis and monitoring of cognitive difficulties were shifting to GPs and community health nurses (Primary Health Care, 2019).

It was noted that home care services had not developed formal work methods related to supporting families of persons with dementia, but our interviewees did describe practices that they used and found helpful in such cases. They discussed how important it was to develop rapport and trust before starting anything else, and how they might need to visit many times before they could start helping the person with dementia with personal hygiene. They understood that much of the work in the home relates to assisting the person to live as normal life as possible by cueing and directing everyday activities that have somehow been lost. The home care nurses also described how much of their work is directed to the relatives:

> Our role is to support and guide the relatives in their own home, with sincerity and humility. Give them time and allow them to go over things and help them to figure out ways to make things work in their daily life… It is important for the family to know their strengths, what they do well. Good communication between family members is the most vital element, and we can guide them with this in family meetings. But to do so we need time, and sorry to say, we don't have that time… Dementia care at home demands patience and consideration for vulnerable families, but our reality is speed and the pressure of workload
>
> (KI16 – Home Care).

Another home care nurse described how they tended to relate the family and different services and facilitate transitions when needed:

> Home care nurses play a role as a coordinator of services… We have an overview of the situation and needs, evaluate changes and get the right support, like consulting specialists and arranging respite. We also offer suggestions for specialised day programs and try to facilitate transition into the program
>
> (KI07 – Home Care).

However, this contribution from home care services did not seem to work out in all cases. Directors of the day programs interviewed were concerned about weaknesses in the home care services, such as inconsistent timing and constant staff turnover, that the persons in service and their families experienced negatively. They said that the assistance that the community home care services provided seemed to lack the sound understanding and knowledge of key importance to persons living with dementia.

To respond to the weaknesses in services described above the Icelandic health authorities recently published its first Action Plan for dementia care, outlining numerous initiatives (Ministry of Health, 2020). The plan calls for a formal collaboration between primary healthcare and the hospital's memory clinic in diagnosing and treating dementia. It also emphasises the specific role of a case manager for older people located at each community care centre, in supporting families where someone has dementia (Primary Health Care, 2019), while the memory clinic is expected to focus more on severe and difficult cases of dementia (Ministry of Health, 2020).

3.5 | Help from the voluntary sector

When mapping the trajectory of dementia, an important additional source of support cannot be overlooked. In 1985, relatives and others interested in supporting persons with dementia funded

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Alzheimer Iceland. Membership fees, public fundraising and support from private and public entities finance this independent association. It has stood vigil over its members' repeatedly voiced concerns over the lack of formal services and has taken action where needed (Alzheimersamtökin, n.d.). As part of a pioneering movement in the Nordic countries, it aims at increasing knowledge and understanding of dementia. The association has published educational material and has provided individual consultation to families (Alzheimer Iceland, n.d.). It has also organised support groups for relatives and runs many of the specialised day programs. They base their work on Tom Kitwood's theory of person-centred care (1997). Emphasising that even though people have been diagnosed with dementia, they continue to be thinking and feeling individuals with their own personal histories. The association identifies dementia as a family illness, highlighting the relatives' situation, as well as persons with dementia (Alzheimersamtökin, n.d.). One staff member described how, as the realities of a dementia diagnosis sink in, some families seek information and support. As she said:

> They want information about practical matters like what to do in certain situations and need assurance that what they are doing is the right thing to do. We cannot emphasise enough the importance of the person-centred approach – different ways for different people – and what works today may not work tomorrow. It is important to strengthen the family members' self-image as specialists on taking care of their loved one. They know him best
>
> (KI08 – Alzheimer Iceland).

The support provided by Alzheimer Iceland is an informal service, outside the formal dementia trajectory, and families turn to it on their own terms. No formal pathway directs families in need to seek this support. The KI from Alzheimer Iceland pointed out the importance of closer collaboration between service sectors in enabling outreach to families: 'Our contact with the memory clinic is limited, but there sadly is no communication between us, primary health care, and social services' (KI08 – Alzheimer Iceland).

4 | DISCUSSION

We have provided insights into how KIs in dementia care, both managers and practitioners, understand and envision the situation of families and their support needs. Our findings revealed how parties involved in dementia care have mainly understood it as a specialised service, requiring advanced medical knowledge of the disease and medication. The attention has largely centred on making an accurate diagnosis of the condition and exploring possible medical treatments—i.e. focusing on symptoms and behaviour. Thus, we can say that dementia services have primarily focused on the individual experiencing cognitive decline, and on the illness (Gjødsbøl & Svendsen, 2018; Moreira, 2010). Some consultation, although fragile, has been available to families. Focusing on the cognitive difficulties leaves out the holistic view of the family's situation. Adjusting to a new life with dementia is in the family's hands and seems to be viewed as a private matter where each family must find its own way.

Key informants acknowledged the families' situation was difficult. However, they were unsure of how the public services might be helpful. Alzheimer Iceland has contributed where the formal system has fallen short. For example, it has developed a comprehensive accessible website. In addition, it provides individual consultation, support groups for relatives, and specialised day programs. However, these measures have not been well integrated with the formal healthcare system.

At the same time, primary healthcare, including GPs, community health nurses and home care services, participates limitedly in dementia care. Informed parties described the services as poorly equipped and co-ordinated for responding to the needs of these families. As noted in our findings, towards the end of data collection, a policy shift had begun. The shift involved a transfer of dementia services to primary care, particularly in the early stages of the illness. This provides an opportunity to re-define these services, placing the family at the centre (Moreira, 2010; Moser, 2011). Addressing dementia in families through this understanding shifts the focus to how actors with different backgrounds contribute to care-giving. Dementia care becomes a joint project. It unites different actors, the person experiencing dementia and relatives in a collective project to make life as good as possible.

Dementia can be understood as indeterminate and open to intervention (Gjødsbøl & Svendsen, 2018). Ceci Symonds Brown and Judge (2020) observed that families develop arrangements so that [6] life at home can continue. They called for increased understanding and support of the arrangements that families make among those providing services. Some relatives attempt to isolate their loved one to prevent moments of confusion and disorientation (Berry, 2014), while others aim at maintaining abilities by prioritising things that have been valued (Le Galès & Bungener, 2019). Our KIs were aware of these differences, and some had developed care practices consistent with these ideas. In particular, the practitioners at the special day programs focused on individual strengths and guiding the family on a daily basis. The privilege of day care professionals was their close contact with both the memory clinic and home care staff. With daily evaluations of the persons with dementia and their family connections they were also able to assess and react to the detailed variations in the illness's behaviour and process. These findings are in line with the empirical studies of Gústafsdóttir (2011, 2014), suggesting that day programs can bring contentment and structure to families, by strengthening ties and easing the impact of dementia. However, specialised day programs do become available late in the process. Families need support earlier in the illness trajectory. Studies have shown that families appreciate flexible and individually tailored respite and home care services (Kampanellou et al., 2019). In light of its holistic and family-centred approach, primary care, [7] including home care, may be well placed to provide such services.

Such ideas can be noticed in the recently published Action Plan for dementia care (Ministry of Health, 2020) calling for integration between the memory clinic and primary care and transfer of the initial diagnosis and monitoring to primary healthcare.

Experiences from other countries, such as the EVIDEM-ED and Better Care Fund projects in the UK, show that such transitions are complex, and call for more than focused education of staff and formal planning (Harlock et al., 2019; Wilcock et al., 2013). Integration of services and collective emphasis does not happen instinctively. It is a long-term pursuit. It requires a shared vision and strong leadership as well as funding and educational focus (Harlock et al., 2019). Enhancing the participation and management of primary care, community-based physicians, nurses and home care services can potentially lead to a more holistic and helpful services.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest with respect to the research, authorship and/or publication of this article.

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Paper II

Paper II

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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

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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).

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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.

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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 (Gudnadottir *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

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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.

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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.

1. The case of Einar and Elin:

Generating a safe space and avoiding discomfort.
A protective shield built around the one with dementia, followed by an isolation of the care provider.

2. The case of Birgir and Barbara:

Fluctuating between being in and out of control of daily life situations.
The importance of being able to enjoy time with the loved one at home. Along with the feeling of instant helplessness and emotional breakdown, leading to a dramatical cry for help.

3. The case of Gunnar and Greta:

A long-time practice in reaching out for and accepting help.
A knowledge and recognition of their own vulnerable situation, leading to a sincere understanding on their need for support and competence 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

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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.

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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

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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 housekeeping 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.

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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

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> 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 was 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

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> 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.

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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:

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> 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

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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

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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 (Gudnadottir *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

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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

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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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Paper III

Paper III

When a space opens up: Families' experiences of specialised dementia day programme placements

(In review)

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