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Supportive strategies used by family members and formal caregivers in social interaction with deaf people with dementia

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In memory of my
parents Lahja and Martti
and brother Arto

Abstract

The declining ability to interact that accompanies dementia poses significant challenges for both family members and formal caregivers of people with dementia. However, limited attention has been given to the experiences and needs of deaf people who use national sign languages (SLs) because deaf people have largely been excluded from many studies. Due to the unique nature of SL as a visual-spatial language, the methods used to explore dementia and establish diagnoses in hearing people cannot be directly applied.

With this doctoral dissertation, I aimed to gain knowledge about social interaction of deaf people with dementia, focusing on Finnish Sign Language (FinSL) users, and to improve support services for deaf people with dementia. The study had three objectives: understanding the effects of dementia on deaf people, exploring strategies for providing support, and identifying factors that can enhance the abilities of family members and formal caregivers to communicate support. Family members and formal caregivers were chosen because they are typical interaction partners and support providers of deaf people with dementia. The dissertation comprises three published peer-reviewed articles.

Study I gathered family members' perceptions of changes in communication with deaf parents with dementia. Study II analyzed video recordings of interactions between formal caregivers (healthcare professionals) and deaf people with dementia in a dementia-specialized home of the Service Foundation for the Deaf. Study III interviewed formal caregivers to understand their perceptions of interaction with deaf people with dementia and strategies of supportive communication. The findings indicated various changes in language, interaction ability, memory, and behavior in deaf people with dementia. Eye contact was crucial for interaction among deaf people. Family members and formal caregivers need tools and skills to effectively support deaf people with dementia, emphasizing the importance of interpersonal communication competence along with specialized training in FinSL and dementia manifestation in deaf people.

In conclusion, this dissertation argues that deaf people with dementia benefit from support provided in SL, enabling them to feel acknowledged and seen. This highlights the need for expertise in national SL and for specialized knowledge of deaf people with dementia for family members and formal caregivers. It also highlights the need for family members and formal caregivers to receive support based on expertise in national SL and specialized knowledge of deaf people with dementia.

Keywords: CODA, dementia, deafness, Finnish Sign Language, formal caregiver, social interaction, supportive communication

Tiivistelmä

Muistisairauden aiheuttama vuorovaikutuskyvyn heikkeneminen haastaa sekä muistisairaan henkilön omaiset että hoitohenkilökunnan. Toistaiseksi liian vähäistä huomiota on kiinnitetty yleensä tutkimusten ulkopuolelle jätettyjen suomalaisia viittomakieliä käyttävien viittomakielisten kuurojen tarpeisiin ja kokemuksiin. Viittomakielten visuospatiaalisen erityisyyden vuoksi muistisairauden tutkimiseen kuuroilla ihmisillä ei voida sellaisenaan soveltaa kuulevien ihmisten tutkimisessa käytettyjä menetelmiä.

Tällä väitöskirjatutkimuksella oli kolme tavoitetta: saada syvällistä ymmärrystä muistisairauden vaikutuksista kuurojen ihmisten vuorovaikutukseen, selvittää, millä tavoin kuuroja muistisairaita ihmisiä voidaan tukea ja tunnistaa tekijöitä, jotka voivat parantaa omaisten ja hoitajien kykyä tarjota tukea. Väitöskirjassa tutkittiin suomalaisten viittomakielisten kuurojen muistisairaiden ihmisten vuorovaikutuksen muutoksia omaisten ja hoitajien näkökulmasta sekä omaisten ja hoitajien tarjoamaa tukea haastatteluiden ja videoaineiston avulla. Omaiset ja hoitajat valittiin, koska he ovat useimmiten vuorovaikutuksessa kuurojen muistisairaiden ihmisten kanssa ja siten myös tyypillisimpiä tuen tarjoajia. Väitöskirja koostuu kolmesta julkaistusta vertaisarvioidusta artikkelista sekä yhteenveto-osuudesta.

Väitöskirjan tulokset osoittavat, että kuurot muistisairaat ihmiset käyttävät viittomakieltä, puhetta tai näiden yhdistelmää, mutta he poikkeavat keskustelun aiheesta ja heillä on vaikeuksia löytää oikeita viittomia ja seurata keskusteluja. Muistisairailla ihmisillä ilmenee kielen, vuorovaikutuskyvyn ja käyttäytymisen muutoksia. Perheenjäsenille haastavinta oli se, että muistisairas läheinen toistaa samoja asioita jatkuvasti. Hoitajat korostivat vaikeuksia ymmärtää iäkkäämpien kuurojen käyttämää viittomakieltä. Perheenjäsenet ja hoitajat tarvitsevat taitoja ja välineitä tukeakseen tehokkaasti kuuroja muistisairaita ihmisiä. Ensiarvoisen tärkeää ovat vuorovaikutuskyvyt, viittomakielentaito ja erityistietämys kuuroilla ihmisillä ilmenevistä muistisairauksista.

Tulokset osoittavat, että vaikka hoitajat tukevat kuuroja muistisairaita ihmisiä, heidän tukensa ei aina ole riittävää. Riittämättömät viittomakielentaidot, erityisesti puutteet iäkkäiden ihmisten käyttämässä kielessä, ja puutteelliset tuen antamisen taidot heikentävät hoitajien antamaa tukea.

Loppupäätelmänä esitetään, että kuurot muistisairaat ihmiset hyötyvät viittomakielisestä tuesta, jonka avulla he tulevat nähdyiksi ja heidän tarpeensa tulevat esille. Omaiset ja hoitajat tarvitsevat myös tukea, joka perustuu viittomakielten tuntemukseen ja erityistietämykseen kuuroista muistisairaista ihmisistä.

Asiasanat: CODA, hoitaja, muistisairaudet, suomalainen viittomakieli, supportiivinen kommunikaatio, viittomakielisyys, vuorovaikutus

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I have been privileged to participate in INTERDEM Academy's summer schools in Maastricht, the Netherlands (2015), and in Nottingham, UK (2016). I want to thank all the speakers, the organizers and my fellow PhD researchers for the inspiring discussions, group work and various study trips. It was heartwarming to be part of a European dementia-research community and meet some of my peers later on other occasions, e.g., the 27th Alzheimer Europe Conference in Berlin, Germany (2017).

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1990-luvulla, filosofiset pohdinnat ovat osoittautuneet tarpeellisiksi vielä väitöskirjan valmistumisen kynnyksellä. Sisarusteni lapsia haluan kiittää monista yhteisistä hetkistä, kuten kesäreissuista. Sukupolvesta toiseen jatkuva elämäketju tulee teissä todeksi.

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Sieppijärvellä 8.1.2024
Minna Rantapää

Contents

List of original publications

This thesis is based on the following publications:

I Rantapää, M., & Pekkala, S. (2016). Changes in communication of Deaf people with dementia: A thematic interview with A close family member. *Dementia, 15*(5), 1205–1218. https://doi.org/10.1177/1471301214557183

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III Rantapää, M., Virtanen, I. A., & Pekkala, S. (2023). Formal caregivers' perceptions of everyday interaction with Deaf people with dementia. *Clinical gerontologist*. (ahead-of-print), 1–14. https://doi.org/10.1080/07317115.2023.2167623

The publications are referred to in the text by their roman numerals.

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List of abbreviations

AD	Alzheimer’s Disease
ADI	Alzheimer’s Disease International
CA	Conversation Analysis
CERAD	Consortium to Establish a Registry for Alzheimer’s Disease
CODA	Children of Deaf Adults
CST	Cognitive Stimulation Therapy
FinSL	Finnish Sign Language
ICBCS	Interactive Coping Behavior Coding System
MMSE	Mini-Mental State Examination
RN	Registered Nurse
SL	Sign Language
SLT	Speech and Language Therapist
VNVIS	Verbal and Nonverbal Interaction Scale
WHO	World Health Organization

Foreword

The first time I met a person with dementia was at a care home where I worked for a summer. It was the mid-1980s and I was 18. There, one lady lived downstairs where the residents were more capable of doing their daily activities, although they could no longer live at their homes. Those who needed more help lived upstairs. One day I saw the lady doing something in her room as she put a thing on her night table. She told me she was baking. I got a little confused because I could see there was no oven. The following summer I was working in a ward at a health center where I cared for a woman who was about 60 years old. She could not talk anymore, and she was lying on her side in a fetal position like a baby. She needed help with everything: feeding, washing, getting dressed and even changing her posture in bed. A decade or so later, my mother was visiting me and my family. She came to visit us a few times a year because we lived a long way apart. During her visits, she always baked some of her favorite cakes and this time was no different. However, when I tasted the cake she had made, the frosting was not sweet but salty: Instead of powdered sugar, she had used potato flour. Later, she was diagnosed with Alzheimer's disease, and this was perhaps one of the first signs of the illness.

Although I had training as a registered nurse (RN), I was not familiar with dementia. Even when I worked in a health center and administered Mini-Mental State Examinations (MMSE) as part of the routines of dementia detection in a primary care team, I did not really know what it was like to have dementia. It was not until my mother was diagnosed and during the years afterwards that I gradually learned what it was like – and what it was like to be the daughter of a mother with dementia. At first, she could live in her apartment with the help of home care, but later she had to move to a nursing home. Luckily, it was a home where Finnish Sign Language was used because my mother was deaf. I was very happy that she got a place in a facility where she could be safe and mingle with other residents and personnel using FinSL. She enjoyed living there and she was called "granny" among the others who were much younger than she was. I think living in that home gave her many good and happy years.

However, the motivation for this doctoral dissertation originates not from my own experiences and interests. When it was time to do my master's thesis in Health Sciences, I contacted the Service Foundation for the Deaf in Finland and inquired whether they had an idea of what could be worth researching. I wanted to study something that would be useful for the deaf community in Finland. At the same time, they had been contacted by the University of Helsinki searching for someone to join their research team on deaf people with dementia and communication. Good luck or destiny, that is how I found this path.

During the doctoral process I have learned that there are not many people globally who know about deaf people with dementia. The knowledge gathered among hearing people with dementia cannot be applied directly to deaf people, at least not until more research has been done. Because the deaf culture represents a collective rather than individualistic culture, it has been quite natural and essential to study the social interaction of deaf people with dementia and the supportive communication provided by family members and formal caregivers. "What happens to one, happens to all" is a very existential thought in the deaf community. However, in the community dementia is not necessarily well known, and it carries a stigma. Furthermore, it is ultimately important that deaf people have access to their own language during the whole dementia journey from detection onwards and that they consequently receive care and support.

Life is not solely in our own hands and not all our plans come true straight away. No journey is merely arriving at the destination, but it is the journey there that is what matters and is rewarding. Meanwhile, during this journey, I have learned much about myself, as a Child of Deaf Adults (CODA) and as an RN. I have also gotten answers to the questions I had when I was young, and even later, when my mother fell ill with dementia. Lastly, all the people I have met during this journey I cherish in my heart forever, and for them, I am most grateful. Thank you for your voices and signs that meaningful communication is a fundamental right and requirement.

1 Introduction

Dementia, known as "muistisairaudet" (*memory diseases*) in Finland, is a chronic condition that falls under the category of memory disorders (Duodecim, 2021). It is a significant public health concern, along with other chronic diseases, such as cardiovascular disease, diabetes, and asthma. Dementia places a substantial financial burden on the healthcare system; in addition, the disease has far-reaching effects on individuals living with the condition, as well as their families, other social relationships, and caregivers (Finnish Institute for Health and Welfare, 2022). Family caregivers—particularly spouses, who are predominantly women—often take on the responsibility of caring for individuals with dementia, despite insufficient recognition and support (World Health Organization [WHO], 2023b). The impact of dementia on individuals is profound; it progressively impairs cognitive and functional abilities, resulting in increased reliance on others for daily tasks and care (Bebbington, 2023).

There is a great body of research on various stages that may follow dementia, such as deteriorating language (e.g., Agbavor & Liang, 2022; Bayles et al., 2020; Calzà et al., 2021; Ellis & Astell, 2017; Li et al., 2016; Pekkala et al., 2013; Pozzebon et al., 2016; Tsantali et al., 2013; Walker et al., 2023) and cognition (e.g., Aggio et al., 2018; Kadlec et al., 2018). It has also been shown that dementia affects sensory and motor functions (e.g., Albers et al., 2015; Liou et al., 2020). Dementia may cause a memory deficit (e.g., Chen et al., 2019; Gagliardi & Vannini, 2022). It can also change behavior, causing agitation (e.g., Cummings et al., 2015; Panca et al., 2019; Sano et al., 2022). Furthermore, caring for people with dementia (e.g., Cameron et al., 2020; Ericson-Lidman et al., 2014) and communication in dementia (e.g., Alsawy et al., 2017; Chichirez & Purcărea, 2018) have also been subjects of research.

While extensive research exists on various aspects of dementia and social interaction, previous studies have primarily focused on mainstream hearing communities, excluding people with hearing or vision impairments. Research on social interaction among hearing people with dementia has been conducted on communication gestures (e.g., Glosser et al., 1998) and on awareness through interaction in daily activities (e.g., Öhman et al., 2008). The effectiveness of communicative strategies used by family (e.g., Savundranayagam & Orange, 2014) and formal caregivers (e.g., Wilson et al., 2012) has been researched. Studies have also explored methods to improve and enhance interaction for people with dementia (e.g., Egan et al., 2010; Elkins, 2011; Fried-Oken, 2018). However, research specific to older deaf[1] SL users has focused on activities of daily living (ADL) dependence, social interaction, and perceived health (Werngren-Elgstörm et al., 2005). Some researchers have highlighted the importance of health communication research among deaf people (Meador & Zazove, 2005).

Happily, deaf people with dementia have received growing attention in academic research (Atkinson et al., 2015; Fleurion et al., 2020; Hake & Farlow, 2006; Jones., 2015; Parker et al., 2010; Quinto-Pozos, 2014; Young et al., 2016). While some studies have explored the impact of hearing loss on cognitive decline (Chen et al., 2015; Gurgel et al., 2014; Lin et al., 2011, 2013; Yamada et al., 2016), this dissertation centers on the cultural minority of deaf people who use a national SL. The aim is to understand the changes in social interaction that follow dementia among the older members of the signing deaf community, rather than focusing on the hearing loss. Deaf people do not have direct access to information and services delivered in spoken language (Ferguson-Coleman et al., 2020), highlighting the importance of understanding how dementia manifests in their social interaction and how they can be supported. This dissertation addresses the gap in research concerning social interaction of deaf people with dementia who use sign language (SL).

The aim of this dissertation is to explore the social interaction of deaf people with dementia, the impact of dementia on their social interaction, the resulting changes, and how family members and formal caregivers communicate support and enhance the well-being of those affected. Social interaction is a fundamental human need, and understanding the changes that occur in the interaction abilities of deaf people with dementia is crucial for their well-being. Family members and formal caregivers are most often in interaction with deaf people with dementia and accordingly typical support providers for them. Therefore, they are chosen for this study. Through empirical qualitative research, this dissertation aims to shed light on the social interaction of deaf people with dementia. The primary objective is to understand and describe their interactions with family members and formal caregivers. Ultimately, this dissertation aims to provide a description and understanding of how supportive communication for deaf people with dementia provided by their family members and formal caregivers can be enhanced.

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[1] In some communities and research, "Deaf" with a capital "D" refers to people identifying as a minority with its own language and culture (the Deaf community; Sheppard & Badger, 2010), whereas "deaf" refers to people with hearing loss. This practice was in fact utilized in Studies I–III. However, this distinction is not universally agreed upon. It is possible that the preference for "Deaf" has become less emphasized in recent years, as language and cultural norms evolve (Emmorey, 2023; Fenlon et al., 2015; de Meulder et al., 2019). Therefore, this dissertation utilizes "deaf" with a lowercase "d."

This dissertation comprises themed chapters. Chapter 2 establishes the theoretical dimensions and previous investigations of deaf people with dementia. Chapter 3 outlines the aims and research questions. Chapter 4 describes the methodology and ethical considerations. Chapter 5 presents the research results. Chapter 6 discusses the significant findings, focusing on changes in social interaction and supportive communication. It also explores the implications of the findings and provides suggestions for future research.

2 Review of the literature

> "Communication is the means by which
> people maintain interpersonal attachments."
> (Ward et al., 2008, p. 646)

Social interaction of deaf people with dementia is a phenomenon that is not widely known. In general, the wider population and healthcare professionals in particular tend not to recognize deaf people as being members of a sociocultural (Ladd & Lane, 2013) community that uses visual-spatial SL. Rather, they concentrate on the deaf person's hearing deficit. Consequently, when a deaf person with or without dementia seeks care in public health services, primary care physicians, neurologists and care personnel usually are not aware of the availability of SL interpreters and how to order one, even though according to the Sign Language Act (359/2015, §3) all people in Finland have the right to use their native language. Furthermore, adequate interpreter services must be arranged for patients using healthcare services according to the Act on the Status and Rights of Patients (785/1992, §3–4). In addition, the linguistic rights of deaf SL users are laid down in the Constitution of Finland (731/1999, §6, §17) and in the Act on the Interpreting Services of Disabled Persons (133/2010, §10).

In social interaction with family members and formal caregivers, deaf people no doubt experience confusion when facing the changes that come with dementia without getting thorough information and support in their own language, SL (Ferguson-Coleman et al., 2014). Receiving a dementia diagnosis may be shocking for some (Rochford-Brennan, 2022). For others, it may be rather a confirmation of presumptions (Kergoat, 2022). However, for a deaf person, getting support from their own community may be difficult due to lack of knowledge and fear of stigma, and especially so because of being a member of a collective culture in which it is considered that what happens to one happens to all in the community (Ferguson-Coleman & Young, 2018).

This literature review begins with the medical perspective of dementia and continues with the personhood perspective towards the social and cultural perspective of dementia and deafness. Next, person-centered dementia care is considered. The review concludes with interactional perspective and supportive communication, which form the theoretical frame of this dissertation.

2.1 The impacts of dementia on social interaction

Globally, over 55 million people live with dementia, and the number is projected to increase to 78 million by 2030 (Gauthier et al., 2021). As a result, dementia has become a leading cause of residential care needs among older people (WHO, 2023b). Dementia is an umbrella term for various neurogenerative illnesses that cause declines in memory and other cognitive abilities (Aggio et al., 2018; American Psychiatric Association, 2013; Setién-Suero et al., 2022). Dementia affects language (e.g., Bayles et al., 2020; Walker et al., 2023) and performance of tasks (e.g., Aggio et al., 2018). Furthermore, it affects behavior (van der Linde et al., 2016). Dementia also affects motor (Albers et al., 2015; Lawrence et al., 2014) and finger dexterity (Liou et al., 2020; Suzumura et al., 2018). Thinking and social abilities deteriorate severely enough to interfere with one's activities of daily living and social autonomy (American Psychiatric Association, 2013). Accordingly, a strong link has been found between health status (frailty) and accumulated health deficits in dementia (Wallace et al., 2021).

Alzheimer's disease (AD) is a prevalent form of dementia, accounting for approximately 60%–70% of all dementia cases (Jack et al., 2018; WHO, 2023b). AD is characterized as a continuum consisting of six stages, each representing different levels of cognitive impairment and functional impact on daily activities (Jack et al., 2018). Table 1 displays the stages of AD.

Table 1 The stages of Alzheimer's disease (Jack et al., 2018).

Stage	Features of cognitive abilities
Unimpaired	Individuals in this stage do not show any cognitive decline or functional impairment.
Transitional cognitive decline	Mild changes in cognitive abilities may be observed, but these changes do not significantly affect daily activities.
Cognitive impairment with mild functional impact on more complex activities of daily life	Cognitive decline becomes more noticeable, resulting in mild difficulties with complex tasks.
Mild dementia	Cognitive impairments become more evident, and individuals may require assistance with basic activities of daily living.
Moderate dementia	Cognitive decline progresses further, leading to significant difficulties with daily activities and a greater need for assistance and supervision.
Severe dementia	Individuals experience severe cognitive impairment and loss of independence and require extensive support for all aspects of daily life.

Typical AD commonly manifests with memory impairment and various cognitive functions, such as abstract and conceptual thinking, decline (Allone et al., 2018; Bebbington et al., 2023; Laczó et al., 2022). Sensorimotor or visual-motor declines (Albers et al., 2015; Tippett et al., 2012), as well as spatial navigation difficulties (Howett et al., 2019), are also present. AD typically affects executive and visual-spatial functions (Walker et al., 2023). Furthermore, AD causes psychological changes, such as affective and behavioral changes (Cummings et al., 2015; van der Linde et al., 2016).

Language impairment is an early sign and typical in AD (Bayles et al., 2020; Calzà et al., 2021). AD is related to progressive cognitive declines, including impairments in speech, e.g., changes in voice production (Agbavor & Liang, 2022). In addition, speech tempo and pauses in speech can occur (Szatloczki et al., 2015). AD challenges both comprehension and production of language (Tsantali et al., 2013). Language impairment manifests itself as difficulties in word finding and paraphrasing as well as challenges in social interaction, e.g., in the form of decreased talk and responses to interpersonal communication (Pozzebon et al., 2016). However, people with dementia can maintain their communicative abilities during mild to moderate stages of dementia, although linguistic challenges can emerge in the early stages of dementia (Calzà et al., 2021; Pekkala et al., 2013). Therefore, the ability to initiate and maintain interactions with other people declines in the continuum of dementia (Evans et al., 2007; Walker et al., 2023). Eventually, these problems may lead to the inability to use speech and language (Ellis & Astell, 2017).

Emotional processing is strongly affected in AD (e.g., Setién-Suero et al., 2022). Consequently, people with AD can experience rapid changes in mood, irritability and outbursts exhibiting behavior consistent with emotional distress, manifesting motor activity, verbal or physical aggression, and behavior that leads to excess disability not caused by any other disorder (Cummings et al., 2015). Furthermore, behavioral, and depressive symptoms are more severe in AD with agitation compared to AD without agitation (van der Mussele et al., 2015). Increases in changes in language and social interaction create social deprivation and reduce the quality of life of people with dementia and their caregivers (Saunders et al., 2011). Reduced social participation is associated with the risk of dementia (Rafnsson et al., 2020).

In Finland, the national recommendation for examining patients with memory disorders in primary care includes some cognitive tests used as part of the diagnosing process (Duodecim, 2021). The Consortium to Establish a Registry for Alzheimer’s Disease (CERAD, Morris et al., 1989) was created to develop materials for early diagnosis, which consist of eight sets of tests including the Mini-Mental State Examination (MMSE, Folstein et al., 1975). MMSE is a short cognitive test recommended for the detection of a more advanced memory disorder and annual follow-ups of AD after the diagnosis has been disclosed. The maximum score on MMSE is 30 points, and mistakes lower the score. Scores of 25–30 with an apparent memory decline demand further examination, and scores of 24 or less are considered deviant. Several tasks on the MMSE demand linguistic skills, and education and social status are found to affect the MMSE result. Both CERAD and MMSE have been translated into FinSL (Rainò, 2010).

As regards further language assessment in diagnosing dementia, the Arizona Battery of Communication Disorders of Dementia (ABCD) is a standardized assessment tool specifically developed to evaluate cognition and language abilities in individuals who are at risk for mild cognitive impairment or have mild to moderate dementia (Bayles et al., 2020). The ABCD consists of various subtests that assess different aspects of language and cognitive function. These subtests include evaluations of language comprehension, language expression, verbal memory, visual-construction abilities, and mental status. In addition, the ABCD includes screening tasks to identify any potential issues related to illiteracy or hearing loss that may affect the assessment results. By utilizing the ABCD, clinicians and researchers can obtain a comprehensive evaluation of an individual's language and cognitive abilities, providing valuable insights into their overall communicative and cognitive functioning. However, the ABCD has not been translated into FinSL.

In sum, dementia affects language and memory functions of an individual causing word-finding difficulties, losing the thread of a discussion, and repetition of ideas and phrases (Bayles et al., 2020). As a result, when communication skills of people with dementia deteriorate, dementia affects their social interaction with others. Furthermore, psychological well-being and losing oneself, combined with deteriorating communication skills, have an impact on the quality of life of people with dementia (Savundranayagam et al., 2016). AD reduces well-being capacity for adaptation and resilience, which means the ability to compensate for major events that threaten an individual's life or function (Meléndez et al., 2018). Consequently, the need for social support among people with dementia increases.

This dissertation concentrates on AD because it is the most common cause of dementia and there is a great body of diverse research on AD. In addition, the deaf people with dementia participating in this dissertation were clinically diagnosed with AD. How AD impacts deaf people will be explored next, concentrating on changes of memory and communication processes.

2.2 Deaf people with dementia

When discussing deafness and aging, the hearing deficit often becomes the focus (Chen et al., 2015; Viljanen et al., 2014). However, there are diverse perspectives to deafness that the mainstream community is usually not aware of (Ferguson-Coleman & Young, 2018; Young & Hunt, 2011). Firstly, age-related hearing deterioration concerns people using spoken language, who continue using spoken language. Secondly, congenital or infancy deafness concerns people who are born deaf or become deaf in early childhood, often using SL. Consequently, the crucial difference is the language. Furthermore, in the latter case, it is also a matter of identifying with the deaf community (Sheppard & Badger, 2010).

2.2.1 Deafness and Sign Language in light of dementia

Hearing deterioration is a natural part of aging, and even though hearing aids have become more advanced, we can expect people to experience reduced hearing later in life. Globally, 1.5 billion people (20% of the global population) are estimated to live with hearing loss, of which 430 million have disabling hearing loss (WHO, 2023a). Approximately 30% of European people over 50 have difficulties in hearing, seeing, or both (Viljanen et al., 2014). Hearing loss has been shown to be associated with a decrease of physical functioning in older people, and to be associated with a 31% risk for disability and need for care in women (Chen et al., 2015). Furthermore, hearing loss has also been connected to the incidence of all-cause dementia (Lin et al., 2011). However, these studies have concerned people using spoken languages, and it is not known whether deaf people using SL have a similar risk.

Sensory difficulties have been associated with social inactivity, particularly with dual sensory loss (Viljanen et al., 2014). Decreased social activity is a known risk factor for cognitive decline, and in nursing homes, residents with both dual sensory loss and social inactivity are at risk of a faster decline of cognitive function (Yamada et al., 2016). People with dementia have less frequent social interaction compared to people with mild cognitive impairments (Samtani et al., 2021). However, the quality rather than the quantity of social interaction is associated with the risk of AD (Amieva et al., 2010). Although hearing loss is considered to increase social deprivation and cognitive decline, there is more to it. Other, and perhaps more influential, determinants are different health and socioeconomic issues (Viljanen et al., 2014).

Deaf people form a cultural-linguistic group, yet one distinctive from ethnic minorities (Young & Hunt, 2011), and represent a collective rather than individualistic culture (Kusters, 2014). Furthermore, deaf culture is strongly visual (Ferguson-Coleman & Young, 2018). Visuality plays a significant role in cultural components, i.e., language, behavioral norms, values, and traditions (Minnesota Deaf and Hard of Hearing Services Division, 2023). Along with language, deaf community has its behavioral norms, such as eye contact, hand waving or tapping the shoulder for getting attention (Minnesota Deaf and Hard of Hearing Services Division, 2023). Additionally, conversations are typically open and direct, and an interest is taken in other people's connection with the deaf community. Sightline, to be able to see each other to communicate, is essential for deaf people (Ferguson-Coleman & Young, 2018).

In recent decades, the world for deaf people in Finland has undergone significant changes, particularly in the realms of deaf education, occupational opportunities, work choices, and access to services such as SL interpreters. These changes stand in strong contrast to the experiences of the deaf people discussed in this dissertation, who grew up over 50 years ago. During that time period, both in Finland and in many other countries globally, schools for the deaf followed an oralistic approach from the late 19th century until the 1970s (Ladd & Lane, 2013; Salmi & Laakso, 2005). Under this oralistic tradition, teachers primarily communicated with deaf children through clear mouthing, aiming for them to learn to speak and lip-read (Ladd, 2003). During the last few decades, FinSL has evolved from a banned and stigmatized language to a legitimate one which is studied and researched on the university level and used within various domains of the Finnish community, from day care to television news. Another major change is in the FinSL alphabets, which are now the international ones, whereas many older deaf people use the old ones.

Furthermore, the use of SL was strictly prohibited in schools for the deaf, and deaf children faced physical punishment if caught using it (Ladd & Lane, 2013; Salmi & Laakso, 2005). Consequently, many older deaf people today may still strongly feel that you should speak to hearing people. However, it is important to note that in Finland, it is common for deaf people over the age of 75 to employ various communication methods depending on their conversation partners. In their interactions with non-signing hearing people, these older deaf people often utilize speech, lip-reading, writing, and mime. Conversely, when communicating with other deaf people, they typically rely on FinSL. This fluid adaptation to different communication modes reflects the diverse ways in which older deaf people in Finland engage in effective communication with people from different linguistic backgrounds. How AD affects FinSL and the ways deaf people interact with other people is yet not known.

2.2.2 Deaf people with dementia as a minority

Despite AD being described over a century ago (Alzheimer, 1907) and the extensive research conducted on this topic, there is a growing body of studies specifically focused on deaf people with dementia (e.g., Allan et al., 2005; Atkinson et al., 2015; Falchook et al., 2013; Ferguson-Coleman & Young, 2018, 2023; Ferguson-Coleman et al., 2023; Harris et al., 2020, 2021; Hepner et al., 2022; Young et al., 2018). Globally, there is a lack of available statistics regarding the prevalence of dementia among deaf people. However, it is crucial to gather knowledge about the well-being and health of minority groups, including deaf people, to design and enhance support services that are tailored to their specific needs. Understanding the unique experiences and challenges faced by deaf people with dementia is essential for the development of effective interventions and support systems. By addressing the specific needs of this population, healthcare and social service providers can ensure that appropriate care and assistance are provided to enhance clients' overall well-being and quality of life. Further research and attention are required to bridge the gap in knowledge and to promote inclusive practices that prioritize the health and welfare of deaf people affected by dementia.

Previous research on ethnic minorities has indeed highlighted challenges in the diagnosis and organization of dementia care (e.g., Kenning et al., 2017; Lewis et al., 2021). Similar difficulties can arise when addressing the needs of deaf people with dementia, because there may be a lack of shared language and cultural understanding between them and their hearing caregivers (Harris et al., 2020, 2021). Consequently, communication barriers can impede effective interaction and limit social opportunities within care homes (e.g., Hanssen, 2013). Furthermore, deaf people with dementia often feel that their experiences and needs are not recognized or understood by the hearing world, primarily due to the absence of a common language (Allan et al., 2005). Consequently, deaf people with dementia may experience social isolation and loneliness as their unique needs and experiences go unrecognized (Parker et al., 2010). This sense of disconnection can lead to feelings of isolation and frustration. Interestingly, deaf people may also face difficulties within the deaf community itself, as there is often a lack of awareness and understanding about dementia (Ferguson-Coleman et al., 2014; Ferguson-Coleman & Young, 2018).

To address these challenges, it is crucial to amplify the voices of deaf people with dementia. Their unique perspectives and experiences need to be acknowledged and considered in research, policy development, and service provision. By promoting awareness, education, and cultural sensitivity, we can work towards creating inclusive environments that support the well-being and dignity of deaf people with dementia.

The development of dementia assessment specifically designed for deaf people in Europe is relatively recent. To the best of the author's knowledge, cognitive assessment translations in SLs, such as FinSL in Finland (Rainò, 2010), British Sign Language (BSL) in the United Kingdom (Denmark et al., 2016), and French Sign Language (FSL) in France (Fleurion et al., 2021), have been validated. The United Kingdom may boast the first specialist cognitive clinic for the deaf, i.e., a neurology clinic with deaf awareness and proficiency in BSL (Harris et al., 2020, 2021). However, the availability of care opportunities tailored to deaf people with dementia in SL are still limited (Ferguson-Coleman et al., 2020), and the views of care home staff and deaf people may differ (Hepner et al., 2022). Addressing this gap requires increased awareness and education among hearing healthcare professionals about the deaf community, SL, and the cultural aspects of deafness. Efforts should also focus on promoting the development and accessibility of comprehensive dementia care services that are inclusive of deaf people and their unique communication needs. By fostering a supportive and understanding environment, we can strive to improve the well-being of deaf people with dementia.

In summary, existing research on deaf people with dementia has highlighted the detrimental impact of dementia on language skills (Falchook et al., 2013; Hake & Farlow, 2006). Additionally, dementia affects SL communication among deaf people, leading to the use of inappropriate signs, incorrect structure, difficulty constructing sentences, and altered signing space (Ferguson-Coleman & Young, 2018). Moreover, the relationships between deaf people with dementia and their family members and formal caregivers are influenced by the condition (Parker et al., 2010). A notable characteristic observed in deaf people with dementia who belong to a visually-oriented culture is their tendency to disengage from conversations by avoiding eye contact when discussing unpleasant topics. This communicative behavior is seen as a way of expressing discomfort and actively excluding oneself from the conversation (Ferguson-Coleman & Young, 2018). These findings emphasize the importance of understanding the unique challenges faced by deaf people with dementia, particularly in relation to their communication abilities and social interaction. By recognizing these specific issues, appropriate support and interventions can be developed to enhance the well-being and quality of life of deaf people with dementia.

Previous literature on deaf people without dementia has shown that members of the deaf community experience worse mental health and worse cardiovascular and sexual health outcomes than non-deaf individuals (Malebranche et al., 2020). Deaf people often have higher levels of underdiagnosis, and their medical conditions are undertreated (Harris et al., 2020). Furthermore, deaf patients with cognitive symptoms have difficulties obtaining an accurate and timely diagnosis (Harris et al., 2021). In addition, health care providers lack cultural competence in providing care to deaf people, e.g., they do not always provide interpreters in medical settings, or they provide insufficient care due to communication barriers (Lesch et al., 2019). A recent intervention review of 46 studies showed that interventions that promote healthcare equity, health education amongst deaf patients, and healthcare providers' awareness of communication barriers and cultural sensitivity are promising in providing more equitable care for deaf patients (Morisod et al., 2022).

Research on deaf people with dementia consists mainly of case studies (e.g., Falchook et al., 2013; Hake & Farlow, 2006; Parker et al., 2010) and other small-scale studies (Ferguson-Coleman & Young, 2018; Young et al., 2016), which is natural, considering the relatively small deaf community. What is often thoroughly discussed in these studies is the consideration of the sociocultural perception of deafness (see Ferguson-Coleman et al., 2014, 2018, 2020; Young et al., 2016, 2020). Development of linguistic-cultural assessment tools for deaf people (Atkinson et al., 2015; Denmark et al., 2016; Fleurion et al., 2021; Rogers et al., 2018a) and a specialist cognitive clinic (Harris et al., 2020, 2021) has been successful in some deaf communities. However, not all deaf communities are alike; e.g., in the Netherlands, a project plan for developing a specialized outpatient clinic for deaf and hard-of-hearing patients was terminated due to lack of interest and need (Smeijers et al., 2020).

2.3 Dementia care

Dementia care refers to care for people living with dementia (Reid, 2018). It comprises a process of care from disclosing diagnosis and sharing information (Kergoat, 2022; Yates et al., 2021) to providing support for daily life (Fazio et al., 2018). Support for daily life typically suggests “routines of care,” e.g., physical care, such as getting washed, dressed, and fed (Cations et al., 2018; Ward et al., 2008). In addition, dementia care comprises enabling meaningful activities (Gilster et al., 2018) and, finally, end-of-life-care (Handley et al., 2022; Hennings et al., 2010).

Approximately 60% of older adults diagnosed with AD or other forms of dementia continue to live in the community, with only 25% of them living alone (Fazio et al., 2018). As the disease progresses, people with AD typically rely more on the support and care provided by family members and unpaid caregivers, as well as community-based and residential care providers (Reid, 2018). Regarding informal caregivers, it is often spouses who provide constant care at home (Boylstein & Hayes, 2012). In addition, dementia care is provided by adult children, and formal caregivers, i.e., healthcare professionals (Reid, 2018).

People with dementia require increasing assistance to manage their daily activities and ensure their well-being as their cognitive abilities decline. The involvement of family members and caregivers becomes crucial in supporting and meeting the needs of individuals with dementia throughout the different stages of the disease. Consequently, dementia affects not only the person living with dementia but their family and nursing staff (Pozzebon et al., 2016; Small et al., 2005). Although it is common that the spouse becomes the caregiver, the adult daughter or daughter-in-law is more likely than the adult son or son-in-law to provide care when a spouse is not available (Haberkern et al., 2015; Hoff, 2015; Pope et al., 2012; Smith & Rodham, 2022).

Degeneration in language production and comprehension may cause frustration both in the person with dementia and in the family member because they are not able to communicate in the same way as before dementia, and boredom and tiredness accompany repeating themselves (Morris et al., 2020). Furthermore, family members may feel confused when the roles in the family change and interpersonal dependency increases, not to mention grief and emotionally intense interactions that follow dementia (Pozzebon et al., 2016). Therefore, family caregivers of people with dementia experience psychological distress (Abreu et al., 2018). Previous studies have found that, e.g., adult daughters perceive that dementia of their parents impacts their identity and creates a duality of roles, although, at the same time, they step up to the challenge and find help (Smith & Rodham, 2022).

Additionally, formal dementia care covers, e.g., respite services, adult day centers and dementia care in care or nursing homes (Ericson-Lidman et al., 2014; Fazio et al., 2018; Gilster et al., 2018; Handley et al., 2022; Savundranayagam et al., 2007; Åhlin et al., 2022). Community-based and residential care providers play an essential role in delivering specialized care and services to enhance the quality of life for those with AD (Reid, 2018). However, globally 85% of over 55 million people with dementia are not receiving any post-diagnosis care (Alzheimer's Disease International [ADI], 2022). As a result, there is an urgent need for post-diagnosis treatment, care, and support services for people with dementia. What is seen as relevant for dementia care is person-centered care, support for caregivers, and an evolving role for clinicians through the continuum of dementia (Lee & Hillier, 2022). Furthermore, a care model that enables cohesive relationships between people with dementia and informal and formal caregivers is considered essential. In sum, dementia care is communicated in interaction, throughout the care process in the continuum of dementia. Figure 1 illustrates dementia care during the continuum of dementia based on the dementia care practice recommendations by the Alzheimer's Association (Fazio et al., 2018).

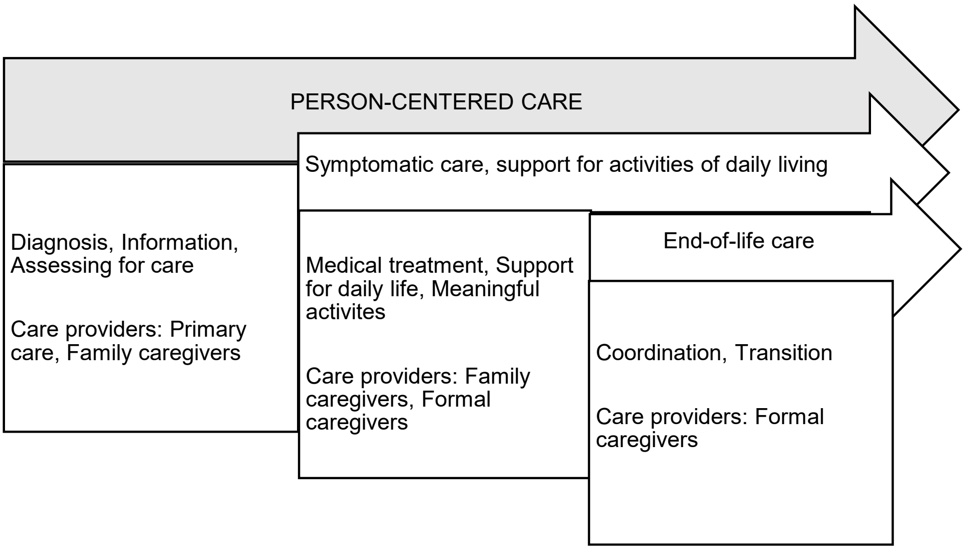


Figure 1 Dementia care practices and care providers (modified from Fazio et al., 2018).

2.3.1 Dimensions of dementia care

Dementia is incurable and progressive (Mitchell et al., 2010). Consequently, pharmacological interventions are utilized to postpone the progression of symptoms or avert disease progression while nonpharmacological, e.g., neuropsychological, interventions are being developed (Amieva et al., 2016; Rodakowski et al., 2015). Cognitive interventions combined with other nonpharmacological inventions, e.g., physical exercise, are optimal for having a positive effect on cognition, neuropsychological symptoms, depression, quality of life, basic activities of daily living, and instrumental activities of daily living in individuals with AD (Xiang & Zhang, 2023). To conclude, cognitive interventions consist of cognitive rehabilitation, cognitive training, and cognitive stimulation (Kim, 2015; Xiang & Zhang, 2023).

Cognitive rehabilitation is often overlooked in dementia care but can significantly improve memory and related everyday functions (Cations et al., 2018). The field draws from stroke and brain injury rehabilitation and aims to enhance language, social interaction, and self-care in a person's natural environment (Clare, 2017). Individualized and person-centered, cognitive rehabilitation enables people with dementia to engage meaningfully in daily life with their families and communities (Bahar-Fuchs et al., 2019; Bayles et al., 2020; Clare, 2017; Øksnebjerg et al., 2020). Cognitive training involves standardized tasks to improve specific cognitive impairments individually or in groups (Bahar-Fuchs et al., 2019). It has shown promising results in enhancing cognitive functions and activities of daily living in people with dementia (Kim, 2015).

Cognitive Stimulation Therapy (CST) is a group-oriented, evidence-based approach using enjoyable social activities, such as reminiscence therapy, as well as multisensory stimulation and learning principles to enhance cognitive function and behavior (Cafferata et al., 2021; Lobbia et al., 2019; Oliveira et al., 2021). CST, based on person-centered care principles, has shown positive effects on cognition, quality of life, communication, and social interaction in people with dementia (Bahar-Fuchs et al., 2019; Spector et al., 2011; Xiang & Zhang, 2023). These interventions, especially CST, hold promise for application in deaf people with dementia, particularly in small group settings.

2.3.2 Dementia care for deaf people in Finland

In the case of deaf people developing dementia, there can be significant delays in obtaining a diagnosis, receiving appropriate treatment, and accessing the necessary support (Harris et al., 2020, 2021; Young et al., 2016). This is primarily due to the scarcity of care services available in SL and the limited options for nursing homes that cater specifically to deaf people with dementia (Parker et al., 2010; Rogers et al., 2018b). Consequently, deaf people encounter numerous challenges that adversely affect their quality of life (Parker et al., 2010).

One of the primary challenges faced by deaf people with dementia is the lack of a common language with their caregivers, making effective communication difficult (Parker et al., 2010). Furthermore, when it comes to diagnosing their condition, they may encounter barriers when interacting with physicians and nurses, necessitating the use of SL interpreters (Ferguson-Coleman et al., 2020; Harris et al., 2020, 2021; Parker et al., 2010). However, this reliance on interpreters can lead to misunderstandings and misinterpretations, further complicating their care.

In Finland, the estimated number of people living with various memory diseases is over 190,000 (ca. 3.5%) out of the total population of 5.5 million, and annually ca. 14,500 people are diagnosed with dementia, the majority being over 80 years of age (Finnish Institute for Health and Welfare, 2022). According to the Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons (980/2012), the goal is for older people to stay at home with the help of homecare and community nurses, if possible, and to postpone admission to a long-term-care unit until inevitable. For the older person to stay at home is also often the aim of the family caregivers of people with dementia

(Lord et al., 2016). Family caregivers see residential care as the last resort and try to cope as long as possible (Cole et al., 2018).

For a deaf person with dementia, living in an environment with non-signing caregivers confuses and frustrates them, as well as creates sadness (Parker et al., 2010). Even when sharing a common language, caregivers with an overload in residential care have been found to avoid communication with hearing residents with dementia (Tappen et al., 1997; Ward et al., 2008). In addition, communication is often considered difficult or impossible with persons with advanced dementia (Tappen et al., 1997). However, the opportunity to interact socially with others is essential to dementia care (Hepner et al., 2022).

Loneliness and social deprivation for deaf people can be more damaging than for hearing people, who can get information from radio and TV and who can more easily communicate with, e.g., healthcare professionals (Parker et al., 2010). Not only information in SL but also cultural equivalence of the healthcare information for deaf people is often lacking (Ferguson-Coleman et al., 2014; Harris et al., 2020, 2021; Hepner et al., 2020; Lesch et al., 2019; Young et al., 2016). Although deaf people with dementia may lose their language more easily when not regularly communicating in their own language, i.e., SL, it might be possible for them to gain back their SL and interaction abilities when admitted to a Home for deaf people. Therefore, it is important to explore whether SL abilities could be strengthened in a signing environment.

There are limited number of nursing homes or municipal care units that offer care in FinSL and provide a living environment where deaf people with dementia can be among their peers. This scarcity of suitable care facilities specifically designed to meet the needs of deaf people with dementia exacerbates their communicative isolation and deprives them of social stimulation, ultimately contributing to a decline in their interaction skills and negatively impacting their overall quality of life (see Hepner et al., 2022; Parker et al., 2010).

There are no global statistics of how many deaf people live with dementia. In Finland, approximately 3000 people out of the total population of 5.5 million are deaf FinSL users (Kuurojen Liitto, 2023). Estimations using the national incidence rate (5% of people aged 65–75 years have moderate to severe dementia) of people with dementia (Finnish Institute for Health and Welfare, 2022) may mean that ca. 155 deaf people in Finland have dementia. In comparison, in the United Kingdom the estimated number of deaf people with dementia is ca. 450–850 (Young et al., 2014).

In Finland, access to home care services in FinSL is provided by the Service Foundation for the Deaf in six towns, alongside a few private service providers (Service Foundation for the Deaf, 2018). However, it is noteworthy that these services are not available throughout the entire country. Providing FinSL services for people with dementia depends on the financial commitment of their hometown.

Consequently, while some deaf people with dementia may have access to FinSL services, others may not be as fortunate. Furthermore, in Finland, there is only one nursing home (referred to as "Home") specifically designed to cater to the needs of deaf people with dementia. This Home includes a dedicated care unit for people with dementia, accommodating approximately 20 residents. Additionally, there are two other deaf-specific homes where deaf residents with dementia coexist with other older deaf people requiring full-time care (Service Foundation for the Deaf, 2018). Staff members working in these homes are either expected to have knowledge of FinSL or are required to learn it to effectively communicate with the residents.

Although the opportunity to be admitted to a deaf-specific home can be beneficial for some older deaf people, it often means being separated from their families and relatives, as these homes may be located far away (see Hepner et al., 2022). However, living in a deaf-specific home provides a chance to socialize with other deaf people and staff who use FinSL because it forms a small deaf community of its own. It may also evoke memories of their childhood when they lived in dormitories at government schools for the deaf (see Salmi & Laakso, 2005).

In summary, dementia care for the incurable, progressive syndrome of dementia consists of pharmacological and cognitive interventions that mainly postpone symptoms but can also have a positive effect on them. In Finland, CERAD (including MMSE; Morris et al., 1989), a cognitive assessment for dementia, was translated into FinSL less than two decades ago (Rainò, 2010), but no linguistic assessment tools in FinSL exist. Finally, dementia care in FinSL is provided by the Service Foundation for the Deaf and some private service providers, and nursing home dementia care services are provided by the Service Foundation (Service Foundation for the Deaf, 2018).

2.4 Supportive communication in dementia care

Although dementia is experienced by an individual, it has impacts on the surrounding social reality, such as interactional relationships. Therefore, dementia is in fact experienced in a relational context (Pozzebon et al., 2016). This means that dementia affects communication that takes place in daily interactions (de Vries & Drury-Ruddlesden, 2019). Conversation is caring in the sense that care is delivered through communication, and therefore communication and social interaction are essential in dementia care (e.g., Conway, 2014). Previous research has found that when communication is seen as part of a planned care activity, applied in an individual’s care plan, and carried out regularly, it can enhance the well-being of people with dementia living in nursing homes (Söderlund et al., 2016). In this dissertation, communication, particularly supportive communication, is the key element in care for deaf people with dementia and accordingly has been chosen as the perspective.

2.4.1 Interpersonal communication in relationships of care

In this dissertation, communication is viewed as the sharing of existence with others, and relationships are seen as communicative processes through which meanings are created and shared (Baxter, 2004). Social interaction plays a vital role in forming and sustaining personal relationships (Berger, 2005). Therefore, the concept central to this study is interpersonal communication, a complex social process referring to the exchange of messages that carry meaning in social interaction and involving reciprocal exchanges aimed at constructing shared realities and achieving social goals (see Burleson, 2010). Furthermore, social interaction contributes to establishing and preserving one's sense of personhood and promoting overall well-being (Hall et al., 2018). In the context of people with dementia, interpersonal communication becomes an act of care and a fundamental aspect of their well-being (Baker et al., 2015). However, people with dementia may encounter challenges in reciprocating meaningful messages and sustaining conversations in interpersonal relationships.

In research, message-centered interpersonal communication is said to focus on messages that represent cognitive, linguistic, social, and behavioral structures (Burleson, 2010). Interpersonal communication has three functions: interaction management, relationship management and instrumental functions. However, interaction is not just about sending and receiving messages – it is a continuous and simultaneous process in which both partners co-operate and share their perceptions and create a common understanding (Chichirez & Purcărea, 2018). What is relevant is meaning making, i.e., to study and give meanings to turns in conversations and, in the context of this dissertation, understand how dementia affects the ability to give and interpret meaning in social interaction.

Research on interpersonal communication and people with dementia has scrutinized informal interactions, such as those with family members (e.g., Coleman et al., 2021; Jones, 2015; Kim et al., 2022; Pope et al., 2012; Savundranayagam & Orange, 2014; Smith & Rodham, 2022). For example, spouses may feel the loss of their partner and other emotionally affecting processes, such as recognizing change along with living in a crisis and gradually adapting, adjusting, accepting, and moving forward (Molyneaux et al., 2012; Pozzebon et al., 2016). It is likely that dementia changes the formerly equal relationships between spouses, as well as the parent-child relationship, resulting in the family member becoming the support-giving partner in the relationship (Fazio et al., 2018; Karner & Bobbitt-Zeher, 2005).

Even though family members perceive loss and challenges in communication, they also experience continuity in the relationship and make efforts to support their spouse or parent despite the deficits in their abilities (Gillies, 2012). In addition, family members use various facilitative and disabling verbal and nonverbal communicative strategies in supporting their spouse or parent with dementia (Kim et al., 2022). First, facilitative communicative strategies include, for example, suggestion; praise or positive feedback; reassurance; providing information; and using humor. Second, disabling communicative strategies that are often unhelpful include speaking louder, writing, asking questions, correcting, and domineering or ignoring (Kim et al., 2022; Savundranayagam & Orange, 2014). Family members in interpersonal relationships with people with dementia would benefit from information on beneficial strategies to communicate support.

Some researchers have studied professional interactions in contexts other than dementia. Professional or formal interaction refers to the situation in which one interaction partner represents a profession, e.g., a healthcare professional being a formal caregiver, and in which the interaction is a tool for work and the place where the work is done (Gerlander & Isotalus, 2010). Significant to professional interpersonal interaction in the context of dementia is that the professional establishes a therapeutic relationship, explores thoughts and emotions, understands the care recipient's perspective, and guides them towards better health and well-being (Chichirez & Purcărea, 2018; Ward et al., 2008). In professional interpersonal relationships, various emotions are present – both one's own and the other person's emotions (Ward et al., 2008; de Witt & Ploeg, 2016). Furthermore, issues that are communicated per se (e.g., illness, death, hope) are emotional, and dealing with moral issues when communicating is demanding for both interaction partners (Gerlander & Isotalus, 2010; de Witt & Ploeg, 2016).

Effective communication skills of healthcare professionals have been shown to enhance the satisfaction, health, and well-being of care recipients during professional interactions (Brock et al., 2013). Additionally, these skills contribute to the well-being and job satisfaction of healthcare professionals themselves (Thompson et al., 2011). Conversely, interactional problems can lead to malpractice in healthcare (Reader et al., 2014). Research has highlighted the need for improvement in the communication skills of healthcare professionals because experience alone may not lead to significant improvement (Ruben, 2016). Further training, supervision, and regular reflection on practice can aid in managing healthcare professionals' emotional journey (Yates et al., 2021). In dementia research, the focus has shifted from language deficits caused by dementia to pragmatic interaction challenges (Hays et al., 2004; Jones, 2015). These challenges not only hinder the comprehension of communication partners but also elicit various emotional responses during interaction. Regrettably, very few studies have explored interpersonal communication in deaf people with dementia. Therefore, there is an international research gap on social interaction of deaf people with dementia.

A recent review on deaf people with dementia and care homes in Scotland (Hepner et al., 2022) revealed some inconsistencies and deviation in the perspectives of deaf service users and hearing health care providers. Inconsistencies were found on language and communication, cultural needs, transition to care homes and requirements for effective care provision. Although social interaction was not the focus of the review, it is worth noting that from the care home staff's perspective, difficulties in communication rise from deafness, whereas deaf people with dementia worry about their gradual loss of SL. However, there is a growing body of studies on life story work where adaptations for deaf people with dementia have been explored (e.g., Ferguson-Coleman & Young, 2018; Young et al., 2020). They show promising results in deaf people with dementia being appreciated for using their voice and becoming seen.

In summary, this dissertation examines the concept of interpersonal communication and its significance in forming and maintaining personal relationships. It emphasizes the importance of meaningful message exchange in social interaction and its role in promoting well-being, particularly in the context of people with dementia. The research highlights the challenges faced by people with dementia in reciprocating meaningful messages and sustaining conversations in relationships. It also explores the communication strategies used by family members and formal caregivers to support people with dementia. The study emphasizes the need for effective communication skills among healthcare professionals to enhance the satisfaction and well-being of care recipients. Additionally, it recognizes the emotional aspects of professional interactions and the importance of managing healthcare professionals' emotional journey. The research contributes to a better understanding of the complexities of interpersonal communication in the context of dementia and the need for further exploration in deaf people with dementia.

2.4.2 Supportive communication in care of people with dementia

Providing support is an essential aspect of human interaction, and social support is exchanged and communicated within interpersonal relationships, in which individuals express their supportive intentions (Burleson, 2009; Feeney & Collins, 2015). Support plays a crucial role in effective coping and is therefore a key element in healthcare (Uchino, 2009). It has been suggested that social support can help prevent cognitive decline and delay the progression of dementia (Minghella & Schneider, 2012b). Social support encompasses the perception of being cared for and having support available when needed, the actual assistance received, and the level of integration within one's social network (Gottlieb & Bergen, 2010). It can manifest in various forms, such as peer support groups, professional-led support groups, and informal helping relationships (Gottlieb & Bergen, 2010; Hagan, 2020). Ultimately, social support is subjective and depends on an individual's perception of whether their social needs are being met and to what extent (Joyce et al., 2022).

Dimensions of social support consist of (1) emotional/informational support, (2) tangible support, and (3) positive social interaction, and (4) affectionate support (Jones et al., 2019; Pillemer & Holtzer, 2016). Emotional/informational support and positive social interaction are associated with cognitive functions and therefore, social interaction can carry positive potential for people living with dementia (Pillemer & Holtzer, 2016). Another definition of social support consists of (1) emotional, (2) informational, (3) instrumental, (4) esteem and (5) companionship dimensions of support (Gottlieb & Bergen, 2010). Furthermore, emotions and other support needs, as well as social support, are communicated verbally and nonverbally. This dissertation focuses on supportive communication which covers all dimensions of social support.

Social support in the context of deaf people with dementia is intriguing to study in the sense of how they as members of a collective and visual culture can be supported. Although a disclosing diagnosis of dementia is essential, what happens afterwards can be life-changing (Minghella & Schneider, 2012a; Yates et al., 2021), i.e., how family members and formal caregivers, who often are hearing, communicate support for deaf people with dementia. In addition, it is significant to find out in what ways deaf people with dementia have access to social support and if they do not, what needs to be done so that they do. In this dissertation social support refers also to network support, i.e., social networks in which deaf people with dementia communicate with other, e.g., deaf people in deaf clubs. However, the concept supportive communication was chosen because it is the most appropriate and accurate concept when supportive strategies appear interactionally.

Supportive communication refers to communicative behavior enacted by interaction partners intentionally benefiting or helping another; effective comforting messages are person-centered and promote the quality of supportive communication (Burleson & MacGeorge, 2002). Supportive communication is a complex process of exchanging messages to seek and provide support (Virtanen, 2015). For example, supportive communication may be considered as something during which the support-giver listens, interprets and emotionally engages while verbally and nonverbally responding to the emotions of the support-seeker (Burleson, 2009; Jones, 2011). The most common support providers for people with dementia are family members, i.e., spouses, daughters, and daughters-in-law (Jones, 2015; Pope et al., 2012; Smith & Rodham, 2022), as well as healthcare professionals in community care and in nursing homes (Ericson-Lidman et al., 2014; Ward et al., 2008). In the context of deaf people with dementia, this dissertation focuses on coping with the illness with the support of another, i.e., family members and formal caregivers.

The concept of “interactive coping” refers to a functional process where one interaction partner has a problem and the other one communicates verbally and nonverbally, being either helpful or unhelpful (Barbee & Cunningham, 1995). The effects of supportive messages typically depend on many factors, which include the characteristics of the support provider, the support receiver, and the interactional context (e.g., Burleson, 2010). Effective communication is essential to understanding the needs of each person with dementia and providing genuine and quality care (Johnsson et al., 2018; Nguyen et al., 2019; Wiechula et al, 2016). This dissertation utilizes the concept supportive communication instead of interactive coping. Supportive communication is seen as mainly aimed toward deaf people with dementia and not as reciprocal exchange of support, i.e., support is communicated by family members and formal caregivers for deaf people with dementia. Supportive interaction in this context refers to the functional process between deaf people with dementia and family members or formal caregivers.

Good communication for people with dementia is researched mainly through the perceptions of family members and formal caregivers who consider using short sentences and yes/no-questions, along with attuning and incorporating personhood, as the most effective strategies (Alsawy et al., 2017). Furthermore, eye contact and touch as nonverbal strategies can improve communication with people with dementia (van Manen et al., 2021). However, meanings of communicative gestures may vary, depending on culturally and linguistically diverse group membership (Cameron et al., 2020; Kontos, 2012). In addition, supportive strategies may differ from person to person due to the uniqueness of each individual and the phase of their dementia (Savundranayagam & Moore-Nielsen, 2015). Finally, when communication opportunities are utilized effectively, people with dementia can take part in reciprocal interaction that enhances significant expression (Morris et al., 2020). While some research has been carried out on supportive communication for people with dementia (Jones et al., 2019; Joyce et al., 2022), there is yet very little understanding on supportive communication for deaf people with dementia.

In this dissertation, the concept of supportive communication is employed to examine the relationship between deaf people with dementia and their formal caregivers. There is a vital difference between informal and formal relationships, i.e., professional relationships, in that the latter is an asymmetric relationship (Gerlander & Isotalus, 2010). Whereas informal relationships provide mutual seeking and giving of support (see e.g., Virtanen, 2015), professional relationships do not. Therefore, the relationship between a deaf person with dementia and a formal caregiver is not equal because formal caregivers do not seek support from the persons they care for. Moreover, the professional caregiver is seen as an expert at the epistemic level, with responsibilities at the legal and ethical level, but at the human level, the interaction between the caregiver and the person with dementia is considered symmetrical, because it involves two human beings (Gerlander & Isotalus, 2010). Consequently, finding a balance in the asymmetrical nature of the caregiver-patient relationship has been a goal in professional interactions (Peltola, 2023).

There are doubts about whether a fully symmetrical relationship can be achieved (Engeström, 2013). This is particularly relevant in a relationship between a formal caregiver and a person with an illness impacting their cognition. When living in a Home, formal caregivers interact with people with dementia daily, unlike family members, who may visit less frequently. This dissertation contributes to the body of research by exploring and showing what happens in supportive interaction between formal caregivers and deaf people with dementia.

A person-centered approach to care is highlighted for use in long-term care of persons with dementia (Fazio et al., 2018; Savundranayagam, 2014). Furthermore, communication is essential in providing person-centered care (Savundranayagam et al., 2016), because social interaction is a basic human need (Fazio et al., 2018; Harnett, 2014). Person-centered communication extends beyond merely supporting the communication of information to include the development and maintenance of rewarding relationships (Kitwood, 1997). Accordingly, person-centered communication sets the individual as a person in the center, responds to the individual's emotions, and values the individual's affections, choices, and needs (Williams et al., 2018).

A person-centered approach to care involves positive interaction that consists of five key elements: recognition, negotiation, validation, facilitation, and collaboration (Ryan et al., 2005). Recognition includes eye contact and using the person's name; negotiation refers to consulting with the person with dementia about their preferences, desires, and needs; validation refers to acknowledgement of the person's feelings and to conveying a sense of empathy and understanding; and facilitation refers to communication used to initiate and sustain interactions (Mundadan et al., 2023; Savundranayagam et al., 2007). Collaboration refers to working together: the initiative and abilities of the person with dementia are involved in daily life (Savundranayagam et al., 2007), because the person with dementia has assets as well as needs (Minghella & Schneider, 2012b).

Since people are unique and messages are diverse, a person-centered supportive interaction refers to a specific type of behavior and social interaction (Burleson, 2009; Jones & Bodie, 2014; Mundadan et al., 2023; Savundranayagam & Moore-Nielsen, 2015; Williams et al., 2018). Competent listeners are attentive, understanding, responsive, friendly, and able to sustain conversational flow (Jones et al., 2019; Mundadan et al., 2023; Savundranayagam & Moore-Nielsen, 2015).

Furthermore, typical to person-centered supportive interaction are eye contact, smiling and laughing, verbal and physical composure, and asking questions. Accordingly, supportive people have knowledge about the feelings and emotional states, i.e., human emotion and its dynamics, and about nonverbal, linguistic strategies through which supportive interactions can be communicated (Burleson, 2009; Jones & Bodie, 2014).

Person-centered supportive communication consists of (1) an outcome, i.e., supportive messages, and (2) message qualities, e.g., helpfulness, appropriateness, and sensitivity (Jones & Bodie, 2014). Remarkably, person-centered supportive communication can vary from unhelpful and hurtful low person-centeredness to high person-centeredness, which legitimizes and validates the recipient and makes them feel better (Burleson, 2009). Previous studies have found that people with dementia in a residential home reacted positively to the person-centered communication of caregivers by cooperating and contributing to conversations, and negatively to missed opportunities by resisting care and exhibiting distress (Savundranayagam et al., 2016). Missed opportunities for person-centered communication refer to occasions where the tactic could have been used to support the personhood of an individual with dementia but was not (Savundranayagam, 2014; Savundranayagam et al., 2007).

In summary, this dissertation sheds light on the importance of interpersonal communication and, particularly, supportive communication in the context of deaf people with dementia. The study emphasizes the role of social support in effective coping and well-being for people with dementia. Social support can take various forms, and its effectiveness depends on the individual's perception of whether their needs are being met. The research identifies various dimensions of social support and highlights the significance of supportive communication in relationships with family members and formal caregivers. Understanding the unique challenges faced by deaf people with dementia and the strategies used by their support networks can pave the way for better care and improved communication. The study advocates for a person-centered approach to care, recognizing the individual's emotions, choices, and needs, and promoting positive interactions that validate and support their personhood. By delving into the complexities of supportive communication, this dissertation contributes to the field of dementia research and provides valuable insights for enhancing the well-being of deaf people with dementia.

3 Aims of the study

This dissertation is focused on three primary aims. Firstly, it aims to gain a comprehensive understanding of how dementia affects the social interaction of deaf people. Secondly, it seeks to explore supportive strategies provided by family members and formal caregivers for deaf people with dementia. Family members and formal caregivers are typically the ones mainly engaged in social interaction with deaf people with dementia and, accordingly, the ones who have the most opportunities in communicating support for them. Lastly, it aims to identify the key elements that can enhance the abilities of family members and formal caregivers in providing support.

The research questions of this dissertation are:

1) What changes do family members and formal caregivers perceive in social interaction with deaf people with dementia?
2) How do family members and formal caregivers support deaf people with dementia?
3) What are successful supportive strategies for deaf people with dementia?
4) How can supportive communication be improved for deaf people with dementia?

This dissertation includes three studies. Study I examines the changes in communication experienced by deaf people with dementia as perceived by their family members. The study focuses on how family members adapt their communication and support strategies in response to these changes. In this context deaf people with dementia are referred to as "parent(s)" because there were no spouses among family members; they were all adult children.

Study II investigates the social interaction between formal caregivers, i.e., healthcare professionals, and deaf people with dementia residing in a nursing home for older deaf people. In this context they are referred to as "residents." The study aims to describe the nature of social interaction and how deaf residents with dementia express their needs. Additionally, it explores the ways in which formal caregivers communicate support and how deaf residents with dementia respond to this support.

Study III explores the perceptions of formal caregivers regarding their social interaction with deaf residents with dementia. The study aims to depict the challenges faced by caregivers and the supportive strategies they employ to overcome these challenges. Moreover, it highlights the support provided by caregivers to deaf residents with dementia and the support that caregivers themselves require to enhance their interactions with them. Table 2 portrays the specific research questions for Studies I, II and III.

Table 2 Aims and research questions of Studies I–III.

Note. RQ = Research question.

Study I	Study II	Study III
RQ1: What changes in communication are perceived by family members with dementia?	RQ1: How do deaf people with dementia express their needs in social interaction?	RQ1: What challenges do formal caregivers face in their social interaction with deaf people with dementia?
RQ2: How do family members modify their communication to accommodate the changes in deaf people with dementia?	RQ2: How do formal caregivers provide social support for deaf people with dementia?	RQ2: How do formal caregivers overcome the challenges in their interaction with deaf people with dementia?
	RQ3: How do deaf people with dementia respond to the social support provided by formal caregivers?	RQ3: What support do formal caregivers provide for deaf people with dementia?
		RQ4: What support do formal caregivers require to improve their interaction with deaf people with dementia?

4 Methods

4.1 Methodological philosophy

This dissertation investigates the supportive strategies provided by family members and formal caregivers. It explores the nature of social interaction in this context, aiming to understand its underlying characteristics and dynamics. Additionally, the dissertation examines the various communicative strategies employed by family members and formal caregivers to provide support to people with dementia. As its ontological dimension, this study seeks to shed light on the nature of social interaction and support within the specific context of deaf people with dementia.

Epistemologically, this dissertation delves into the perceptions of family members and formal caregivers regarding the social interaction of deaf people with dementia and the supportive strategies employed by them. The research aims to understand the knowledge and beliefs held by these key members regarding the nature of social interaction in this context. It explores their subjective understanding and interpretation of the interactions, as well as their insights into the strategies utilized to provide support. By examining these epistemological dimensions, this study seeks to uncover the ways in which knowledge about social interaction is constructed and shaped by family members and formal caregivers, contributing to a deeper understanding of the social dynamics and support mechanisms surrounding deaf people with dementia.

Methodology refers to the methods that the researcher chooses to find answers to the ontologically and epistemologically guided questions as a way of thinking and acting (see e.g., Schwandt, 2015). Methodology is the lens a researcher looks through, and the choice of a methodology is linked to what a researcher wants to achieve by answering the research questions in a particular way (Birks, 2014). Methodologically, this dissertation utilizes interviews and observation in gaining answers to the research questions presented in Chapter 3.

Social constructivism, rooted in the ideas of philosopher Ludwig Wittgenstein, posits that reality is both subjective and relative (Snyder, 2006). In this perspective, reality is constructed by individuals based on their experiences and contexts, and research involves reconstructing this reality (Birks, 2014; Guba & Lincoln, 1994). Knowledge is shaped by people’s views, meanings, and experiences within their historical and cultural context, expressed through language (Gergen, 1989). In this dissertation, the understanding of dementia and deaf people in social interaction is constructed and mediated through language.

Relativism is the belief that certain concepts have subjective features that depend on the individual's history, culture, and context (Baghramian & Carter, 2022). Perceptions are shaped in social interaction and expressed through language. Relativism also asserts that phenomena are influenced by independent variables like culture and language, leading to varying interpretations and no single definitive truth, as knowledge and phenomena are shaped by the surrounding context (Baghramian & Carter, 2022).

This dissertation is based on the principles of social constructivism and relativism, recognizing that the reality of social interaction among deaf people with dementia is shaped through relationships and interactions with others, as are the supportive strategies employed by family members and formal caregivers. The understanding and interpretation of these interactions are influenced by the perspectives and experiences of all involved parties, including deaf people with dementia, family members, and formal caregivers.

Moreover, this research acknowledges that realities are ever-evolving and continually constructed through social interaction. Through interviews, family members and formal caregivers share their perceptions and experiences of social interaction with deaf people with dementia, discussing potential changes and challenges in these interactions, as well as the supportive strategies they utilize. By exploring and illustrating these perspectives and experiences, this study aims to enhance our comprehension of the intricate nature of social interaction within this specific context.

In academic research, a qualitative design is recommended when there is a comprehensive interest in understanding people's perspectives, thoughts, and actions in relation to their circumstances, as well as the meanings they attribute to phenomena in their lives (Taylor et al., 2015). In the context of healthcare, a qualitative descriptive design aims to gain insights into relatively unknown phenomena from the viewpoint of participants, including healthcare professionals (Neergaard et al., 2009). The specific aims and context of the study serve as the foundation for adopting a qualitative descriptive design (Doyle et al., 2020). The researcher selects the most suitable methods to address the research questions, and throughout the study, the collected data remain closely connected to the phenomenon under investigation (Sandelowski, 2010). To achieve this, the researcher must be observant of people's actions and explore their significance (Antelius et al., 2018).

4.2 Research methodology

Based on the preceding literature review, this dissertation was designed to address a gap in the literature concerning social interaction of deaf people with dementia. This study utilized a qualitative descriptive design (Doyle et al., 2020) because the focus was to explore and describe the yet little-known phenomenon, the social interaction of deaf people with dementia as perceived by family members and formal caregivers. A qualitative approach was chosen because it is considered appropriate when having a holistic interest in people as well as in their thinking and behavior in the context of their past and present situation and the meanings they connect to the events in their lives (Taylor et al., 2015).

Methods include choice and recruitment of participants or sampling, data generation or collection, fieldwork, data recording, data analysis and the reporting of a study (Birks, 2014). Historically, interviews, focus groups, and non-participant observation have been the commonly favored research methods in studies on dementia (Keady et al., 2018). Additionally, the research methods in dementia research in the field of nursing are similar and utilize, e.g., semi-structured interviews (e.g., Ducharme et al., 2014; Kamalraj et al., 2021; Karner & Bobbitt-Zeher, 2005; Massimo et al., 2013; Ward et al., 2008), in-depth interviews (e.g., Boylstein & Hayes, 2012; Gillies, 2012; Harris et al., 2021; Molyneaux et al., 2012), and observation (e.g., Söderlund et al., 2016; Williams et al., 2018; Wilson et al, 2012).

Previous studies have investigated people with dementia using linguistic tests in clinical settings (e.g., Bayles, 2003; Blair et al., 2007; Calzà et al., 2021). However, quantitative methods and particularly those conducted in clinical settings give only a limited amount of information on how an individual with dementia manages social interaction with other people. Some researchers have used observation as a research method in studying people with dementia (e.g., Söderlund et al., 2016). Such studies have produced knowledge about real-life situations (e.g., Antelius et al., 2018; Peoples et al., 2020). Furthermore, in-depth interviews (e.g., Ferguson-Coleman & Young, 2018; Young et al., 2014) have yielded valuable information on the minority group of deaf people with dementia who, perhaps for the first time, have been able to participate in research and contribute meaningful stories of their experiences with having dementia.

Family caregivers of people with dementia have been involved in research through semi-structured (e.g., Novek & Menec, 2023; Peoples et al., 2020; Saga et al., 2021; Smith & Rodham, 2022), in-depth interviews (e.g., Pope et al., 2012; Pozzebon et al., 2016), and focus groups (Ferguson-Coleman et al., 2014), generating substantial data. Some researchers have also used quantitative questionnaires to explore family members' perceptions of end-of-life care quality (e.g., de Boer et al., 2017), which may raise concerns about representativeness. Participating in person-centered intervention studies can provide support to family caregivers, allowing them to share their experiences and feel acknowledged (e.g., Aoun et al., 2018). In-depth interviews offer family caregivers a platform to elaborate on the everyday challenges they encounter (e.g., Pozzebon et al., 2016). In terms of deaf people, storytelling has been used as a method and found to be beneficial in research on deaf people with dementia because storytelling is typical for the deaf culture (Ferguson-Coleman & Young, 2018; Young et al., 2020).

Researchers have explored the impact of supporting people with dementia by collecting data from dyads, which consist of people with dementia and their informal caregivers, using quantitative methods like structured questionnaires, self-report scales, and other indexes (e.g., Brites et al., 2020). However, the caregiving process is complex and dynamic, and questionnaires may not fully capture certain aspects, such as emotion regulation strategies.

Formal caregivers' perceptions of interactions have been examined using vignettes that portray interactions between a person with dementia and a formal caregiver (e.g., Savundranayagam et al., 2007). Additionally, studying conversations of dyads, such as people with dementia and formal caregivers in residential care (see, e.g., Baker et al., 2015), can provide valuable insights into the supportive strategies employed by formal caregivers and the results can be used in training.

4.2.1 Data gathering methods

A qualitative descriptive design (Doyle et al., 2020) was utilized in this dissertation, and thematic (Polit & Beck, 2012) and semi-structured (Kim et al., 2017) interviews were conducted using the purposive sampling technique described in Elo et al. (2014). The focus was on family members' and formal caregivers' perceptions of the interaction of deaf people with dementia, and hence, they were the target groups of the interviews. In addition, the data comprise field work (see also Antelius et al., 2018), observation (see also Dick, 2014), and video recordings of dyadic interaction of deaf residents with dementia and formal caregivers in a nursing home for older deaf people (hereafter Home).

The methods in qualitative descriptive design include purposive sampling techniques (Palinkas et al., 2015), which involve selecting those participants that have knowledge and experience of the research phenomenon and can respond to the research aims (Ritchie et al., 2003). Accordingly, sampling requires maximum variation to identify the shared pattern that arises from heterogeneity (Palinkas et al., 2015). Typical of qualitative descriptive design is the small sample that should cover the study aims (Ritchie et al., 2003), and the data saturation is used as the gold standard for sample size (Fusch & Ness, 2015). However, the amount of information the sample holds relevant to the study is seen as more important than the number of participants (Malterud et al., 2016).

A qualitative descriptive design utilizes diverse data sources to explore the who, what, and where of a phenomenon (Sandelowski, 2000). The most common data collection method is semi-structured face-to-face interviews (Kim et al., 2017), with telephone interviews also being used (Ward et al., 2015). Observational data is also collected (Sandelowski, 2000; Lambert & Lambert, 2013), though often considered supplementary (Kim et al., 2017). Interviews are particularly valuable as they provide insights into feelings, thoughts, and intentions that may not be observable or accessible through other means, such as documents (e.g., Thoft & Ward, 2022). The structure of qualitative interviews can vary, ranging from structured or semi-structured to open-ended and in-depth formats (e.g., Backhouse & Ruston, 2022; Hoel et al., 2021; Thoft & Ward, 2022).

The data in this dissertation are multimodal (see Young & Temple, 2014). Thematic interviews (Polit & Beck, 2012) in Study I were conducted in Finnish or FinSL, depending on the interviewees' preference. Eight interviews were conducted in total: Six in the interviewees' homes, one at their workplace, and one at the author's home. The interviews were audio or video recorded with permission, ranging from 48 minutes to 2 hours and 22 minutes, with an average duration of 1 hour and 13 minutes. The total data amounted to 9 hours and 48 minutes. The themes explored included communication before the onset of dementia, changes in communication, and strategies used by deaf parents with dementia and their family members to enhance understanding.

Individual semi-structured interviews (Kim et al., 2017) in Study III were conducted in Finnish or FinSL, audio or video recorded, and lasted from 27 to 63 minutes, totaling 9 hours and 41 minutes. Transcriptions resulted in 123 single-spaced pages using Times New Roman font size 12. Ten interviews were conducted face-to-face in a quiet room in the Home, one at the interviewee's home, and two by telephone. The interviews covered participants' background information, work experience with deaf and other people with dementia, FinSL proficiency, and perceptions of social interaction and supportive communication with deaf residents. Participants shared their perceptions and illustrated them with their experiences during the interviews.

In Study II, fieldwork, and observation (Dick, 2014) were conducted in the Home. The fieldwork included a 2-week period of familiarization with the residents with dementia and the staff, followed by a 6-week data gathering period. The researcher acted as an observer participant, where the researcher's role was known, and participation was secondary to observation (Antelius et al., 2018; Dick, 2014). The participation involved sitting with the residents, engaging in casual conversations, sitting with the caregivers during daily reports, and joining the residents in activities like handicrafts and sing-alongs in FinSL, but not participating in nursing tasks. The observation data consisted of 21 video recordings of one-on-one interactions between deaf people with dementia and formal caregivers, lasting for 15 minutes each and covering various topics of their choice. The conversation partners were sitting in the resident's room in such a way that they could see each other well but were also visible to the camera. The camera was placed ca 2–3 meters away from them near the door. The total data amounted to 5 hours and 25 minutes. The transcriptions of the data were done in detail in Finnish, resulting in 106 single-spaced pages using Times New Roman font size 12.

In summary, this dissertation employed triangulation, a qualitative research approach that involves using multiple methods or data sources to gain a comprehensive understanding of phenomena (Moon, 2019). Method and data triangulation (Carter et al., 2014) were achieved through the use of interviews, observations, and participant observation in the field. The multiple data sources included thematic (see Polit & Beck, 2012) and semi-structured interviews (see Kim et al., 2017) with family members and formal caregivers, as well as video data capturing social interaction between deaf people with dementia and their formal caregivers. Table 3 depicts the research methodology.

Table 3 Research methodology.

Note. ICBCS = Interactional Coping Behavior Coding System (Barbee & Cunningham, 1995).

Triangulation		
Study	I, III	II
Method	Interviews: Thematic interviews Semi-structured interviews	Observation: Fieldwork Video data
Data and participants	Thematic interviews of family members (*N = 8*) Semi-structured interviews of formal caregivers (*N = 13*)	Video data of interactions of deaf people with dementia (*n = 5*) and formal caregivers (*n = 9*)
Data gathering	2012–2013 2016–2017	2016
Analysis	Inductive content analysis	Inductive content analysis ICBCS

4.2.2 Participants

Study I invited all family members of deaf people with dementia, irrespective of their relationship or gender. To be eligible, participants needed to be family members using Finnish/Swedish or FinSL and having regular weekly contact with the person with dementia. This inclusive approach aimed to gather diverse perspectives and experiences within the family context.

In Studies II and III, purposive sampling (Elo et al., 2014) was used, and all formal caregivers responsible for the care of deaf people with dementia were invited to participate, regardless of their gender and hearing status. The criteria for formal caregivers included being involved in day-to-day care in the Home and being able to communicate in FinSL. By including both deaf and hearing caregivers, the study aimed to gain diverse perspectives and experiences in the caregiving context. Participants included CODAs in Study I, deaf people with dementia in Study II, and formal caregivers working with deaf people with dementia in Studies II and III.

Study I included a total of eight participants ($N = 8$), comprising both deaf and hearing family members of deaf people with dementia. Equal opportunity was given to both groups to participate, and interviews were conducted in their preferred language, in FinSL or Finnish. The participants were adult CODAs, with one being deaf and seven being hearing, representing various age groups, and residing in different regions of Finland. Recruitment was done in collaboration with the staff at the Homes of the Service Foundation for the Deaf in Finland and the Services Department of the Finnish Association of the Deaf.

Before participating in the study, all participants in Study I were fully informed, in FinSL or Finnish, about the research and provided with additional information through a handout. They were also encouraged to ask any questions they had before giving their consent. Written consent was obtained from all participants. It was explained to them that participation was voluntary and that they could withdraw at any point without consequences. Additionally, considering that recounting experiences could be stressful, empathy was shown during the interviews, and short breaks were taken when needed to ensure paticipants’ comfort and well-being (Pesonen et al., 2011).

Study II included a total of five deaf people with dementia (hereafter deaf residents) ($n = 5$) and nine formal caregivers ($n = 9$). The recruitment of participants was carried out in collaboration with the Home of the Service Foundation for the Deaf in Finland. Initially, eight potential deaf candidates were identified by the head of staff based on clinical criteria, including being a deaf FinSL user showing signs of dementia. While a formal dementia diagnosis was not mandatory, deaf residents with suspected dementia were considered for inclusion in the study. All deaf residents were diagnosed with AD.

Considering that people with dementia may have difficulty understanding and remembering information, as well as challenges in communication and decision-making, proxy decision makers were contacted for their participation in the research (Black et al., 2013; de Medeiros et al., 2022). Information sheets and consent forms were sent to six individuals who had a family member as a trustee, and a reminder letter was also sent. Ultimately, six written consents were received.

However, consent was not a one-time event but an ongoing process of continuous information, explanation, and agreement, i.e., "process consent" (Antelius et al., 2018; Dewing, 2007; Ferguson-Coleman & Young, 2018). Therefore, the willingness of deaf residents to participate was ascertained before every interaction session, and one deaf resident eventually declined to participate.

In Study II, twelve formal caregivers (*N* = 12) from the Home were invited to participate, of whom three declined and nine agreed to take part. The participants represented diverse age groups and working experience, with three being native FinSL users (deaf or hearing people who learned FinSL in childhood) and six having learned FinSL later in life. Their ages ranged from approximately 20 to 50 years, and their work experience varied from a few months to over 20 years. They were informed that participation was voluntary, anonymous, and confidential, and they had the right to withdraw from the study at any time without providing explanations or facing consequences.

In Study III, thirteen caregivers (*N* = 13), including practical nurses, nurses, and dementia specialists, who worked with deaf people with dementia participated. They were recruited during the data gathering of Study II. Most of the caregivers worked in the Home, while a few worked in the deaf community. Among the participants, three were native FinSL users and ten were non-natives who acquired FinSL as adults. All participants provided consent for the study. Considering the small number of deaf residents and their formal caregivers in Finland, the number of participants was deemed sufficient for the research (see Cleary et al., 2014). Table 4 displays an overview of the demographic information of the participants.

Table 4 Participants in studies I–III.

Note. CODA = Child of Deaf Adults, N/A = Not applicable, AD = Alzheimer's disease, FinSL = Finnish Sign Language, y = years.

[a] Training concerned only formal caregivers in Study III. Dementia-nurse-training or similar comprised of all further training in dementia reported by the participants, typically a one-year training provided by vocational colleges.

Study	**I**	**II**	**II, III**
Participant	Family member (CODA) (*N* = *8*)	Deaf people with dementia (*n* = *5*)	Formal caregivers (*N* = *13*)
Age	~30–60 years	~80–90 years	~20–50 years
Dementia diagnosis	N/A	AD (*n* = *5*)	N/A
FinSL background	FinSL in childhood with parent Yes (*n* = *4*) No (*n* = *4*) Deaf (*n* = *1*) Hearing (*n* = *7*)	Deaf FinSL users (*n* = *5*)	Natives (deaf or CODA) (*n* = *4*) Non-natives (*n* = *9*)
Dementia-nurse-training[a]	N/A	N/A	Yes (*n* = *9*) No (*n* = *4*)
Work experience with deaf people with dementia	N/A	N/A	<3y (*n* = *3*) 3–8y (*n* = *4*) >9y (*n* = *6*)

4.2.3 Data analysis

In qualitative descriptive design, the data analysis is data driven (Lambert & Lambert, 2013), and the interpretation is presented at a level that those whom the research is about are easily able to understand and can use the findings in healthcare practice (Chafe, 2017). Furthermore, an explorative approach to analysis, i.e., inductive approach, is commonly needed (Kim et al., 2017). The most commonly used data analysis techniques are content and thematic analysis (Vaismoradi et al., 2013), which offer competent ways of the lower-level interpretation often required in qualitative descriptive research (Doyle et al., 2020). The findings are presented with the help of authentic quotations from the interviews (Sandelowski, 2010). In addition, a thematic summary of findings develops an interpretation of a common theme (Willis et al., 2016).

Data were analyzed using inductive content analysis (Elo & Kyngäs, 2008; Vaismoradi et al., 2013) and the Interactional Coping Behavior Coding System (ICBCS, Barbee & Cunningham, 1995). The data analysis methodology is displayed in Table 3. The data analysis in Study I followed the principles of inductive content analysis (Elo & Kyngäs, 2008). The analysis of the transcribed material followed a systematic process. Initially, the transcriptions were carefully read multiple times to gain familiarity with the data. Next, the researcher identified units of analysis, which corresponded to meaningful segments or themes within the transcribed material. These themes were selected based on their relevance to the research questions and objectives.

In the next phase, the identified themes were further refined through a process of simplification, abstraction, and consolidation. Similarities and dissimilarities among the themes were examined, and subcategories were created to capture the nuances within each theme. This allowed for a more detailed and comprehensive understanding of the data. The subcategories were then organized under higher-order headings to create a coherent structure for the analysis. Through this process, four main categories emerged: (1) means of communication, (2) interaction, (3) language comprehension, and (4) social relationships and communication. These categories represented the overarching concepts that encapsulated the findings of the analysis. Overall, this systematic approach to analysis ensured that the data were thoroughly examined, and the key themes and categories were identified. It allowed for a comprehensive exploration of the research questions and provided a solid foundation for drawing meaningful conclusions from the data.

The data analysis in Study III followed the principles of inductive content analysis (Elo & Kyngäs, 2008; Vaismoradi et al., 2013). Following an in-depth analysis of the transcripts, significant words and expressions were identified as units of meaning. These units were then assigned codes using the qualitative analysis software ATLAS.ti, resulting in a total of 355 codes. The occurrence of these codes was carefully evaluated, and similar codes were grouped together and renamed as deemed appropriate.

The next step involved combining the codes to form subcategories, which were further abstracted and collapsed into categories based on their similarities. This process allowed for a more systematic organization of the data and facilitated the identification of overarching themes and patterns. In the final stage of analysis, the subcategories were grouped under higher-order headings to create a coherent structure for the findings. Three main categories emerged from this process: (1) challenges in interaction, consisting of four subcategories, (2) strategies in supporting interaction, comprising three subcategories, and (3) support for family members and caregivers, consisting of two subcategories.

This analytical approach, facilitated using ATLAS.ti, enabled systematic exploration and organization of the data. It provided a comprehensive understanding of the challenges faced in interaction, the strategies employed to support interaction, and the support needed by family members and caregivers. By categorizing and collapsing the codes into meaningful themes, the analysis revealed important insights and contributed to the overall findings of the study.

In the video data (Study II), the data analysis first followed the principles of inductive content analysis (Elo & Kyngäs, 2008). The analysis process began by reading the transcripts multiple times to gain familiarity with the data and identify the units of analysis. These units were defined as interaction sequences in which a discernible topic was discussed. A total of 479 sequences were identified, examined, and organized according to the utterances of the dyadic partners involved. An utterance was considered a meaningful reaction carrying independent meaning, resulting in a total of 1936 utterances. The next step involved open coding, where each utterance was assigned a code based on its content. These codes were then condensed and grouped into categories with similar codes. This process helped to identify common themes and patterns in the data. To further analyze the communicative behaviors of the caregivers, the ICBCS was employed. Each of the 1936 utterances was assigned a code from the ICBCS, utilizing 18 of the 28 available categories. This allowed for a more nuanced understanding of the caregivers' communication strategies.

Finally, the codes were examined within the context of the interaction sequences, leading to the identification of supportive strategies employed by the caregivers. Five supportive strategies emerged from this analysis: (1) interaction maintenance, (2) emotional support, (3) instrumental support, (4) informational support, and (5) memory support. These strategies represented the ways in which the caregivers provided support and assistance to the deaf people with dementia during the interactions. By employing a systematic analysis approach and utilizing the ICBCS framework, this study was able to capture and categorize the communicative behaviors of the caregivers and identify specific supportive strategies employed in their interactions with deaf people with dementia.

4.2.4 Ethical questions

When conducting research involving vulnerable individuals, such as those with dementia, ethical considerations are of utmost importance. Informed consent and respect for autonomy are crucial principles that must be upheld. Researchers should provide clear and understandable information about the research to individuals with dementia, consider their cognitive impairments and adapt communication methods accordingly (Antelius et al., 2018). Written consent can be obtained from the participants themselves or their family members when appropriate (Black et al., 2013). Throughout the research process, researchers must prioritize the well-being and best interests of individuals with dementia, ensuring their comfort and safety and responding to any signs of distress.

Ethical review boards provide oversight to ensure that the research upholds the rights and dignity of participants and minimizes potential harm. In this dissertation, ethical guidelines were followed, and approval was obtained from the University of Helsinki Ethical Review Board of the Humanities and Social and Behavioural Sciences (30/2016). Participants in each study participated voluntarily and had the right to withdraw at any time. Data were kept securely, and participant details were anonymized to protect their privacy within the deaf community in Finland.

4.2.5 Researcher’s reflection

In qualitative research, the researcher’s self-reflexivity is essential, because their personal characteristics and experiences can influence the research process and interpretation of findings (Pezalla et al., 2012). The researcher’s familiarity with the topic and participants can facilitate trust and understanding, but it may also introduce bias (Antelius et al., 2018; Berger, 2015; Davis et al., 2010; Young & Temple, 2014). The interviews are always a collaboration between two partners, i.e., the interviewer and the interviewee. The researcher’s task is to create the social interaction, the unique conversational space, in which the participants feel safe enough to share their thoughts (Owens, 2006). The researcher’s own experiences within the culture and the phenomena under research can be beneficial: they play a role in the interactive nature of interviews (Antelius et al., 2018; Thorpe et al., 2018). Furthermore, familiarity may help, providing an easier entrée by knowing about the topic and understanding the participants (Berger, 2015). The researcher is a CODA and native in FinSL, which eliminated the need for an interpreter and helped establish a confidential relationship with participants (see Antelius et al., 2018; Ferguson-Coleman & Young, 2018). Confidentiality among older deaf people is important, and with the researcher being an outsider, i.e., not familiar from childhood in that deaf community, it was essential for deaf participants to trust the researcher (see Antelius et al., 2018).

Study II involved a two-month fieldwork period in the Home, providing valuable insights into residents' daily lives and communication. Conversations with deaf residents and nursing home personnel further contributed to the holistic perspective and credibility of the research findings (see Antelius et al., 2018). Throughout this period, the researcher maintained a personal diary to record observations and reflections. The observational phase of the study provided valuable insights into the daily life and routines within the Home. By immersing herself in the environment, the researcher was able to observe and document various aspects of the residents' experiences. This included gaining an understanding of FinSL as used by the residents. Additionally, the researcher had the opportunity to learn about the residents' personal histories and their life stories as well as the medical facts (i.e., diagnosis and medication), which contributed to a deeper contextual understanding of their communication.

The fieldwork period served as a crucial foundation for subsequent data analysis and interpretation (see Antelius et al., 2018). It enabled the researcher to develop a comprehensive understanding of the social interaction, support mechanisms, and challenges encountered by deaf residents in the Home. Throughout the fieldwork, the researcher adhered to ethical considerations, ensuring the privacy, dignity, and confidentiality of the participants. The observational approach facilitated an in-depth exploration of the unique sociocultural context of the Home and provided rich qualitative data that formed the basis for subsequent analysis and findings.

When conducting research, it is essential for researchers to be mindful of their own identities and how they relate to their informants (Antelius et al., 2018). The author of this dissertation possesses unique personal and professional experiences that have enriched understanding of the relationships examined in the study. As the daughter of a deaf parent with dementia, the researcher has gained firsthand insight into the dynamics and complexities of the participants' relationships. This personal connection has likely enhanced the author's empathetic understanding and ability to interpret the participants' experiences.

The researcher's work as an RN in a residential home for older deaf people, where some residents also had dementia, has provided valuable firsthand experience and knowledge, and exposed her to the lived experience of dementia and the specific support needs that arise in such settings. Engaging in conversations with family members, other CODAs, and personnel in the nursing home has further enriched the researcher's insights. These conversations have allowed the author to gain diverse perspectives on what it means to have a parent with dementia and the challenges and rewards associated with caring for deaf people with dementia. The researcher’s interactions with personnel in the nursing home have provided valuable insights into the caregiving process and the impact of supportive environments on the well-being of people with dementia.

The holistic perspective gained from these personal and professional experiences has likely informed the analysis and writing process of the dissertation, contributing to a more comprehensive and nuanced understanding of the social interaction and support needs of deaf people with dementia. Such authentic insights and diverse perspectives enhance the credibility and contribute to the overall richness of the dissertation. The researcher’s self-reflexivity and unique experiences have enhanced the depth and relevance of the study, providing a comprehensive understanding of the social interaction and support needs of deaf people with dementia. However, the researcher must be aware of the possible impact their background can have on interpreting the data. They need to be conscious of the possibility of biased perceptions, which could result in confirmation of results similar to one’s own experiences. The state of intentional “not-knowing” and curiosity towards both the familiar and the unfamiliar have been my goals.

5 Results

The chapter will primarily focus on two main themes that emerged from the data: the perceived changes in social interaction among deaf people with dementia and the supportive communication provided by family members and formal caregivers. The reader is recommended to read the original publications for a comprehensive body of results (see Studies I–III).

The first theme, the perceived changes in social interaction, encompasses the various shifts and adaptations observed by family members and formal caregivers in the communication patterns of deaf people with dementia. The findings shed light on how the cognitive decline among people with dementia impacts their ability to engage in meaningful interactions and maintain social connections. These changes were described and analyzed in terms of communication difficulties, alterations in language comprehension, and shifts in social relationships and communication dynamics.

The second theme, the supportive communication provided by family members and formal caregivers, explores the strategies and approaches employed to assist deaf people with dementia in navigating their social interaction. The findings reveal the diverse ways in which family members and formal caregivers provide support, including maintaining the continuity of communication, offering emotional support, providing instrumental assistance, sharing relevant information, and aiding with memory-related tasks. The chapter will delve into these supportive strategies and highlight their significance in enhancing the well-being of deaf people with dementia. By delving into these significant findings, this chapter aims to provide a comprehensive understanding of the perceptions of family members and formal caregivers regarding the social interaction and support for deaf people with dementia. It offers valuable insights into the challenges faced, the strategies employed, and the impact of supportive communication on the overall well-being of both deaf people with dementia and those who care for them.

5.1 Perceived changes in social interaction

Family members (Study I) and formal caregivers (Study III) had perceived some similar kinds of changes in social interaction of deaf people with dementia. The changes comprised (1) linguistic changes, (2) changes in interpersonal communication, (3) changes in memory, and (4) physical and nonverbal changes (see Figure 2).

5.1.1 Linguistic changes

The findings of this study indicate that deaf people with dementia exhibit changes in their language use patterns. It was observed that they may use less FinSL and rely more on speaking with family members and caregivers, although their speech may be unclear (Studies I, III). Moreover, in signing environments, they tend to sign more and speak less.

Two key findings emerged from the analysis. Firstly, even after developing dementia, deaf people with dementia continue to use speech and lip-reading when communicating with hearing people, while using FinSL with their deaf or hearing family members and within the deaf community (Study I). However, it was noted that their speech production and signing may vary, with some individuals producing less speech and signing more, or vice versa (Studies I, III). Secondly, formal caregivers perceived that deaf people with dementia switch language based on their interaction partner following a similar pattern (Study III).

Both family members and formal caregivers perceived similar kinds of linguistic changes, e.g., deaf people with dementia forgetting signs or replacing a sign with another not fitting the context (Studies I, III). The results also shed light on the fact that the participants, both family members and formal caregivers, perceived the reciprocal difficulties in comprehension that occur during social interaction between deaf people with dementia and their interaction partners (Studies I, II, III). Both family members and formal caregivers reported that deaf people with dementia experience challenges in understanding concepts and topics, as well as difficulties in comprehending medical jargon used by physicians and FinSL used by SL interpreters. Additionally, it was perceived that SL interpreters and younger nurses encounter difficulties in comprehending deaf people with dementia (Studies I, III). Finally, fingerspelling and the FinSL style of older deaf people appear to be particularly challenging for non-native formal caregivers, although native formal caregivers also occasionally face difficulties (Studies II, III).

These findings highlight the importance of considering the specific communication needs and challenges faced by deaf people with dementia to communicate support and promote effective care. Strategies and interventions for improving comprehension and facilitating communication between deaf people with dementia and their interaction partners, including family members, formal caregivers, and other healthcare professionals, may help address the identified difficulties and enhance care quality for deaf people with dementia.

5.1.2 Changes in interpersonal communication

The findings of this study indicate that deaf people with dementia exhibit a decrease in their level of initiative and engagement during interactions compared to the time before the onset of dementia (Study I). It was perceived particularly by family members that their relatives may become more passive and less proactive in their communication with others (Study I). Additionally, difficulties in maintaining the conversational flow were noted when a deaf person with dementia lost track of the conversation during an interaction (Study I). Furthermore, it was found that deaf people with dementia may not always react or respond appropriately during interactions with others, which can hinder effective communication (Study II). The results also suggest that deaf people with dementia experience challenges in participating in group interactions, which was perceived particularly by formal caregivers (Study III). Therefore, deaf people with dementia may struggle to engage with multiple individuals simultaneously, leading to difficulties in social interaction within a group setting.

In terms of social relationships, the findings indicate that as perceived by family members, deaf people with dementia have fewer social connections in FinSL compared to the time before the onset of dementia (Study I). The decline in social relationships appears to be particularly prominent in the home environment when a person is living alone. It was noted that community-based care services in FinSL are not nationally available throughout Finland. However, the results suggest, as perceived by both family members and formal caregivers, that when transitioning to a nursing home specifically designed for older deaf people, the use of FinSL for social relationships may increase (Studies I, III).

These findings highlight the importance of addressing the communication and social interaction difficulties faced by deaf people with dementia. Strategies that promote active engagement, facilitate conversational flow, and provide appropriate support during group interactions can enhance the overall communication experience for deaf people with dementia. Furthermore, ensuring access to community care services in FinSL and creating specialized care environments that support FinSL-based social relationships can contribute to improved social well-being of deaf people with dementia.

5.1.3 Changes in memory

The findings of this study reveal that deaf people with dementia experience a decline in their memory functions (Studies I, II, III). Specifically, the results indicate that repetitiveness poses a significant challenge for family members, who find it particularly tiresome (Study I). On the other hand, formal caregivers perceive the repetition of stories by deaf people as a symptom of dementia and do not find it as challenging to manage (Study III). However, the results suggest that formal caregivers tend to change the topic when a deaf person with dementia repeats sad or uncomfortable memories (Study II). This indicates a tendency to redirect the conversation away from distressing content.

Consequent to memory difficulties, family members perceived that their parents with dementia encounter difficulties using household appliances like washing machines at their home (Study I). Additionally, formal caregivers report that deaf people with dementia may struggle to remember the current day or time of the year (Study III). Finally, formal caregivers perceive that residents may also struggle to find their way within the care facility (Home) and face challenges in completing daily tasks, such as selecting appropriate clothing (Study III).

These findings highlight the impact of dementia on memory functions among deaf people and the specific challenges faced by both family members and formal caregivers in managing these symptoms. Understanding these difficulties can inform the development of tailored support strategies and interventions that address memory impairments and enhance the overall well-being of deaf people with dementia.

5.1.4 Physical and nonverbal changes

The findings of Study III suggest that formal caregivers perceive changes in the physical dexterity of deaf people with dementia. These changes manifest in signs that are smaller in size and less clear fingerspelling (Studies II, III). Furthermore, the alterations in hand and finger dexterity affect the clarity of signs and disrupt the usual signing space. For instance, signs that should be performed in front of the face may be performed in front of the chest or lower.

Additionally, the results indicate that deaf people with dementia may exhibit changes in their nonverbal communication, such as expressing pain and mood changes, including episodes of anger and conflicts with others (Study III). As a result, they may turn their head away and lose eye contact with their interaction partner, such as a caregiver. This loss of eye contact is particularly significant in SL communication because it leads to a complete breakdown in interaction. SL interaction relies heavily on visual cues, and without eye contact, effective communication becomes impossible.

These findings shed light on the impact of dementia on the physical dexterity of deaf people and the associated challenges in their communicative behavior. It emphasizes the importance of understanding and addressing these changes to provide appropriate support and facilitate meaningful interactions for deaf people with dementia. The findings are displayed in Figure 2.

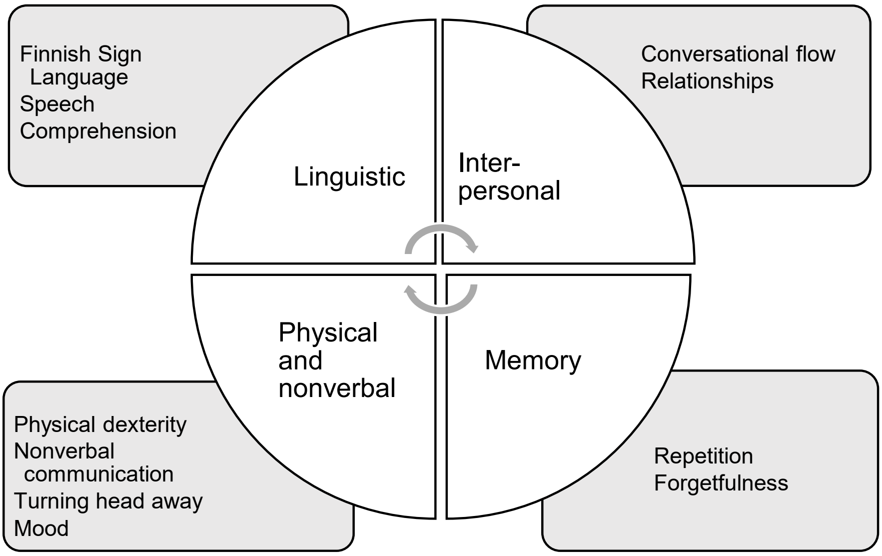


Figure 2 Changes in social interaction of deaf people with dementia as perceived by family members and formal caregivers.

5.2 Supportive communication provided by family members and formal caregivers

The results show that both the family members (Study I) and the formal caregivers (Studies II, III) provide diverse social support for deaf people with dementia. The reader is encouraged to turn to the original publications for details (see Studies I–III).

5.2.1 Supportive strategies communicated by family members

The findings indicate that family members play a crucial role in communicating support to deaf people with dementia, adapting their communication to accommodate changes in language ability (Study I). Firstly, when linguistic changes occur, family members continue to use FinSL as a primary means of communication. Secondly, when there are disruptions in conversational flow, family members take on the role of initiators and leaders in social interaction with their parents with dementia. They provide cues and assume responsibility for maintaining the flow of the interaction.

Thirdly, when comprehension difficulties arise, the family members employ strategies such as repeating, modifying, and explaining messages. They closely observe deaf people with dementia to assess their understanding and anticipate potential mood changes or conflicts. Additionally, family members perceive that they act as informal interpreters, processing the messages expressed by their parents and by others. However, changes in physical dexterity affecting the location, form, and movement of signs may make FinSL more challenging to comprehend.

Fourthly, in cases where deaf people with dementia have fewer social relationships in FinSL within their former home environment, family members support them by regularly visiting and assisting with daily activities. Lastly, family members noted an increase in social interaction and engagement after their deaf parent with dementia transitioned to a FinSL environment, such as a nursing home for the deaf.

These findings highlight the important role family members play in communicating support to deaf people with dementia, adapting their communication strategies and actively engaging in the well-being and care of their parents. Their efforts contribute to maintaining social connections and enhancing the well-being of people with dementia in the deaf community. Figure 3 depicts the supportive strategies provided by family members (Study I).

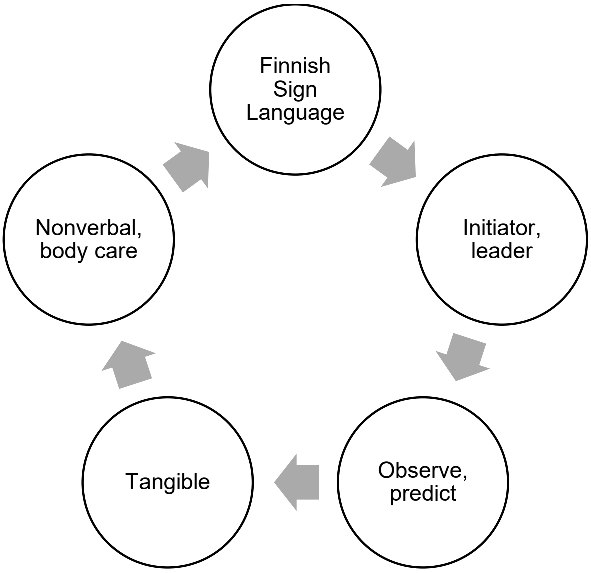


Figure 3 Supportive strategies for deaf people with dementia communicated by family members.

5.2.2 Supportive strategies communicated by formal caregivers

The results show that formal caregivers recognize the various needs of deaf people with dementia and communicate support accordingly (Studies II, III). The results indicate that formal caregivers used five supportive strategies: (1) interaction maintenance, (2) emotional support, (3) instrumental support, (4) informational support, and (5) memory support (Study III).

In terms of interaction maintenance, formal caregivers took the initiative by initiating topics and guiding the interaction. They employed various strategies such as asking questions, changing topics, and offering insights and suggestions to assist deaf residents who faced difficulties in responding. Emotional support was another important aspect, whereby caregivers provided comfort and empathy when deaf residents expressed sadness or communicated physical pain, sad memories from their past, how it feels to have dementia, or thoughts about death. Caregivers demonstrated compassion, remaining calm and present, actively engaging with the concerns of deaf residents.

Instrumental support was provided through practical advice and actions. Caregivers offered concrete suggestions as part of their advice, while their actions involved providing practical assistance or engaging in activities on behalf of or together with the residents. Additionally, caregivers offered informational support by providing relevant information, such as details about upcoming events and available services within the Home. This type of support encompassed offering perspectives and suggestions on how to address problems.

Memory support was identified, with caregivers reminding deaf residents about important dates, family visits, and previous conversations. They utilized verbal cues and personal photographs to aid in memory recall and provide memory support. In conclusion, the results show that the caregivers perceived the deaf residents being happy to interact with them and that they were mainly satisfied with the support the caregivers provided (Study II).

These findings highlight the important role formal caregivers play in communicating support to deaf people with dementia in the various needs and changes that follow dementia. The supportive strategies provided by formal caregivers (Studies II, III) are depicted in Figure 4.

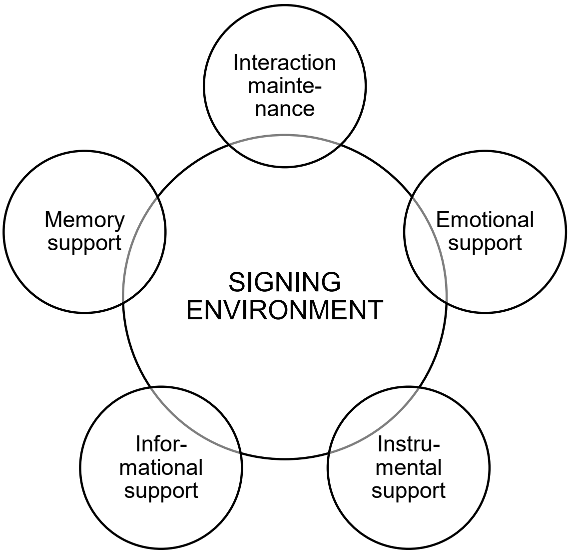


Figure 4 Supportive strategies for deaf people with dementia communicated by formal caregivers.

5.2.3 Features of successful supportive strategies communicated by formal caregivers

The findings reveal that formal caregivers perceive successful support for deaf people with dementia as a combination of various strategies. These strategies include getting to know the person with dementia, interactional strategies, and linguistic strategies (Study III).

Getting to know the person with dementia involves engaging in discussions with the individual themself and interviewing their family members to gather information about their life history. Family members, having known their deaf relative with dementia for a significant period, possess valuable insights into their personalities, interactions, and preferences before the onset of dementia. Caregivers document important details on a board and display it in the resident's room, enabling other staff members to easily access and learn about their personal history, likes, and dislikes. The results emphasize the importance of creating an environment that supports the needs of deaf residents with dementia, ensuring that caregivers are readily available when assistance is required.

Interactional strategies encompass the caregiver's ways of communicating and creativity (Study III). Caregivers are encouraged to be attentive, calm, empathetic, persistent, tolerant, and willing to dedicate time to deaf residents with dementia, ensuring that they feel acknowledged. Additionally, caregivers demonstrated creativity by finding alternative options to communicate meaning when understanding was lacking and by breaking down complex instructions into smaller, more manageable units.

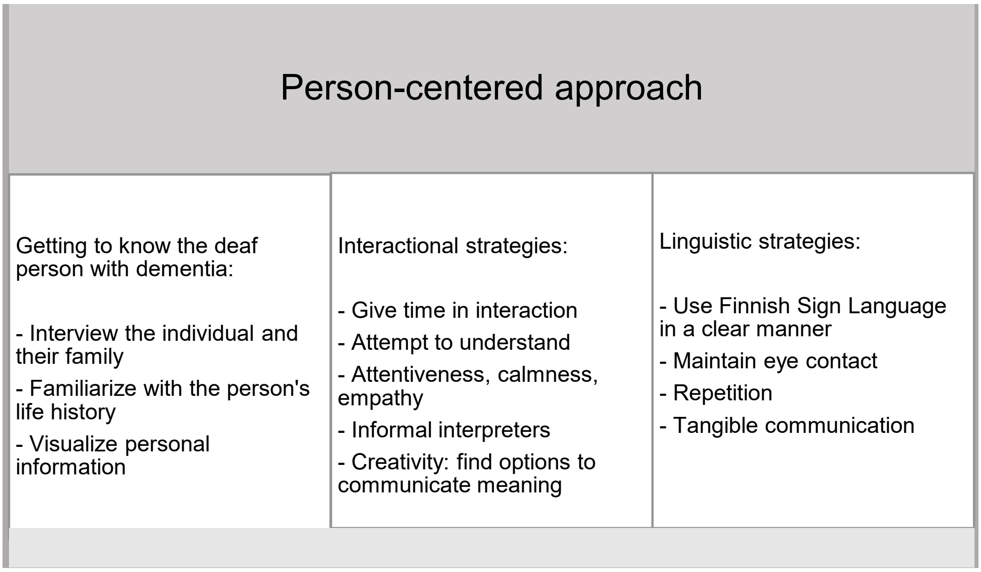
Linguistic strategies encompass the approaches used by formal caregivers to communicate support for deaf residents with dementia (Study III). Maintaining attentive eye contact and using FinSL in a comprehensible manner were identified as effective strategies employed by formal caregivers. Effective strategies include communication techniques such as asking questions, suggesting words or signs, and interpreting nonverbal gestures to understand what deaf residents want to express (Study II). Caregivers make an effort to confirm their understanding of the messages conveyed by deaf residents with dementia. Nonverbal gestures, such as pointing and guiding, are also employed by caregivers in their efforts to support deaf residents. Touch can be used to provide comfort or guidance when a deaf resident with dementia lacks language skills. Whereas touch can potentially elicit aggressive behavior in some cases, it is important to note that touch is more meaningful for deaf people than for hearing people and a vital part of deaf culture, i.e., for getting attention. Additional supportive linguistic strategies involve the use of repetition and tangible communication, in which caregivers lead the person to the desired location or show them the object being referred to (Study III).

These findings highlight the significance of the person-centered approach in providing successful support to deaf people with dementia. By understanding the individuals' personal history, tailoring their communication approaches, and fostering a supportive environment, formal caregivers can enhance the overall well-being and quality of care of deaf people with dementia. The results highlight the various linguistic strategies employed by formal caregivers to communicate support for deaf people with dementia. By utilizing these strategies, caregivers aim to overcome communication barriers, ensure understanding, and provide tangible support when SL communication is limited. While formal caregivers employ various successful supportive strategies, there were instances in which their actions, such as pointing out memory deficits, ignoring expressed sentiments, changing conversation topics, or repeating information, elicited annoyance from deaf people with dementia, leading to topic changes (Study II). Additionally, unsuccessful interactions were observed when misunderstandings arose, often due to difficulties in comprehending the FinSL style used by older deaf people with dementia and similar-looking signs.

Furthermore, the results indicate that both family members (Study I) and formal caregivers (Study III) serve as informal interpreters between deaf people with dementia and physicians and SL interpreters. Family members, particularly CODAs, who have previously acted as informal interpreters between their parents and the hearing world, possess valuable insights in identifying communication difficulties (Study I). Formal caregivers for their part also take on the role of informal interpreters between deaf residents and their family members, especially as dementia progresses, providing them with information about the condition (Study III).

The results demonstrate that successful support is communicated in an empathetic relationship where formal caregivers are present, calm, positive, and attentive towards deaf residents with dementia. The more equal the relationship, the more supportive the communication tends to be. Ultimately, providing time and space and acknowledging the life experiences and history of deaf residents with dementia appear to be fundamental elements of supportive communication.

In sum, the findings emphasize the crucial role of formal caregivers in facilitating communication and support for deaf residents with dementia. Successful interactions are fostered through understanding individual communication needs, fostering an empathetic environment, and valuing the unique experiences of the individual with dementia. Figure 5 illustrates the strategies associated with successful supportive communication as reported by formal caregivers.



Person-centered approach

Getting to know the deaf person with dementia:	Interactional strategies:	Linguistic strategies:
- Interview the individual and their family - Familiarize with the person's life history - Visualize personal information	- Give time in interaction - Attempt to understand - Attentiveness, calmness, empathy - Informal interpreters - Creativity: find options to communicate meaning	- Use Finnish Sign Language in a clear manner - Maintain eye contact - Repetition - Tangible communication

Figure 5 Successful supportive communication strategies for deaf people with dementia communicated by formal caregivers.

6 Discussion

This dissertation was guided by three main aims. The first aim was to gain a comprehensive understanding of how dementia affects the social interaction of deaf people by examining the perceptions of family members and formal caregivers on changes faced by deaf people with dementia. This study aimed to shed light on the unique linguistic, communication, and social aspects of their interaction with others.

The second aim was to explore supportive strategies provided by family members and formal caregivers of deaf people with dementia. Family members and formal caregivers were chosen because they are the ones who most typically interact with deaf people with dementia during the continuum of dementia and therefore have the most opportunities in communicating support for them. This involved examining the communication dynamics, interactions, and relationships between deaf people with dementia and their caregivers, including both family members and formal caregivers. By identifying successful supportive strategies, we can enhance the well-being of deaf people with dementia.

The third aim was to identify the key elements that can enhance the abilities of family members and formal caregivers in providing support. By understanding the perspectives and experiences of family members and formal caregivers, this study aimed to uncover strategies, interventions, and resources that can further empower them in their caregiving roles. This included exploring ways to improve general communication, comprehension, and overall supportive communication. Through these three aims, this dissertation seeks to contribute to the knowledge surrounding dementia in the deaf community and provide practical insights for improving supportive communication for deaf people with dementia.

6.1 Changes in social interaction among deaf people with dementia

Deaf people with dementia face diverse linguistic changes similar to the findings of previous research concerning hearing people with dementia (e.g., Agbavor & Liang, 2022; Pozzebon et al., 2016; Walker et al., 2023). Deaf people with dementia appear to repeat words, signs, and sentences (see also Nguyen et al., 2019). They have difficulty comprehending (see also Tsantali et al., 2013) and remembering information (see also de Medeiros et al., 2022). Their abstract and conceptual thinking also declines (see also Allone et al., 2018). The findings of this dissertation reveal that deaf people with dementia have difficulty comprehending concepts, topics, medical information, and other people. The sign and word vocabulary of deaf people with dementia decreases, and some signs become incorrect or unclear. As dementia advances, this leads to deaf people with dementia tending to use less FinSL and more spoken words, but their speech may be unclear. However, since the oralistic approach in the 19th century failed to make all deaf people speak, their speech may never have been clear enough for others to comprehend. A more detailed explanation of linguistic and grammatical changes that were present in the interaction of the deaf people with dementia is beyond the scope of this dissertation and left for future research.

Deaf people with dementia become passive and show less initiative, consistent with the previous research on hearing people with dementia (see also Walker et al., 2023). They also lose the thread of conversation (see also Bayles et al., 2020). In addition, along with sign- and concept-finding difficulties and paraphrasing, these changes affect the conversational flow (see also Tsantali et al., 2013). Furthermore, the present study shows that participation in groups may become more difficult (Study III) as the social cognitive deterioration follows dementia (see also Setién-Suero et al., 2022). Finally, deaf people with dementia have fewer social relationships (Study I), which is also shown in the previous research on hearing people with dementia (see also Rafnsson et al., 2020). Deaf people may lose their own familiar FinSL community with shared experiences, i.e., their social network, during the continuum of dementia. When transitioned to a Home, it takes time before a person with dementia gets acquainted with other residents and personnel in that specific deaf community. Furthermore, this attunement may not succeed at all.

Among people with dementia, the deaf community is unique in the switching between two languages, i.e., FinSL and spoken language (Finnish), also called ‘translanguaging’ (de Meulder et al., 2019). Older deaf people have been taught to speak and lip-read at school (Ladd, 2003; Ladd & Lane, 2013; Salmi & Laakso, 2005). Along with the memory of the stigma of FinSL, their background may have an impact on their switching language when falling ill with dementia, and they revert to the spoken language. They may switch languages, depending on whether their interaction partner is hearing or deaf. To ask, “are you hearing or deaf?” or “what school did you attend?” is very common among older deaf people, because deaf people share an interest in other people’s connection with the deaf community (Ferguson-Coleman & Young, 2018; Minnesota Deaf and Hard of Hearing Services Division, 2023). When the interaction partner is hearing, deaf people with dementia may try to speak with or without signing. Their speech may although be unclear and difficult to comprehend, particularly for those who are not used to listening to it.

Accordingly, using FinSL may benefit the reciprocal comprehension. On the other hand, the previous studies on hearing bilingual people with dementia show that they often lose their second language (e.g., Brice et al., 2014; Gollan et al., 2010; Ellajosyula et al., 2020; Lind et al., 2018). Furthermore, deaf people with dementia may also switch languages, e.g., use their non-dominant language (Finnish) in a naming test to name a picture they cannot name in their dominant language (FinSL) (see also Gollan et al., 2010; Rantapää et al., 2015). However, the dominance difference between the two languages diminishes in the continuum of dementia (Lind et al., 2018).

Communication challenges refer to family members and formal caregivers unable to make themselves understood by a person with dementia and vice versa (Nguyen et al., 2019). It may be difficult for family members to accept the communication and memory changes that follow dementia (Study I). This contrasts with previous research, which has found that family members feel frustration and confusion when roles change, i.e., a parent-child-relationship may turn in such a way that the adult child becomes the caregiver (e.g., Pozzebon et al., 2016). Regarding CODAs of older deaf people, they may have already acted as informal interpreters for their parents and taken care of running errands as children. Therefore, the change of roles in this context may be minimal. However, not all CODAs can use FinSL, and the communication within the family has been "speaking with big mouth movements," i.e., coping with daily interaction using homemade language when the interaction has never been very deep. In addition, family members feel boredom and tiredness when their parent keeps repeating the same phrases over and over again (see also Morris et al., 2020). Accordingly, forgetfulness and change of personality may hit family members harder than formal caregivers who have in their professional role to carry the emotional burden dementia may cause.

Most deaf people with dementia today use the older style of FinSL (Studies II, III). Particularly young formal caregivers are seldom native in FinSL and they may have been exposed to and learned the modern FinSL. They can have difficulty understanding older deaf people with dementia. When formal caregivers have difficulty comprehending the FinSL style of older deaf people, it may lead to formal caregivers being unable to provide care due to refusal or resistance and uncertainty about what to say (see also Nguyen et al., 2019). Furthermore, deaf people with dementia have difficulty understanding rapid signing, concepts, and FinSL used by SL interpreters. Regarding older deaf people, the FinSL they use differs from the FinSL learned by SL interpreters. One major difference is the fingerspelling of SL alphabets: older deaf people use the old ones and SL interpreters the new. In addition, deaf people with dementia may not always comprehend complicated sentences, instructions, or hypernyms, or jargon used by physicians because it is not SL interpreters' business to explain but merely to translate.

Deaf people with dementia face deteriorating memory and nonverbal changes that can be manifested as forgetfulness, repetition of phrases and sentences, and looking away when in a conflict. The results are in line with previous research on the deaf community (see also Allan et al., 2005; Ferguson-Coleman & Young, 2018) and other minorities (see also Hanssen, 2013; Kenning et al., 2017; Lewis et al., 2021). Deaf people with dementia have difficulty remembering recent events, supported by previous studies that depict hearing people with dementia facing deteriorating memory and cognitive functions (e.g., Bebbington et al., 2023; Laczó et al., 2022). Furthermore, dementia affects the ability to orient to time and location (see also Howett et al., 2019).

Significant to deaf people with dementia is deteriorating finger dexterity, also shown in previous studies on hearing people (Liou et al., 2020; Suzumura et al., 2018). This is crucial for deaf people because SL is a visual-spatial language, i.e., produced by hand and body movements, facial expressions, and the position of the eyes (Institute for the Languages in Finland, 2023). The changes affect the clarity of SL (Ferguson-Coleman & Young, 2018) and make it more difficult for the interaction partner to comprehend. For those to whom SL is not familiar, these changes can be equivalent to a quieter voice or unclear speech when using spoken language (Agbavor & Liang, 2022; Szatloczki et al., 2015).

Deaf people with dementia turn their heads away when facing a conflict in which a total breakdown of interaction follows. Conventionally, turning one's head away is considered linguistic, and for deaf people, a sign of being not interested in interacting (Ferguson-Coleman & Young, 2018). Eye contact in general has diverse functions: (1) gaze averted from the interaction partner refers to the thinking phase, (2) gaze towards the interaction partner refers to a request for assistance, and (3) exchange of gaze refers to how interaction folds evenly (see Reza Majlesi et al., 2018). However, in the context of deaf people with dementia, turning one's head away and losing eye contact is one way for a deaf person with dementia to express aggression, frustration, or other negative feelings (see also Ferguson-Coleman & Young, 2018). This creates a challenge for family members and formal caregivers in communicating support.

In visual languages like SL, gaze plays a crucial role in active participation during conversations (Ferguson-Coleman & Young, 2018). Visual cues, facial expressions, and body language are vital for comprehension and communication. In SL, gaze is an active and necessary part of the conversation, enabling individuals to fully understand and contribute. Without visual engagement, crucial information and nuances may be missed. Therefore, for SL users, gaze is essential to actively participate and avoid exclusion, ensuring a complete exchange of ideas and information.

In summary, this dissertation highlights the unique challenges faced by deaf people with dementia in social interaction with other people. The linguistic changes and cognitive impairments faced by deaf people with dementia impact their ability to comprehend and express themselves effectively. Switching between FinSL and spoken language adds further complexity to their communication. Family members and formal caregivers also face challenges in understanding and communicating support to deaf people with dementia. The findings emphasize the importance of tailored strategies and interventions to improve communication and enhance the overall care provided to this vulnerable population. Moreover, the study emphasizes the significance of self-reflexivity in the research process and the role of the researcher as an instrument to gain authentic insights into the experiences of the participants. By acknowledging the cultural and linguistic context of deaf people with dementia, researchers and caregivers can create inclusive and supportive environments that cater to their specific communication needs. Ultimately, this research contributes to a better understanding of the unique communication challenges faced by deaf people with dementia and provides valuable insights for enhancing their well-being and quality of life.

6.2 Supportive communication by family members and formal caregivers

Family members and formal caregivers are often responsible for maintaining interaction with deaf people with dementia (see also Jootun & McGhee, 2011; Wilson et al., 2012). For example, family members and formal caregivers take initiative; shape the content and the form of a message, making it simpler and clearer; and lead the interaction (see also Purves & Phinney, 2012/2013). People with dementia in nursing homes in general often rely on formal caregivers to create social interaction, e.g., initiating or facilitating interaction between the residents (see also Adlbrecht et al., 2021; Söderlund et al., 2016).

Formal caregivers are usually responsible for topic selection and emotion regulation of deaf people with dementia. They often choose the topics instead of letting deaf people with dementia take the initiative. They ask questions to prompt interaction (see also Söderlund et al., 2016). However, this has been found to be problematic and unsupportive when a person with dementia has a declining episodic memory (Seixas-Lima et al., 2020). Furthermore, there are three types of interactions: (1) interaction mostly led by caregivers, (2) interaction more evenly shared with partners in which people with dementia initiate and elaborate on topics, and (3) interaction in which people with dementia talk most and caregivers communicate support (Baker et al., 2015). Accordingly, caregivers may use different strategies when communicating with people with dementia, varying from accommodative to impeding communication. Those who reflect back the responses of the person with dementia sustain engagement, whereas inattentive engagement impedes communication. As a result, engagement with full attention and choosing a topic of interest to deaf people with dementia is considered supportive communication.

Supportive communication provided by formal caregivers in dementia care is essential in coping with dementia (see also Davis et al., 2022; Karner & Bobbitt-Zeher, 2005). Supportive strategies addressed to communication changes consist of engaging in active attention and interpretive efforts to discern the intended meaning and communicative intentions of the interlocutor. Furthermore, a formal caregiver using supportive communication minimizes causes or triggers of problematic behavior and tries different ways to communicate (see also Nguyen et al., 2019).

Since personhood is shaped in relationships with others, it needs to be continuously found, fulfilled, and confirmed (Kitwood and Bredin, 1992). What a person with dementia may need is another person, e.g., a caregiver, to prevent decline and losing oneself and to maintain personhood. Consequently, in the continuum of dementia, the process needs to be upheld (Kitwood & Bredin, 1992). Formal caregivers can establish relationships with deaf people with dementia by taking the initiative and giving time, suggesting that they employ high person-centered communication skills (see also Ericsson et al., 2013). Furthermore, physical proximity of deaf people with dementia to their caregivers and the friendly gestures of the caregivers in a calm and pleasant atmosphere can help build trust and an equal relationship and produce positive feelings in both interaction partners. Talking about the photos of family members may help deaf people with dementia remember their close relationships (see also Fazio et al., 2018). In other words, the role of a caregiver is to become the memory of the person with dementia, and knowing the person is the key in care and in developing a mutual trust and relationship (Fazio et al., 2018). Additionally, formal caregivers provide emotional support for deaf people with dementia, e.g., by acting empathetic; being attentive, calm, and present; and showing compassion when deaf people with dementia express sadness (see also Ward et al., 2008). All in all, employing multiple communicative strategies is supportive in interaction with people with dementia (see also Wang et al., 2019).

Care should be based on knowing the person and supporting the dignity and choices of an individual (see also Fazio et al., 2018). As regards high person-centered supportive communication, knowing the biography of a person with dementia makes interaction more fruitful through sharing memories and by discussing something caregivers know about a deaf individual’s life history (see also Minghella & Schneider, 2012b; Polk, 2005). Life story work seems to be an effective method that encourages deaf people with dementia to communicate actively and share their memories in the form of storytelling, which is typical for the deaf community (Ferguson-Coleman & Young, 2018; Young et al., 2020). Deaf people with dementia need support in building their reality and daily life. Family members can provide knowledge about the biography, habits, likes and dislikes of an individual with dementia for the formal caregivers. Respectively, formal caregivers can refer to this information when interacting with deaf people with dementia.

Formal caregivers successfully use strategies of a high person-centered approach, resulting in being attentive, calm, empathetic and tolerant when communicating support to deaf people with dementia (see also Mundadan et al., 2023; Ryan et al., 2005; Savundranayagam et al., 2007; Williams et al., 2018). Furthermore, formal caregivers described using nonverbal strategies and creativity in interaction with deaf residents. They try to use FinSL in a clear manner, maintain eye contact, and find other ways to express themselves. They ask questions and give alternatives to enhance the interaction of deaf residents. They also use tangible interaction, such as the use of objects, and lead deaf residents to the place they intended, e.g., bathroom.

Nonverbal communication increases as verbal communication decreases along with advancing dementia (see also Kontos, 2012). When communication becomes limited, the meaning of nonverbal communication increases. However, the nonverbal in SLs differ from the nonverbal in spoken languages in which nonverbal is another layer in interaction, whereas SLs are “non-verbal” and the nonverbal in SLs is linguistic (Ferguson-Coleman & Young, 2018). Furthermore, when deaf people with dementia lose their SL communication skills, they express themselves through social and cultural habits, bodily movements, and other physical cues, such as facial expressions, eye behavior and posture (see also Kontos, 2012). These communicative ways have a significant role in social interaction and implicate meaning as being intentional, communicative, informative, and interactive. This can be seen, e.g., when creating contact and comfort through touch or when evaluating one’s pain (see also Cunningham et al., 2010). In addition, we can still establish meaningful connections with people with dementia (see also Hughes, 2013). Then, the meaning is not given by words or signs, but by context. These connections are constructs of the interpretation of gestures, gaze, grimaces, mime, and diverse motions, but might also involve techniques, also called “Adaptive Interaction” – a means of communicating without words addressed to people with dementia who no longer use words (Ellis et al., 2018).

Body work, i.e., feeding, toileting, and helping with daily hygiene, functions as an opportunity to build a bridge to the other person and create a sense of belonging (see also Watson, 2019). Accordingly, bodily actions, such as pushing away a cup, spitting out food or medication, as well as frowning and grinning should be considered as communicative, interactive, informative, and intentional (Kontos, 2012) when caring decisions are made. Finally, knowledge about residents helps formal caregivers to know how to care for them.

Physical surroundings and architecture in which deaf people with dementia live are significant, particularly small compact units where staff use FinSL help deaf residents to feel calm and safe with an easy access to help and care (see also Lüdtke, 2014). Furthermore, a communicative environment in FinSL supports deaf people with dementia to maintain their FinSL, and in dementia-specified units for deaf people, the use of FinSL may even increase. Consequently, a signing environment is highly important in supporting social interaction for deaf people with dementia (see also Parker et al., 2010).

In sum, supportive strategies differ individually (see also Savundranayagam & Moore-Nielsen, 2015). Caregivers who use positive feedback can enhance topic maintenance during interactions with deaf people with dementia (see also Dijkstra et al., 2002). All in all, knowing the biography of a person with dementia helps in understanding their communicative behavior, and behavior in general, as well as predicting and avoiding conflicts. Furthermore, having eye contact and using nonverbal gestures and touch are associated with successful supportive communication (see also van Manen et al., 2021). Successful supportive strategies (see Figure 4 for results) comprise relational strategies, interactional strategies, and linguistic strategies. Figure 6 displays these categories of strategies.

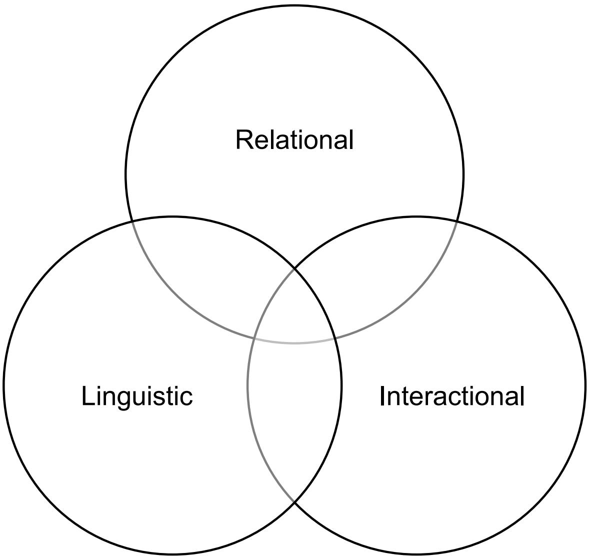


Figure 6 Categories of successful strategies for formal caregivers supporting deaf people with dementia.

6.3 Ways to improve supportive communication

While the results demonstrate that both family members and formal caregivers employ various strategies to support deaf people with dementia, there is room for improvement (Study III). First, fostering an empathetic and supportive environment is essential. Formal caregivers should strive to develop a relationship of trust and understanding with deaf people with dementia, recognizing their unique needs and preferences. This can be achieved through active engagement, patience, and sensitivity to nonverbal cues.

Second, it is crucial to provide special training for family members and formal caregivers to enhance their understanding of dementia and its impact on communication. This can include workshops, seminars, and resources that focus on effective communication strategies and techniques specific to deaf people with dementia.

Third, improving professional collaboration and communication between formal caregivers, SL interpreters, and other healthcare professionals is vital. Regular meetings and discussions can help ensure accurate end consistent information exchange, avoiding misunderstandings and enhancing overall care coordination.

Lastly, providing ongoing support and resources for family members and formal caregivers is essential. This can include access to support groups, counseling services, and educational materials to help them navigate the challenges of caring for deaf people with dementia. By implementing these strategies, the abilities of family members and formal caregivers can be further enhanced, leading to more effective and supportive communication with deaf people with dementia. Figure 7 portrays the ways in which formal caregivers perceive supportive communication can be enhanced.

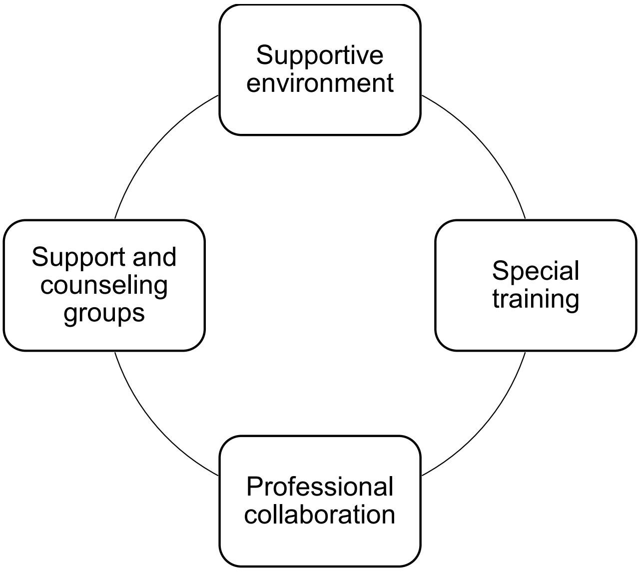


Figure 7 Ways for formal caregivers to improve supportive communication for deaf people with dementia.

Formal caregivers have an important role in giving family members information about dementia and its impact on deaf people (see also Mazaheri et al., 2013). Formal caregivers also help to interpret the expressions of deaf people with dementia when family members have difficulty understanding them. Consequently, formal caregivers experience ambivalent feelings when working with people with dementia (see also de Witt & Ploeg, 2016). Therefore, formal caregivers need emotional support to be capable of providing person-centered care.

Furthermore, formal caregivers discuss and share their ideas with their co-workers in order to solve difficult situations, e.g., conflicts and misunderstandings with deaf people with dementia, (see also Nguyen et al., 2019). Formal caregivers are willing to learn more FinSL, particularly the style used by older deaf people. In addition, the formal caregivers want to educate themselves further on dementia. In particular, they want to learn how dementia impacts deaf people and how to improve support for them. This finding reflects career growth (see also Gilster et al., 2018; Nguyen et al., 2019).

This doctoral dissertation offers valuable insights into the challenges faced by deaf people with dementia and emphasizes the importance of providing effective, supportive communication and care in FinSL, ensuring their needs are recognized and they feel seen and valued. Formal caregivers must receive education and training in deaf culture and the unique communication needs of deaf people with dementia (see also Hepner et al., 2022), particularly understanding the FinSL style of older people. Additionally, the presence of more native signers among healthcare professionals is crucial for creating a fluent signing environment. Creating an active signing environment and fostering linguistic stimulation can enhance the well-being and communication abilities of deaf people with dementia. It is evident that knowledge of the life history of an individual plays a key role in understanding their unique needs and preferences. Therefore, collaboration with family members is essential in tailoring support to individual needs.

Importantly, deaf people with dementia are not solely members of the broader community but are also active members in the visual-cultural deaf community, where they maintain connections, friendships, and cultural identity. However, as they experience declining cognitive skills and changes in social interaction, their involvement in the deaf community may be affected (see Ferguson-Coleman & Young, 2018; Rogers et al., 2018b; Young et al., 2018). The deaf community should also be educated about dementia to provide better support and decrease prejudices, enabling active members to maintain connections and cultural identity (see also Ferguson-Coleman et al., 2014; Young et al., 2016). Finally, by incorporating these findings into practice, we can work towards improving the quality of life and care of deaf people with dementia, recognizing their unique communication and cultural needs.

6.4 Evaluation of the research and future implications

6.4.1 Methodological considerations

The data of this dissertation comprised individual thematic and semi-structured interviews, as well as video recordings of dyadic interactions. The methods of analysis used were inductive content analysis and ICBCS. Furthermore, both data and analysis triangulation were applied.

Interviews are useful in gathering data on a previously little-researched phenomenon (Ritchie et al., 2003), such as the social interaction of deaf people with dementia and their, often, hearing caregivers. While semi-structured interviews have been widely used in research on dementia (e.g., Ericson-Lidman et al., 2014; Kamalraj et al., 2021; Lee & Lee, 2022; Mazaheri et al., 2013), there are very few studies that have used thematic interviews with family members (see Lundin et al., 2021). Consequently, this study adds to literature showing that thematic interviews can encourage family members to describe their experiences freely and accurately compared to the setting of pre-determined and focused topics of a semi-structured interview (see also Adeoye-Olatunde & Olenik, 2021).

Video data have been used in studying interactions between caregivers and deaf people with dementia (e.g., Ferguson-Coleman & Young, 2018; Spanjer et al., 2014) but also among hearing people (e.g., Hall et al., 2018; Kim et al., 2022). Video data are beneficial because they can be reviewed repeatedly, and they capture facial expressions as well as other gestures showing details that could otherwise be missed (see also Williams et al., 2018). Furthermore, video analysis may help reveal the hidden patterns of behavior and the ways that various resources are used in interaction as well as reveal both beneficial and problematic behaviors in interaction (see also Antelius et al., 2018; Reza Majlesi et al., 2018). Video data can yield a deeper understanding of interaction. Finally, utilizing video data helps people with dementia be more included and actively participate in research (Ferguson-Coleman & Young, 2018; Parker et al., 2010; Young et al., 2014; 2018).

Previous studies have utilized the theoretical background and methods of conversation analysis (CA) when studying conversations between formal caregivers and people with dementia (e.g., Hall et al., 2018; Kindell et al., 2017; Webb, 2017). Moreover, CA is interested in the organization of social interaction and not in conversations and language itself (Reza Majlesi et al., 2018). This is to say that CA typically concentrates on exploring turns and repairs in interaction. However, this dissertation aimed to explore the dimensions of relationships in which content analysis is more applicable. Therefore, CA was not chosen as an analysis method. Inductive content analysis (Elo & Kyngäs, 2008; Vaismoradi et al., 2013) can be used when there is no existing theory and little previous research on a phenomenon, as in the case of this dissertation. It aims at producing qualitative answers to the research questions obtained from the data, i.e., words or sentences produced for the interviews. Therefore, inductive content analysis was considered appropriate, albeit laborious and time-consuming, for this dissertation in finding the answers to the research questions.

ICBCS (Barbee & Cunningham, 1995) has not before been applied in studies that have explored interactions of people with dementia in general or interactions of deaf people with dementia. However, it is one of the most thorough coding schemes on social support strategies used in studying supportive communication (Virtanen et al., 2015). Consequently, ICBCS (Barbee & Cunningham, 1995) added value to this dissertation because it was applicable for the purposes of this study in producing a rich and diverse analysis of supportive communication of formal caregivers of deaf people with dementia.

The rigor is considered through credibility, dependability, conformability, and transferability as described in Lincoln and Guba (1984). The author has attempted to be clear about the methodological decisions taken during the study so readers can judge the study’s trustworthiness and ultimately its findings (Hallberg, 2013). Credibility was strengthened by making pilot interviews (Studies I, III). Dependability was achieved by gathering the data in a reasonable time (see Table 3). Conformability was controlled by reporting the process of analysis in detail (see the original publication of Study II). Transferability was attempted by a thorough report of the research process. Regarding inner reliability, a peer analysis was not performed, but the analysis has been under discussion within the research team (see, e.g., van Wijngaarden et al., 2019), and the analysis has been evaluated in time and stayed stable. Finally, the reader is recommended to read the authentic quotations presented in the original publications (Studies I, II, III).

In sum, the triangulation of interview and observation data, inductive content analysis and ICBCS were used in this study. They were found suitable for the purposes of this study in providing unique and precious information on social interaction of deaf people with dementia as well as supportive communication provided by family members and formal caregivers.

6.4.2 Strengths and limitations

The strengths of this dissertation are its specific focus, and unique contribution. The dissertation focused on social interaction of deaf people with dementia, the changes that deaf people with dementia face during the continuum of dementia and the effects they have on social interaction. The dissertation also focused on the supportive communication provided by family members and formal caregivers. This dissertation represents qualitative research on a phenomenon that has thus far not been studied widely. Therefore, it produces unique information and insight that can be used both nationally and internationally to create tools to enhance the interaction of deaf people with dementia and to provide social support for them. The data were gathered through both one-on-one interviews and video data and analyzed carefully using inductive content analysis (Elo & Kyngäs, 2008; Vaismoradi et al., 2013) and the Interactive Coping Behavior Coding System (ICBCS, Barbee & Cunningham, 1995). The methods used to analyze the data proved to be useful for answering the research questions posed.

One strength of this dissertation is that it is one of the first studies with adult CODAs and deaf people with dementia. Study I is internationally a unique contribution in producing scientific knowledge of social interaction of deaf people with dementia through the perspective of their family members. All the participants in Study I were CODAs. Very little research has been conducted on this minority, even though the needs and unique experiences of CODAs are largely unknown. Being a CODA and having a deaf mother with dementia, the author shared common ground with the interviewees, which added to the understanding and interpretation of the interviewees' perceptions of deaf culture and their experiences.

The author was aware of the possible bias, but firstly, the researcher role was helpful in distancing herself and being open to the views of the participants. Secondly, the author kept a diary in which personal views and thoughts were written. Thirdly, it was useful for comparing the personal ideas with the analysis results and keeping them separate. Therefore, the author was confident not to select those participants' perceptions that were strengthening the author's own building blocks of reality but in fact selected those that reflected the participants' reality.

Study II presented unique video data of social interaction between deaf people with dementia and their formal caregivers in a Home for older deaf people including deaf people with dementia participating in the study, which is yet rare (see Ferguson-Coleman & Young, 2018). Study III focused on formal caregivers' perceptions of social interaction of deaf people with dementia, changes in interaction, and caregivers' strategies to provide support for them. In addition to being a CODA, the author is also a RN and, having worked several years with deaf people with dementia (after the data-gathering phase), shares common ground with the formal caregivers interviewed for this dissertation. Consequently, the background and experiences have helped the author to understand and interpret the experiences of both the CODA participants and the formal caregivers.

This dissertation has some limitations. First, the sample size is small, in total 26 participants, which can challenge the generalization of the results of the dissertation. However, the data were gathered until reaching their saturation point and therefore considered adequate (Fusch & Ness, 2015). Furthermore, the saturation point may not be as relevant in qualitative studies as the amount of information (Malterud et al., 2014), which in this dissertation is considered adequate in the context of the Finnish deaf community. Although generalizing the results is often not the aim in qualitative studies (Polit & Beck, 2010) the same way as in quantitative studies, similarities among deaf people with dementia in other countries may be found. Nevertheless, it is essential to take into consideration that every individual is unique in their interaction.

Second, all the participants were female. Therefore, it should be kept in mind that the findings may be skewed and one-sided. However, the study reflects reality in a way, in that female family members are more involved in taking care of their aging spouse or parent than male family members (see also Haberkern et al., 2015; Navaie-Waliser et al., 2002; Pope et al., 2012; Smith & Rodham, 2022). Moreover, they tend to be more interested than males in participating in research and are therefore represented in several areas of research (Steinberg et al., 2021). Furthermore, most of the nurses in healthcare globally (Steinberg et al., 2021; Åhlin et al., 2022) as well in Finland are female and, consequently, more available to participate in research. The participants were female, which reflects the profile of long-term care professionals (see also Mundadan et al., 2023; Savundranayagam et al., 2007; Åhlin et al., 2022). Overall, the results can be applicable for, e.g., speech and language therapists (SLTs) in educating care personnel.

6.4.3 Clinical implications and future directions

Family members and formal caregivers provide support for deaf people with dementia through various means: using supportive communication, adapting communication strategies, offering emotional comfort, providing practical assistance, implementing memory support techniques, encouraging social engagement, and seeking specialized education and training in dementia care within the deaf community. These supportive efforts aim to enhance understanding, alleviate challenges, and promote the overall well-being of people with dementia. It is important for family members and formal caregivers to regularly assess and reassess the support needs of deaf people with dementia, as these needs may change over time. Collaboration with healthcare professionals, support networks, and organizations specializing in deaf and dementia care can further enhance the support provided for deaf people with dementia. One problem is changing SL interpreters, who may over-interpret and try to understand when they actually do not. Deaf people with dementia need continuity, and therefore they should be entitled to use the same SL interpreters whenever they need, e.g., when seeing a physician. In time both parties learn to understand each other better.

Not only family members and formal caregivers but also the deaf community can benefit from knowledge on how dementia affects deaf people. Because dementia is not well known among the deaf community and dementia carries stigma, the whole community needs education about dementia to decrease preconceptions and prejudices. Furthermore, the deaf community needs tools to learn how to support deaf people with dementia instead of leaving them alone.

For clinical implications, the author suggests communication rehabilitation in FinSL provided by SLTs, i.e., direct speech and language therapy, in cooperation with SL teachers. Because the FinSL proficiency of most SLTs may not be sufficient for communication rehabilitation in FinSL, SL teachers could contribute in FinSL proficiency. SLTs specialized in dementia (see Volkmer, et al., 2020) could contribute to the dementia care of deaf people in educating family members and formal caregivers in finding ways to interact with everyone, i.e., indirect speech and language therapy. The focus should be on FinSL, but other visual ways of communication, e.g., pictures and objects, could also be beneficial and worth trying.

One topic for future research could be social support for family members and formal caregivers of deaf people with dementia. CODAs of deaf people with dementia feel sadness and anxiety when their parents fall ill with dementia, which is important to recognize and address. One objective of future research may involve looking at the usefulness of CODA support groups in which CODAs can share their unique experiences compared to support groups for family members of hearing people with dementia. Similar to formal caregivers who have inadequate FinSL proficiency, most CODAs of older deaf people have often not had access to education in FinSL. They have learned “home FinSL” and often communicated with "a big mouth," i.e., they cope in daily interaction with their parents but not more complicated and deeper interaction. Moreover, not all CODAs can FinSL at all.

The issue of person-centered care in dementia care is an important topic that has been widely discussed in research and practice (e.g., ADI, 2022; Savundranayagam et al., 2016; Åhlin et al., 2022). Person-centered care emphasizes the individuality and uniqueness of each person with dementia, taking into account their preferences, needs, and abilities (e.g., Kitwood, 1997; Mundadan et al., 2023; Ryan et al., 2005; Savundranayagam & Moore-Nielsen, 2015). It involves placing the person at the center of the care process and tailoring care interventions and approaches to promote their well-being. In the context of dementia care, person-centered approaches aim to move away from a one-size-fits-all model of care and instead focus on understanding and responding to the individual experiences and capabilities of each person with dementia (Ward et al., 2008). This includes recognizing their personal history, values, and preferences, as well as involving them in decision-making processes regarding their care. However, the extent to which dementia care is truly person-centered can vary.

While many care settings and providers strive to adopt person-centered principles, there can still be challenges and barriers that hinder its full implementation (Ward et al., 2008), and particularly for deaf people with dementia (Rogers et al., 2018b). To ensure that dementia care is person-centered, it is essential to create a supportive environment that values and respects the autonomy and dignity of individuals with dementia. This involves training and educating staff on person-centered principles, promoting effective communication strategies, fostering meaningful social interaction, and involving people with dementia in care planning and decision-making processes (Hepner et al., 2022; Gilster et al., 2018). By adopting a person-centered approach, caregivers and care organizations can enhance the quality of life for people with dementia, promote their well-being, and create a more inclusive and supportive care environment (Ward et al., 2008). Ongoing research and continuous efforts are needed to further develop and implement person-centered practices in dementia care settings.

Whereas the primary focus of dementia care is often centered around managing symptoms and providing support for daily functioning, rehabilitation approaches can play a significant role in improving the quality of life for people with dementia (Kim, 2015; Xiang & Zhang, 2023), another aspect worth exploring in the context of deaf people with dementia. Rehabilitation in the context of dementia care involves interventions aimed at maintaining or improving cognitive, physical, and psychosocial functioning (Clare, 2017). These interventions can include cognitive training, physical exercise programs, occupational therapy, and speech and language therapy, as well as psychosocial interventions (Bahar-Fuchs et al., 2019; Clare, 2017; Øksnebjerg et al., 2020).

However, due to various factors such as limited resources, a lack of awareness, and a prevailing perception that dementia is a progressive and irreversible condition, rehabilitation approaches are not always fully integrated into dementia care settings (West et al., 2022). This can result in missed opportunities to enhance individuals' functioning, independence, and overall well-being. Since the potential benefits of rehabilitation have been recognised, there is a growing interest in incorporating rehabilitation strategies into dementia care (see e.g., Cafferata et al., 2021; Oliveira et al., 2021). Research studies and pilot programs have demonstrated positive outcomes in areas such as cognitive abilities, physical function, behavior, and quality of life when rehabilitation is incorporated into dementia care plans. To improve the provision of rehabilitation in dementia care, it is important to raise awareness among healthcare professionals, policymakers, and caregivers about the potential benefits of rehabilitation interventions. Additionally, integrating rehabilitation approaches into care plans and ensuring access to specialized rehabilitation services can contribute to improving the overall quality of care and outcomes for people with dementia.

References

Abreu, W., Rodrigues, T., Sequeira, C., Pires, R., & Sanhudo, A. (2018). The experience of psychological distress in family caregivers of people with dementia: A cross-sectional study. *Perspectives in Psychiatric Care*, *54*(2), 317–323. https://doi.org/10.1111/ppc.12240

Act on the Interpreting Services of Disabled Persons 2010 (133).

Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons 2012 (980).

Act on the Status and Rights of Patients 1992 (785).

Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semi-structured interviews. *Journal of the American College of Clinical Pharmacy*, *4*(10), 1358–1367. https://doi.org/10.1002/jac5.1441

Adlbrecht, L., Bartholomeyczik, S., Hildebrandt, C., & Mayer, H. (2021). Social interactions of persons with dementia living in special care units in long-term care: A mixed-methods systematic review. *Dementia, 20*(3), 967–984. https://doi.org/10.1177/1471301220919937

Agbavor, F., & Liang, H. (2022). Predicting dementia from spontaneous speech using large language models. *PLOS Digital Health*, *1*(12), 1–14. https://doi.org/10.1371/journal.pdig.0000168

Aggio, N. M., Ducatti, M., & de Rose, J. C. (2018). Cognition and language in dementia patients: Contributions from behavior analysis. *Behavioral Interventions*, *33*(3), 322–335. https://doi.org/10.1002/bin.1527

Albers, M. W., Gilmore, G. C., Kaye, J., Murphy, C., Wingfield, A., Bennett, D. A., Boxer, A. L., Buchman, A. S., Cruickshanks, K. J., Devanand, D. P., Duffy, C. J., Gall, C. M., Gates, G. A., Granholm, A.-C., Hensch, T., Holtzer, R., Hyman, B. T., Lin, F. R., McKee, A. C., ... Zhang, L. I. (2015). At the interface of sensory and motor dysfunctions and Alzheimer's disease. *Alzheimer's & Dementia*, *11*(1), 70–98. https://doi.org/10.1016/j.jalz.2014.04.514

Allan, K., Stapleton, K., & McLean, F. (2005). *Dementia & deafness: An exploratory study*. University of Stirling.

Allone, C., Lo Buono, V., Corallo, F., Bonanno, L., Palmeri, R., Di Lorenzo, G., Marra, A., Bramanti, P., & Marino, S. (2018). Cognitive impairment in Parkinson's disease, Alzheimer's dementia, and vascular dementia: the role of the clock-drawing test. *Psychogeriatrics*, *18*(2), 123–131. https://doi.org/10.1111/psyg.12294

Alsawy, S., Mansell, W., McEvoy, P., Tai, S., 2017. What is good communication for persons living with dementia? A mixed-methods systematic review.

International Psychogeriatics. *29*(11), 1785–1800. https://doi.org/10.1017/S1041610217001429

Alzheimer, A. (1907). Über eine eigenartige erkrankung der hirnrinde [On a peculiar disease of the cerebral cortex]. *Allgemeine Zeitschirft für Psychiatrie und Pscychisch-Gerichtliche Medizin, 64*, 146–148.

Alzheimer's Disease International. (2022, September 20). *Up to 85% of people living with dementia may not receive post-diagnosis care – World Alzheimer Report reveals* [Press release]. https://www.alzint.org/news-events/news/up-to-85-of-people-living-with-dementia-may-not-receive-post-diagnosis-care-world-alzheimer-report-reveals/#:~:text=LONDON%20–%2021%20September%202022%3A%20In,recognised%20as%20a%20human%20right

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5™* (5th ed.). American Psychiatric Publishing, Inc. https://doi.org/10.1176/appi.books.9780890425596

Amieva, H., Robert, P. H., Grandoulier, A.-S., Meillon, C., De Rotrou, J., Andrieu, S., Berr, C., Desgranges, B., Dubois, B., Girtanner, C., Joël, M.-E., Lavallart, B., Nourhashemi, F., Pasquier, F., Rainfray, M., Touchon, J., Chêne, G., & Dartigues, J.-F. (2016). Group and individual cognitive therapies in Alzheimer's disease: the ETNA3 randomized trial. *International Psychogeriatrics*, *28*(5), 707–717. https://doi.org/10.1017/S1041610215001830

Amieva, H., Stoykova, R., Matharan, F., Helmer, C., Antonucci, T. C., & Dartigues, J.-F. (2010). What aspects of social network are protective for dementia? Not the quantity but the quality of social interactions is protective up to 15 years later. *Psychosomatic Medicine*, *72*(9), 905–911. https://doi.org/10.1097/PSY.0b013e3181f5e121

Antelius, E., Kiwi, M., & Strandroos, L. (2018). Ethnographic methods for understanding practices around dementia among culturally and linguistically diverse people. In J. Keady, L.-C., Hydén, A., Johnson, & C., Swarbrick (Eds.), *Social Research Methods in Dementia Studies* (1st ed., pp. 121–139). Routledge. https://doi.org/10.4324/9781315517490-8

Aoun, S. M., Toye, C., Slatyer, S., Robinson, A., & Beattie, E. (2018). A person-centred approach to family carer needs assessment and support in dementia community care in Western Australia. *Health & Social Care in the Community*, *26*(4), 578–586. https://doi.org/10.1111/hsc.12575

Atkinson, J., Denmark, T., Marshall, J., Mummery, C., & Woll, B. (2015). Detecting cognitive impairment and dementia in Deaf people: The British sign language cognitive screening test. *Archives of Clinical Neuropsychology, 30*(7), 694–711. https://doi.org/10.1093/arclin/acv042

Backhouse, T., & Ruston, A. (2022). Home-care workers' experiences of assisting people with dementia with their personal care: A qualitative interview study. *Health & Social Care in the Community*, *30*(3), e749–e759. https://doi.org/10.1111/hsc.13445

Baghramian, M., & Carter, J. A. (2022). Relativism. In E. N., Zalta (Ed.), *The Stanford Encyclopedia of Philosophy (Spring 2022 ed.)*. Stanford University. https://plato.stanford.edu/archives/spr2022/entries/relativism/

Bahar-Fuchs, A., Martyr, A., Goh, A. M. Y., Sabates, J., & Clare, L. (2019). Cognitive training for people with mild to moderate dementia. *Cochrane*

Database of Systematic Reviews, 3(CD013069), 1–289. https://doi.org/10.1002/14651858.CD013069.pub2

Baker, R., Angus, D., Smith-Conway, E. R., Baker, K. S., Gallois, C., Smith, A., Wiles, J., & Chenery, H. J. (2015). Visualising conversations between care home staff and residents with dementia. *Ageing and Society*, *35*(2), 270–297. https://doi.org/10.1017/S0144686X13000640

Barbee, A. P., & Cunningham, M. R. (1995). An experimental approach to social support communications: Interactive coping in close relationships. In B. R. Burleson (Ed.), *Communication yearbook, Volume 18* (pp. 381–413). SAGE.

Baxter, L. A. (2004). Relationships as dialogues. *Personal Relationships*, *11*(1), 1–22. https://doi.org/10.1111/j.1475-6811.2004.00068.x

Bayles, K. A. (2003). Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients. *Journal of Communication Disorders*, *36*(3), 209–219. https://doi.org/10.1016/S0021-9924(03)00020-0

Bayles, K. A., McCullough, K., & Tomoeda, C. K. (2020). *Cognitive-communication disorders of MCI and dementia: definition, assessment, and clinical management* (3rd ed.). Plural Publishing, Inc.

Bebbington, P. (2023). Losing the thread: Experiences of cognitive decline in Alzheimer's disease. *The British Journal of Psychiatry, 222*(4), 151–152. https://doi.org/10.1192/bjp.2022.184

Berger, C. R. (2005). Interpersonal communication: Theoretical perspectives, future prospects. *Journal of Communication*, *55*(3), 415–447. https://doi.org/10.1111/j.1460-2466.2005.tb02680.x

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*, 219–234. https://doi.org/10.1177/1468794112468475

Birks, M. (2014). Practical philosophy. In J., Mills, & M., Birks (Eds.), *Qualitative methodology: A practical guide* (Part I, chapter 2). SAGE. https://doi.org/10.4135/9781473920163

Black, B. S., Wechsler, M., & Fogarty, L. (2013). Decision making for participation in dementia research. *The American Journal of Geriatric Psychiatry*, *21*(4), 355–363. https://doi.org/10.1016/j.jagp.2012.11.009

Blair, M., Marczinski, C. A., Davis-Faroque, N., & Kertesz, A. (2007). A longitudinal study of language decline in Alzheimer's disease and frontotemporal dementia. *Journal of the International Neuropsychological Society, 13*(2), 237–245. https://doi.org/10.1017/S1355617707070269

de Boer, D., Hofstede, J. M., De Veer, A. J. E., Raijmakers, N. J. H., & Francke, A. L. (2017). Relatives' perceived quality of palliative care: Comparisons between care settings in which patients die. *BMC Palliative Care*, *16*(1), 41–41. https://doi.org/10.1186/s12904-017-0224-x

Boylstein, C., & Hayes, J. (2012). Reconstructing marital closeness while caring for a spouse with Alzheimer's. *Journal of Family Issues*, *33*(5), 584–612. https://doi.org/10.1177/0192513X11416449

Brice, A. E., Wallace, S. E., & Brice, R. G. (2014). Alzheimer's dementia from a bilingual/bicultural perspective: A case study. *Communication Disorders Quarterly*, *36*(1), 55–64. https://doi.org/10.1177/1525740114524435

Brites, R., Brandão, T., Moniz Pereira, F., Hipólito, J., & Nunes, O. (2020). Effects of supporting patients with dementia: A study with dyads. *Perspectives in Psychiatric Care*, *56*(3), 614–620. https://doi.org/10.1111/ppc.12476

Brock, D., Abu-Rish, E., Chiu, C.-R., Hammer, D., Wilson, S., Vorvick, L., Blondon, K., Schaad, D., Liner, D., & Zierler, B. (2013). Interprofessional education in team communication: working together to improve patient safety. *Postgraduate Medical Journal*, *89*(1057), 642–651. https://doi.org/10.1136/postgradmedj-2012-000952rep

Burleson, B. R. (2009). Understanding the outcomes of supportive communication: A dual-process approach. *Journal of Social and Personal Relationships*, *26*(1), 21–38. https://doi.org/10.1177/0265407509105519

Burleson, B. R. (2010). The nature of interpersonal communication. In C. R. Berger, M. E. Roloff, & D.R. Roskos-Ewoldsen (Eds.), *The handbook of communication science* (2nd ed., pp. 145–163). SAGE. https://doi.org/10.4135/9781412982818.n9

Burleson, B. R., MacGeorge, E. L. (2002). Supportive communication. In J. A. Daly, & M. L. Knapp (Eds.), *Handbook of interpersonal communication* (3rd ed., pp. 374–424). SAGE.

Cafferata, R. M. T., Hicks, B., & von Bastian, C. C. (2021). Effectiveness of cognitive stimulation for dementia: A systematic review and meta-analysis. *Psychological Bulletin, 147*(5), 455–476. https://doi.org/10.1037/bul0000325

Calzà, L., Gagliardi, G., Rossini Favretti, R., & Tamburini, F. (2021). Linguistic features and automatic classifiers for identifying mild cognitive impairment and dementia. *Computer Speech & Language*, *65*, 1–18. https://doi.org/10.1016/j.csl.2020.101113

Cameron, N., Fetherstonhaugh, D., Bauer, M., & Tarzia, L. (2020). How do care staff in residential aged care facilities conceptualise their non-verbal interactions with residents with dementia and what relevance has this for how residents' preferences and capacity for decision-making are understood? *Dementia*, *19*(5), 1364–1380. https://doi.org/10.1177/1471301218798422

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545–547. https://doi.org/10.1188/14.ONF.545-547

Cations, M., Laver, K. E., Crotty, M., & Cameron, I. D. (2018). Rehabilitation in dementia care. *Age and Ageing*, *47*(2), 171–174. https://doi.org/10.1093/ageing/afx173

Chafe, R. (2017). The value of qualitative description in health services and policy research. *Healthcare Policy*, *12*(3), 12–18. https://doi.org/10.12927/hcpol.2017.25030

Chen, D. S., Betz, J., Yaffe, K., Ayonayon, H. N., Kritchevsky, S., Martin, K. R., Harris, T. B., Purchase-Helzner, E., Satterfield, S., Xue, Q.-L., Pratt, S., Simonsick, E. M., & Lin, F. R. (2015). Association of hearing impairment with declines in physical functioning and the risk of disability in older adults. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, *70*(5), 654–661. https://doi.org/10.1093/gerona/glu207

Chen, M.-S., Chen, W.-R., & Lee, H.-M. (2019). Memory performance of people with different dementia severity for different semantic hierarchies.

Experimental Aging Research, *45*(3), 266–281. https://doi.org/10.1080/0361073X.2019.1609157

Chichirez, C. M., & Purcărea, V. L. (2018). Interpersonal communication in healthcare. *Journal of Medicine and Life*, *11*(2), 119–122. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6101690/

Clare, L. (2017). Rehabilitation for people living with dementia: A practical framework of positive support. *PLoS Medicine*, *14*(3), 1–4. https://doi.org/10.1371/journal.pmed.1002245

Cleary, M., Horsfall, J., & Hayter, M. (2014). Data collection and sampling in qualitative research: Does size matter? *Journal of Advanced Nursing, 70*(3), 473–475. https://doi.org/10.1111/jan.12163

Cole, L., Samsi, K., & Manthorpe, J. (2018). Is there an "optimal time" to move to a care home for a person with dementia? A systematic review of the literature. *International Psychogeriatrics*, *30*(11), 1649–1670. https://doi.org/10.1017/S1041610218000364

Coleman, C., Williams, K., Inderhees, K., & Richardson, M. (2021). Nonverbal communication in dementia family caregiving: using the VNVIS-CG scale for in-home video observations. *Innovation in Aging*, *5*(S1), 478–478. https://doi.org/10.1093/geroni/igab046.1850

Constitution of Finland 1999 (731).

Conway, E. R. (2014). The role of communication in quality dementia care. *Australian Journal of Dementia Care, 3*(1), 31–34. https://dta.com.au/app/uploads/downloads/Communication-and-dementia_AJDC-Vol3-No1.pdf

Cummings, J., Mintzer, J., Brodaty, H., Sano, M., Banerjee, S., Devanand, D. P., Gauthier, S., Howard, R., Lanctôt, K., Lyketsos, C. G., Peskind, E., Porsteinsson, A. P., Reich, E., Sampaio, C., Steffens, D., Wortmann, M., & Zhong, K. (2015). Agitation in cognitive disorders: International Psychogeriatric Association provisional consensus clinical and research definition. *International Psychogeriatrics*, *27*(1), 7–17. https://doi.org/10.1017/S1041610214001963

Davis, L., Botting, N., Cruice, M., & Dipper, L. (2022). A systematic review of language and communication intervention research delivered in groups to older adults living in care homes. *International Journal of Language & Communication Disorders*, *57*(1), 182–225. https://doi.org/10.1111/1460-6984.12679

Davis, R. E., Couper, M. P., Janz, N. K., Caldwell, C. H., & Resnicow, K. (2010). Interviewer effects in public health surveys. *Health Education Research*, *25*(1), 14–26. https://doi.org/10.1093/her/cyp046

Denmark, T., Marshall, J., Mummery, C., Roy, P., Woll, B., & Atkinson, J. (2016). Detecting memory impairment in deaf people: A new test of verbal learning and memory in British Sign Language. *Archives of Clinical Neuropsychology*, *31*(8), 855–867. https://doi.org/10.1093/arclin/acw032

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*(1), 11–25. https://doi.org/10.1177/1471301207075625

Dick, B. (2014). Action research. In J., Mills, & M., Birks (Eds.), *Qualitative methodology: A practical guide*. SAGE. https://doi.org/10.4135/9781473920163

Dijkstra, K., Bourgeois, M., Petrie, G., Burgio, L., & Allen-Burge, R. (2002). My recaller is on vacation: Discourse analysis of nursing-home residents with dementia. *Discourse Processes, 33*(1), 53–76. https://doi.org/10.1207/S15326950DP3301_03

Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, *25*(5), 443–455. https://doi.org/10.1177/1744987119880234

Ducharme, F., Kergoat, M.-J., Coulombe, R., Lévesque, L., Antoine, P., & Pasquier, F. (2014). Unmet support needs of early-onset dementia family caregivers: a mixed-design study. *BMC Nursing*, *13*(1), 49–49. https://doi.org/10.1186/s12912-014-0049-3

Duodecim. (2021) *Muistisairaudet, Käypä hoito -suositus*. Suomalaisen Lääkäriseuran Duodecimin ja Suomen Kardiologisen Seuran asettama työryhmä. Retrieved April 25, 2023, from https://www.kaypahoito.fi/hoi50044

Egan, M., Bérubé, D., Racine, G., Leonard, C., & Rochon, E. (2010). Methods to enhance verbal communication between individuals with Alzheimer's Disease and their formal and informal caregivers: A systematic review. *International Journal of Alzheimer's Disease*, *2010*, 1–12. https://doi.org/10.4061/2010/906818

Elkins, Z. (2011). Communication bridges for patients with dementia. *Primary Health Care*, *21*(10), 16–19. https://www.proquest.com/scholarly-journals/communication-bridges-patients-with-dementia/docview/912754821/se-2

Ellajosyula, R., Narayanan, J., & Patterson, K. (2020). Striking loss of second language in bilingual patients with semantic dementia. *Journal of Neurology*, *267*(2), 551–560. https://doi.org/10.1007/s00415-019-09616-2

Ellis, M., & Astell, A. (2017). Communicating with people living with dementia who are nonverbal: The creation of adaptive interaction. *PloS One*, *12*(8), 1–21. https://doi.org/10.1371/journal.pone.0180395

Ellis, M., Astell, A., & Scott, S. (2018). *Adaptive interaction and dementia: how to communicate without speech*. Jessica Kingsley Publishers.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open, 4*(1), 1–10. https://doi.org/10.1177/2158244014522633

Emmorey, K. (2023). Ten things you should know about sign languages. Current directions in psychological science: *A Journal of the American Psychological Society, 32*(5), 387–394. https://doi.org/10.1177/09637214231173071

Engeström, Y. (2013). Potilas-lääkärisuhteesta yhteistyösuhteeseen. *Lääketieteellinen Aikakauskirja Duodecim, 129*(6), 651–655.

Ericsson, I., Kjellström, S., & Hellström, I. (2013). Creating relationships with persons with moderate to severe dementia. *Dementia*, *12*(1), 63–79. https://doi.org/10.1177/1471301211418161

Ericson-Lidman, E., Larsson, L. F., & Norberg, A. (2014). Caring for people with dementia disease (DD) and working in a private not-for-profit residential care facility for people with DD. *Scandinavian Journal of Caring Sciences, 28*(2), 337–346. https://doi.org/10.1111/scs.12063

Evans, S., Fear, T., Means, R., & Vallelly, S. (2007). Supporting independence for people with dementia in extra care housing. *Dementia, 6*(1), 144–150. https://doi.org/10.1177/1471301207079098

Falchook, A. D., Mayberry, R. I., Poizner, H., Burtis, D. B., Doty, L., & Heilman, K. M. (2013). Sign language aphasia from a neurodegenerative disease. *Neurocase, 19*(5), 434–444. https://doi.org/10.1080/13554794.2012.690427

Fazio, S., Pace, D., Flinner, J., Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist 58*(1), 10–19. https://doi.org/10.1093/ geront/gnx122

Feeney, B. C., & Collins, N. L. (2015). A new look at social support: A theoretical perspective on thriving through relationships. *Personality and Social Psychology Review*, *19*(2), 113–147. https://doi.org/10.1177/1088868314544222

Fenlon, J., & Wilkinson, E. (2015). Sign languages in the world. In A. Schembri & C. Lucas (Eds.), *Sociolinguistics and Deaf Communities* (pp. 5–28). Cambridge University Press. https://doi.org/10.1017/CBO9781107280298.002

Ferguson-Coleman, E., Johnston, A., Young, A., Brown, F., de Sainte Croix, R., & Redfern, P. (2020). How do we know what we don't know? Exploring Deaf people's experiences of supporting their Deaf family member living with dementia. *Dementia*, *19*(5), 1381–1396. https://doi.org/10.1177/1471301218798993

Ferguson-Coleman, E., Keady, J., & Young, A. (2014). Dementia and the Deaf community: knowledge and service access. *Aging & Mental Health*, *18*(6), 674–682. https://doi.org/10.1080/13607863.2014.880405

Ferguson-Coleman, E., & Young, A. (2018). Storying stories to represent the lived experience of Deaf people living with dementia in research. In J., Keady, L.-C., Hydén, A., Johnson, & C., Swarbrick (Eds.), *Social Research Methods in Dementia Studies*, *Volume 1* (1st ed., pp. 169–191). Routledge. https://doi.org/10.4324/9781315517490-10

Ferguson-Coleman, E., Young, A. (2023). "'What have YOU done in the past few years?': Deaf BSL users' experiences caring for people with dementia during COVID-19". *Quality in Ageing and Older Adults*. https://doi.org/10.1108/QAOA-07-2023-0048

Ferguson-Coleman, E., Young, A., Keady, J. (2023). Sign language communities, neighbourhoods and dementia. In: J. Keady (Ed.) *Sign language communities, neighbourhoods and dementia* (pp. 106–126). Open University Press.

Finnish Institute for Health and Welfare. (2022). *Chronic diseases. Memory disorders*. Retrieved March 19, 2023, from https://thl.fi/en/web/chronic-diseases/memory-disorders

Fischer, S. D., & Harry van der Hulst, H. (2011). Sign Language Structures. In M., Marschark, & P. E., Spencer (Eds.), *The Oxford Handbook of Deaf Studies, Language, and Education, Volume 1* (2nd ed., pp. 336–349). Oxford University Press.

Fleurion, V.S., Ridoux, I., Scemama, C., Bouillevaux, I., Ciosi, A., & Drion, B. (2021). Transposition and normalization of the Mini-Mental State Examination in French Sign Language. *Archives of Clinical Neuropsychology*, *36*(6), 990–1002. https://doi.org/10.1093/arclin/acaa125

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*(3), 189–198. https://doi.org/10.1016/0022-3956(75)90026-6

Fried-Oken, M. (2018). Person-centered approaches to communication participation and engagement for individuals with primary progressive aphasia and dementia. *Seminars in Speech and Language*, *39*(3), 195–196. https://doi.org/10.1055/s-0038-1660869

Fusch, P., & Ness, L. (2015). Are we there yet? Data saturation in qualitative research. *Qualitative Report*, *20*(9), 1408–1416. https://doi.org/10.46743/2160-3715/2015.2281

Gagliardi, G., & Vannini, P. (2022). Episodic memory impairment mediates the loss of awareness in mild cognitive impairment. *Frontiers in Aging Neuroscience*, *14*, 1–13. https://doi.org/10.3389/fnagi.2021.802501

Gauthier, S., Rosa-Neto, P., Morais, J. A., & Webster, C. (2021). *World Alzheimer Report 2021: Journey through the diagnosis of dementia*. London: Alzheimer's Disease International.

Gergen, K. J. (1989). Waranting voice and the elaboration of the self. In J., Shotter, & K. J., Gergen (Eds.), *Texts of identity* (pp. 70–81). SAGE.

Gerlander, M., & Isotalus, P. (2010). Professionaalisten viestintäsuhteiden ääriviivoja. *Puhe ja Kieli/Tal och Språk/Speech and Language*, *30*(1), 3–19.

Gillies, B. (2012). Continuity and loss: The carer's journey through dementia. *Dementia*,*11*(5), 657–676. https://doi.org/10.1177/1471301211421262

Gilster, S. D., Boltz, M., & Dalessandro, J. L. (2018). Long-term care workforce issues: Practice principles for quality dementia care. *The Gerontologist*, *58*(S1), 103–113. https://doi.org/10.1093/geront/gnx174

Glosser, G., Wiley, M. J., & Barnoskir, E. J. (1998). Gestural communication in Alzheimer's disease. *Journal of Clinical and Experimental Neuropsychology*, *20*(1), 1–13. https://doi.org/10.1076/jcen.20.1.1.1484

Gollan, T. H., Salmon, D. P., Montoya, R. I., & da Pena, E. (2010). Accessibility of the nondominant language in picture naming: A counterintuitive effect of dementia on bilingual language production. *Neuropsychologia*, *48*(5), 1356–1366. https://doi.org/10.1016/j.neuropsychologia.2009.12.038

Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of Psychosomatic Research*, *69*(5), 511–520. https://doi.org/10.1016/j.jpsychores.2009.10.001

Guba, E. G., &, Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K., Denzin, & Y. S., Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 105–117). SAGE.

Gurgel, R. K., Ward, P. D., Schwartz, S., Norton, M. C., Foster, N. L., & Tschanz, J. T. (2014). Relationship of hearing loss and dementia: A prospective, population-based study. *Otology & Neurotology*, *35*(5), 775–781. https://doi.org/10.1097/MAO.0000000000000313

Haberkern, K., Schmid, T., & Szydlik, M. (2015). Gender differences in intergenerational care in European welfare states. *Ageing & Society*, *35*, 298–320. https://doi.org/10.1017/S0144686X13000639

Hagan, R. J. (2020). What next? Experiences of social support and signposting after a diagnosis of dementia. *Health & Social Care in the Community*, *28*(4), 1170–1179. https://doi.org/10.1111/hsc.12949

Hake, A. M., & Farlow, M. R. (2006). American Sign Language aphasia in Alzheimer disease. *Alzheimer's & Dementia*, *2*(3), S394–S394. https://doi.org/10.1016/j.jalz.2006.05.1340

Hall, K., Lind, C., Young, J. A., Okell, E., & Steenbrugge, W. (2018). Familiar communication partners' facilitation of topic management in conversations with individuals with dementia. *International Journal of Language & Communication Disorders, 53*(3), 564–575. https://doi.org/10.1111/1460-6984.12369

Hallberg, L. (2013). Quality criteria and generalization of results from qualitative studies. *International Journal of Qualitative Studies on Health and Well-Being, 8*(1), 1–1. https://doi.org/10.3402/qhw.v8i0.20647

Handley, M., Parker, D., Bunn, F., & Goodman, C. (2022). A qualitative comparison of care home staff and palliative care specialists' experiences of providing end of life care to people living and dying with dementia in care homes in two countries: A focus group study. *Palliative Medicine*, *36*(1), 114–123. https://doi.org/10.1177/02692163211043374

Hanssen, I. (2013). The influence of cultural background in intercultural dementia care: exemplified by Sami patients: The influence of cultural background in intercultural dementia care. *Scandinavian Journal of Caring Sciences*, *27*(2), 231–237. https://doi.org/10.1111/j.1471-6712.2012.01021.x

Harnett, T. (2014). Framing spaces in places: Creating "respite spaces" in dementia care settings. *Dementia, 13*(3), 396–411. https://doi.org/10.1177/1471301212474144

Harris, M. J., Atkinson, J. R., Judd, K., Bergson, M., & Mummery, C. J. (2020). Assessing Deaf patients in the neurology clinic. *Practical Neurology*, *20*(2), 132–138. https://doi.org/10.1136/practneurol-2019-002422

Harris, M. J., Au, D., Judd, K., Atkinson, J. R., Bergson, M., & Mummery, C. J. (2021). Evaluation of a specialist cognitive clinic for the Deaf community. *Clinical Medicine*, *21*(4), e375–e379. https://doi.org/10.7861/clinmed.2020-1098

Hays, S.-J., Niven, B., Godfrey, H., & Linscott, R. (2004). Clinical assessment of pragmatic language impairment: A generalisability study of older people with Alzheimer's disease. *Aphasiology*, *18*(8), 693–714. https://doi.org/10.1080/02687030444000183

Hennings, J., Froggatt, K., & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Reviews in Clinical Gerontology, 20*, 114–127. https://doi.org/10.1017/S0959259810000092

Hepner, A., Oram R., Denmark, C., Ferguson-Coleman E., Hulme, C, Itturiaga, C., Young., A. (2022). *Deaf people with dementia and care homes in Scotland*. British Deaf Association. https://bda.org.uk/wp-content/uploads/2022/03/FINAL-Deaf-Dementia-Research-Full-Report-2022.pdf

Hoel, K.-A., Rokstad, A. M. M., Feiring, I. H., Lichtwarck, B., Selbæk, G., & Bergh, S. (2021). Person-centered dementia care in home care services – highly recommended but still challenging to obtain: a qualitative interview study. *BMC Health Services Research*, *21*(1), 1–723. https://doi.org/10.1186/s12913-021-06722-8

Hoff, A. (2015). *Current and future challenges of family care in the UK*. Future of an ageing population: Evidence review. Foresight, Government Office for Science. https://dera.ioe.ac.uk/id/eprint/24148/1/gs-15-18-future-ageing-family-care-er09.pdf

Howett, D., Castegnaro, A., Krzywicka, K., Hagman, J., Marchment, D., Henson, R., Rio, M., King, J. A., Burgess, N., & Chan, D. (2019). Differentiation of mild cognitive impairment using an entorhinal cortex-based test of virtual reality navigation. *Brain*, *142*(6), 1751–1766. https://doi.org/10.1093/brain/awz116

Hughes, J. C. (2013). "Y" feel me?' How do we understand the person with dementia? *Dementia*, *12*(3), 348–358. https://doi.org/10.1177/1471301213479597

The Institute for the Languages in Finland. (2023). *On languages. Languages in Finland*. Retrieved June 19, 2023, from https://www.kotus.fi/en/on_language/languages_of_finland#SignlanguagesinFinland

Jack, C. R., Bennett, D. A., Blennow, K., Carrillo, M. C., Dunn, B., Haeberlein, S. B., Holtzman, D. M., Jagust, W., Jessen, F., Karlawish, J., Liu, E., Molinuevo, J. L., Montine, T., Phelps, C., Rankin, K. P., Rowe, C. C., Scheltens, P., Siemers, E., Snyder, H. M., … Silverberg, N. (2018). NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimer's & Dementia*, *14*(4), 535–562. https://doi.org/10.1016/j.jalz.2018.02.018

Johnsson, A., Boman, Å., Wagman, P., & Pennbrant, S. (2018). Voices used by nurses when communicating with patients and relatives in a department of medicine for older people: an ethnographic study. *Journal of Clinical Nursing, 27*(7–8), 1640–1650. https://doi.org/10.1111/jocn.14316

Jones, D. (2015). A family living with Alzheimer's disease: The communicative challenges. *Dementia*, *14*(5), 555–573. https://doi.org/10.1177/1471301213502213

Jones, S. (2011). Supportive listening. *International Journal of Listening, 25*(1–2), 85–103. https://doi.org/10.1080/ 10904018.2011.536475

Jones, S. M., & Bodie, G. D. (2014). Supportive communication. In C. R., Berger (Ed.), *Interpersonal Communication 6* (1st ed., pp. 371–394). De Gruyter. https://doi.org/10.1515/9783110276794.371

Jones, S. M., Woodward, M., & Mioshi, E. (2019). Social support and high resilient coping in carers of people with dementia. *Geriatric Nursing*, *40*(6), 584–589. https://doi.org/10.1016/j.gerinurse.2019.05.011

Jootun, D., & McGhee, G. (2011). Effective communication with people who have dementia. *Nursing Standard, 25*(25), 40–46. https://doi.org/10.7748/ns2011.02.25.25.40.c8347

Joyce, J., Ryan, J., Owen, A., Hu, J., McHugh Power, J., Shah, R., Woods, R., Storey, E., Britt, C., & Freak-Poli, R. (2022). Social isolation, social support, and loneliness and their relationship with cognitive health and dementia.

International Journal of Geriatric Psychiatry, *37*(1), 1–12. https://doi.org/10.1002/gps.5644

Kadlec, H., Dujela, C., Beattie, B. L., & Chappell, N. (2018). Cognitive functioning, cognitive reserve, and residential care placement in patients with Alzheimer's and related dementias. *Aging & Mental Health*, *22*(1), 19–25. https://doi.org/10.1080/13607863.2016.1226766

Kamalraj, P., Savundranayagam, M. Y., Orange, J. B., & Kloseck, M. (2021). Communication in home care: Understanding the lived experiences of formal caregivers communicating with persons living with dementia. *International Journal of Older People Nursing*, *16*(6), 1–10. https://doi.org/10.1111/opn.12401

Karner, T. X., & Bobbitt-Zeher, D. (2005). Losing selves: dementia care as disruption and transformation. *Symbolic Interaction*, *28*(4), 549–570. https://doi.org/10.1525/si.2005.28.4.549

Keady, J., Hydén, L.-C., Johnson, A., & Swarbrick, C. (2018). *Social Research Methods in Dementia Studies: Inclusion and Innovation, Volume 1* (1st ed.). Routledge.

Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. *BMC Psychiatry*, *17*(1), 316–316. https://doi.org/10.1186/s12888-017-1474-0

Kergoat, M.-J. 2022. Initial steps by the clinician after diagnosis. In C., Benoist, & W., Weidner (Eds.), *World Alzheimer Report 2022. Life after diagnosis: Navigating treatment, care and support* (pp. 150–151). Alzheimer's Disease International.

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of Qualitative Descriptive Studies: A Systematic Review. *Research in Nursing & Health*, *40*(1), 23–42. https://doi.org/10.1002/nur.21768

Kim, S. (2015). Cognitive rehabilitation for elderly people with early-stage Alzheimer's disease. *Journal of Physical Therapy Science*, *27*(2), 543–546. https://doi.org/10.1589/jpts.27.543

Kim, S., Liu, W., Daack-Hirsch, S., & Williams, K. N. (2022). Development and psychometric testing of the dyadic communication observational coding scheme in dementia care (DCODE): family dyadic communication in dementia. *Aging & Mental Health* (ahead-of-print), 1–10. https://doi.org/10.1080/13607863.2022.2126819

Kindell, J., Keady, J., Sage, K., & Wilkinson, R. (2017). Everyday conversation in dementia: a review of the literature to inform research and practice. *International Journal of Language & Communication Disorders*, *52*(4), 392–406. https://doi.org/10.1111/1460-6984.12298

Kitwood, T. (1997). *Dementia Reconsidered – The Person Comes First*. Open University Press.

Kitwood, T., & Bredin, K. (1992) Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12*, 269–287. https://doi.org/10.1017/S0144686X0000502X

Kontos, P.C. (2012). Rethinking sociability in long-term care: an embodied dimension of selfhood. *Dementia 11*(3), 329–346. https://doi.org/10.1177/1471301211421073

Kusters, A. (2014). Deaf gain and shared signing communities. In H.-D. L., Bauman & J. J., Murray (Eds.), *Deaf gain: raising the stakes of human diversity* (pp. 285–305). University of Minnesota Press.

Kuurojen Liitto. (2023) *Viittomakieliset*. Retrieved May 16, 2023, from https://kuurojenliitto.fi/viittomakieliset/

Laczó, M., Martinkovic, L., Lerch, O., Wiener, J. M., Kalinova, J., Matuskova, V., Nedelska, Z., Vyhnalek, M., Hort, J., & Laczó, J. (2022). Different profiles of spatial navigation deficits in Alzheimer's disease biomarker-positive versus biomarker-negative older adults with amnestic mild cognitive impairment. *Frontiers in Aging Neuroscience*, *14*, 1–24. https://doi.org/10.3389/fnagi.2022.886778

Ladd, P. (2003). *Understanding Deaf culture: in search of Deafhood* (1st ed.). Multilingual Matters.

Ladd, P., & Lane, H. (2013). Deaf ethnicity, Deafhood, and their relationship. *Sign Language Studies*, *13*(4), 565–579. https://doi.org/10.1353/sls.2013.0012

Laczó, M., Martinkovic, L., Lerch, O., Wiener, J. M., Kalinova, J., Matuskova, V., Nedelska, Z., Vyhnalek, M., Hort, J., & Laczó, J. (2022). Different profiles of spatial navigation deficits in Alzheimer's disease biomarker-positive versus biomarker-negative older adults with amnestic mild cognitive impairment. *Frontiers in Aging Neuroscience*, *14*, 1–24. https://doi.org/10.3389/fnagi.2022.886778

Lambert, V. A., & Lambert, C. E. (2013). Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research, 16*(4), 255–256. https://he02.tci-thaijo.org/index.php/PRIJNR/article/view/5805

Lawrence, E. L., Fassola, I., Werner, I., Leclercq, C., & Valero-Cuevas, F. J. (2014). Quantification of dexterity as the dynamical regulation of instabilities: comparisons across gender, age, and disease. *Frontiers in Neurology, 5*(53), 1–13. https://doi.org/10.3389/fneur.2014.00053

Lee, K. H., & Lee, J. Y. (2022). Social interaction and psychological well-being of persons living with dementia in long-term care. *Innovation in Aging*, *6*(S1), 704–705. https://doi.org/10.1093/geroni/igac059.2578

Lee, L., & Hillier, L. M. (2022). Best approaches to supporting the needs of people living with dementia and their carers. In C., Benoist, & W., Weidner (Eds.), *World Alzheimer Report 2022. Life after diagnosis: Navigating treatment, care and support* (pp. 142–144). Alzheimer's Disease International.

Lesch, H., Burcher, K., Wharton, T., Chapple, R., & Chapple, K. (2019). Barriers to healthcare services and supports for signing deaf older adults. *Rehabilitation Psychology, 64*(2), 237–244. https://doi.org/10.1037/rep0000252

Lewis, J. P., Manson, S. M., Jernigan, V. B., & Noonan, C. (2021). "Making sense of a disease that makes no sense": Understanding Alzheimer's disease and related disorders among caregivers and providers within Alaska native communities. *The Gerontologist*, *61*(3), 363–373. https://doi.org/10.1093/geront/gnaa102

Li, P., Zhou, Y.-Y., Lu, D., Wang, Y., & Zhang, H.-H. (2016). Correlated patterns of neuropsychological and behavioral symptoms in frontal variant of Alzheimer disease and behavioral variant frontotemporal dementia: a comparative case study. *Neurological Sciences*, *37*(5), 797–803. https://doi.org/10.1007/s10072-015-2405-9

Lin, F. R., Metter, E. J., O'Brien, R. J., Resnick, S. M., Zonderman, A. B., & Ferrucci, L. (2011). Hearing loss and incident dementia. *Archives of Neurology*, *68*(2), 214–220. https://doi.org/10.1001/archneurol.2010.362

Lin, F. R., Yaffe, K., Xia, J., Xue, Q.-L., Harris, T. B., Purchase-Helzner, E., Satterfield, S., Ayonayon, H. N., Ferrucci, L., & Simonsick, E. M. (2013). Hearing loss and cognitive decline in older adults. *JAMA Internal Medicine*, *173*(4), 1–7. https://doi.org/10.1001/jamainternmed.2013.1868

Lincoln, Y. S., & Guba, E. G. (1984). *Naturalistic inquiry*. SAGE.

Lind, M., Simonsen, H. G., Ribu, I. S. B., Svendsen, B. A., Svennevig, J., & de Bot, K. (2018). Lexical access in a bilingual speaker with dementia: Changes over time. *Clinical Linguistics & Phonetics*, *32*(4), 353–377. https://doi.org/10.1080/02699206.2017.1381168

van der Linde, R. M., Dening, T., Stephan, B. C. M., Prina, A. M., Evans, E., & Brayne, C. (2016). Longitudinal course of behavioural and psychological symptoms of dementia: systematic review. *British Journal of Psychiatry*, *209*(5), 366–377. https://doi.org/10.1192/bjp.bp.114.148403

Liou, W.-C., Chan, L., Hong, C.-T., Chi, W.-C., Yen, C.-F., Liao, H.-F., Chen, J.-H., & Liou, T.-H. (2020). Hand fine motor skill disability correlates with dementia severity. *Archives of Gerontology & Geriatrics*, *90*, 1–6. https://doi-org.libproxy.helsinki.fi/10.1016/j.archger.2020.104168

Lobbia, A., Carbone, E., Faggian, S., Gardini, S., Piras, F., Spector, A., & Borella, E. (2019). The efficacy of cognitive stimulation therapy (CST) for people with mild-to-moderate dementia: A review. *European Psychologist, 24*(3), 257–277. https://doi.org/10.1027/1016-9040/a000342

Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics*, *16*(1), 68–68. https://doi.org/10.1186/s12877-016-0242-1

Lundin, A., Bülow, P. H., & Jonas Stier, J. (2021). Assistant nurses' positioned accounts for prioritizations in residential care for older people, *The Gerontologist*, *61*(4), 573–581. https://doi.org/10.1093/geront/gnaa154

Lüdtke, I. (2014). Layers of living. In E., Feddersen, & I., Lüdtke. (Eds.), *Lost in space: Architecture and dementia* (pp. 92–101). Birkhäuser.

Malebranche, M., Morisod, K., & Bodenmann, P. (2020). Deaf culture and health care. *Canadian Medical Association Journal (CMAJ), 192*(50), E1809–E1809. https://doi.org/10.1503/cmaj.200772

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

van Manen, A. S., Aarts, S., Metzelthin, S. F., Verbeek, H., Hamers, J. P. H., & Zwakhalen, S. M. G. (2021). A communication model for nursing staff working in dementia care: results of a scoping review. *International Journal of Nursing Studies, 113*, 1–15. https://doi.org/10.1016/j.ijnurstu.2020.103776

Massimo, L., Evans, L. K., & Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: The lived experiences of spouses. *Geriatric Nursing*, *34*(4), 302–306. https://doi.org/10.1016/j.gerinurse.2013.05.001

Matusitz, J., & Spear, J. (2014) Effective doctor-patient communication: an update examination. *Social Work Public Health, 29*(3), 252–266. https://doi.org/10.1080/19371918.2013.776416

Mazaheri, M., Eriksson, L. E., Heikkilä, K., Nasrabadi, A. N., Ekman, S.-L., & Sunvisson, H. (2013). Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing, 22*(21–22), 3032–3041. https://doi.org/10.1111/jocn.12275

Meador, H. E., & Zazove, P. (2005). Health care interactions with Deaf culture. *Journal of the American Board of Family Medicine*, *18*(3), 218–222. https://doi.org/10.3122/jabfm.18.3.218

de Medeiros, K., Girling, L. M., & Berlinger, N. (2022). Inclusion of people living with Alzheimer's Disease or related dementias who lack a study partner in social research: Ethical considerations from a qualitative evidence synthesis. *Dementia*, *21*(4), 1200–1218. https://doi.org/10.1177/14713012211072501

Meléndez, J. C., Satorres, E., Redondo, R., Escudero, J., & Pitarque, A. (2018). Wellbeing, resilience, and coping: Are there differences between healthy older adults, adults with mild cognitive impairment, and adults with Alzheimer-type dementia? *Archives of Gerontology & Geriatrics*, *77*, 38–43. https://doi.org/10.1016/j.archger.2018.04.004

de Meulder, M., Kusters, A., Moriarty, E., & Murray, J. J. (2019). Describe, don't prescribe. The practice and politics of translanguaging in the context of deaf signers. *Journal of Multilingual and Multicultural Development, 40*(10), 892–906. https://doi.org/10.1080/01434632.2019.1592181

Miller, W. R., & Rollnick, S. (2012). *Motivational interviewing: Helping people change* (3rd ed.). Guilford Publications.

Minghella, E., & Schneider, K. (2012a). Rethinking a framework for dementia 1: a journey. *Working with Older People*, *16*(3), 122–131. https://doi.org/10.1108/13663661211260943

Minghella, E., & Schneider, K. (2012b). Rethinking a framework for dementia 2: a new model of care. *Working with Older People*, *16*(4), 180–189. https://doi.org/10.1108/13663661211286710

The Minnesota Deaf and Hard of Hearing Services Division. (2023). *Deaf culture*. https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8022-ENG

Mitchell, S. L., Miller, S. C., Teno, J. M., Davis, R. B., & Shaffer, M. L. (2010). The advanced dementia prognostic tool: A risk score to estimate survival in nursing home residents with advanced dementia. *Journal of Pain and Symptom Management*, *40*(5), 639–651. https://doi.org/10.1016/j.jpainsymman.2010.02.014

Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia, 11*, 483–502. https://doi.org/10.1177/1471301211421070

Moon, M. D. (2019). Triangulation: A method to increase validity, reliability, and legitimation in clinical research. *Journal of Emergency Nursing*, *45*(1), 103–105. https://doi.org/10.1016/j.jen.2018.11.004

Morisod, K., Malebranche, M., Marti, J., Spycher, J., Grazioli, V. S., & Bodenmann, P. (2022). Interventions aimed at improving healthcare and health education equity for adult d/Deaf patients: a systematic review. *European Journal of Public Health, 32*(4), 548–556. https://doi.org/10.1093/eurpub/ckac056

Morris, J.C., Heyman, A., Mohs, R.C., Hughes, J.P., van Belle, G., Fillenbaum, G., Mellits, E. D., & Clark, C. (1989). The consortium to establish a registry for Alzheimer's disease (CERAD): Part 1—clinical and neuropsychological assessment of Alzheimer's disease. *Neurology, 39*(9), 1159–1165. https://doi.org/10.1212/wnl.39.9.1159

Morris, L., Mansell, W., Williamson, T., Wray, A., & McEvoy, P. (2020). Communication empowerment framework: An integrative framework to support effective communication and interaction between carers and people living with dementia. *Dementia, 19*(6), 1739–1757. https://doi.org/10.1177/1471301218805329

Mundadan, R. G., Savundranayagam, M. Y., Orange, J. B., & Murray, L. (2023). Language-based strategies that support person-centered communication in formal home care interactions with persons living with dementia. *Journal of Applied Gerontology*, *42*(4), 639–650. https://doi.org/10.1177/07334648221142852

van der Mussele, S., Le Bastard, N., Saerens, J., Somers, N., Mariën, P., Goeman, J., De Deyn, P. P., & Engelborghs, S. (2015). Agitation-associated behavioral symptoms in mild cognitive impairment and Alzheimer's dementia. *Aging & Mental Health*, *19*(3), 247–257. https://doi.org/10.1080/13607863.2014.924900

Navaie-Waliser, M., Spriggs, A., & Feldman, P. H. (2002). Informal caregiving: Differential experiences by gender. *Medical Care*, *40*(12), 1249–1259. https://doi.org/10.1097/00005650-200212000-00012

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology*, *9*(52), 1–5. https://doi.org/10.1186/1471-2288-9-52

Nguyen, H., Terry, D., Phan, H., Vickers, J., McInerney, F., 2019. Communication training and its effects on carer and care-receiver outcomes in dementia settings: a systematic review. *Journal of Clinical Nursing, 28*(7–8), 1050–1069. https://doi.org/10.1111/jocn.14697

Novek, S., & Menec, V. (2023). Conceptualizing access to community-based supports from the perspectives of people living with young onset dementia, family members and providers. *Dementia*, *22*(1), 180–196. https://doi.org/10.1177/14713012221138145

Oliveira, J., Gamito, P., Souto, T., Conde, R., Ferreira, M., Corotnean, T., et al. (2021). Virtual reality-based cognitive stimulation on people with mild to moderate dementia due to Alzheimer's Disease: A pilot randomized controlled trial. *International Journal of Environmental Research and Public Health, 18*(10), 5290–5303. https://doi.org/10.3390/ijerph18105290

Owens, E. (2006). Conversational space and participant shame in interviewing. *Qualitative Inquiry*, *12*(6), 1160–1179. https://doi.org/10.1177/1077800406293236

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Panca, M., Livingston, G., Barber, J., Cooper, C., La Frenais, F., Marston, L., Cousins, S., & Hunter, R. M. (2019). Healthcare resource utilisation and costs of agitation in people with dementia living in care homes in England - The managing agitation and raising quality of life in dementia (MARQUE) study. *PloS One*, *14*(2), 1–11. https://doi.org/10.1371/journal.pone.0211953

Parker, J., Young, A., & Rogers, K. (2010). "My mum's story: A Deaf daughter discusses her Deaf mother's experience of dementia. *Dementia, 9*(1), 5–20. https://doi.org/10.1177/1471301209353987

Pekkala, S., Wiener, D., Himali, J. J., Beiser, A. S., Obler, L. K., Liu, Y., McKee, A., Auerbach, S., Seshadri, S., Wolf, P. A., & Au, R. (2013). Lexical retrieval in discourse: An early indicator of Alzheimer's dementia. *Clinical Linguistics & Phonetics, 27*(12), 905–921. https://doi.org/10.3109/02699206.2013.815278

Peltola, M. (2023). *Terveydenhuollon ammattilaisen ja diabeetikon välisen vuorovaikutuksen merkitys omahoidolle*. [Doctoral dissertation, Tampere University]. Tampere University Press.

Peoples, H., Pedersen, L. F., & Moestrup, L. (2020). Creating a meaningful everyday life: Perceptions of relatives of people with dementia and healthcare professionals in the context of a Danish dementia village. *Dementia*, *19*(7), 2314–2331. https://doi.org/10.1177/1471301218820480

Pesonen, H.-M., Remes, A. M., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics*, *18*(5), 651–661. https://doi.org/10.1177/0969733011408046

Pezalla, A. E., Pettigrew, J., & Miller-Day, M. (2012). Researching the researcher-as-instrument: an exercise in interviewer self-reflexivity. *Qualitative Research, 12*(2), 165–185. https://doi.org/10.1177/1468794111422107

Pillemer, S. C., & Holtzer, R. (2016). The differential relationships of dimensions of perceived social support with cognitive function among older adults. *Aging & Mental Health*, *20*(7), 727–735. https://doi.org/10.1080/13607863.2015.1033683

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, *47*(11), 1451–1458. https://doi.org/10.1016/j.ijnurstu.2010.06.004

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Lippincott Williams & Wilkins.

Polk, D. M. (2005). Communication and family caregiving for Alzheimer's Dementia: Linking attributions and problematic integration. *Health Communication*, *18*(3), 257–273. https://doi.org/10.1207/s15327027hc1803_4

Pope, N. D., Kolomer, S., & Glass, A. P. (2012). How women in late midlife become caregivers for their aging parents. *Journal of Women & Aging*, *24*(3), 242–261. https://doi.org/10.1080/08952841.2012.639676

Pozzebon, M., Douglas, J., &, Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. *International Psychogeriatrics*, *28*(4), 537–556. https://doi.org/10.1017/S1041610215002239

Purves, B. A., & Phinney, A. (2012/2013). Family voices: A family systems approach to understanding communication in dementia. *Canadian Journal of Speech-Language Pathology and Audiology, 36*(4), 284–300.

Quinto-Pozos, D. (2014). The influence of dementia on language in a signing population. In D. Quinto-Pozos (Ed.), *Multilingual aspects of signed* *language communication and disorder* (1st ed., pp. 1–44). Channel View Publications, Multilingual Matters.

Rafnsson, S. B., Orrell, M., d'Orsi, E., Hogervorst, E., &, Steptoe, A. (2020). Loneliness, social integration, and incident dementia over 6 years: Prospective findings from the English longitudinal study of ageing. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 75*(1), 114–124. https://doi.org/10.1093/geronb/gbx087

Rainò, P. (2010). *Cerad – kognitiviinen tehtäväsarja suomalaiselle viittomakielelle. Ohjekirja*. Kuurojen Palvelusäätiö.

Rantapää, M., Rainò, P., & Pekkala, S. (2015). Muistisairauden vaikutukset viittomakieleen ja niiden arvioinnin haasteet. In: A-M. Korpijaakko-Huuhka, M. Lehtihalmes, & S. Pekkala (Eds.), *Aikuisten neurologisperäiset puheen, kielen ja viestinnän ongelmat: Puheen ja kielen tutkimuksen päivät Helsingissä 26.-27.3.2016* (pp. 131–140). Puheen ja kielen tutkimuksen yhdistyksen julkaisuja; Nro 47. Puheen ja kielen tutkimuksen yhdistys.

Reader, T. W., Gillespie, A. & Roberts, J. (2014). Patient complaints in healthcare systems: A systematic review and coding taxonomy. *British Medical Journal Quality and Safety, 23*(8), 678–679. http://dx.doi.org/10.1136/bmjqs-2013-002437

Reid, D. I. J. (2018). *Doing relationship-centred dementia care: learning from each other for better dementia support*. Jessica Kingsley Publishers.

Reza Majlesi, A., Nilsson, E., & Ekström, A. (2018). Video data as a method to understand non-verbal communication in couples where one person is living with dementia. In J., Keady, L.-C., Hydén, A., Johnson, & C., Swarbrick (Eds.), *Social Research Methods in Dementia Studies, Volume 1* (1st ed., pp. 56–76). Routledge. https://doi.org/10.4324/9781315517490-5

Ritchie, J., Lewis, J. & Elam., J. (2003). Designing and selecting samples. In J., Ritchie, & J., Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp. 78–108). SAGE.

Rochford-Brennan, H. (2022). Responses to disclosure of the diagnosis of dementia. In C., Benoist, & W., Weidner (Eds.), *World Alzheimer Report 2022. Life after diagnosis: Navigating treatment, care and support* (pp. 57–58). Alzheimer's Disease International.

Rodakowski, J., Saghafi, E., Butters, M. A., & Skidmore, E. R. (2015). Non-pharmacological interventions for adults with mild cognitive impairment and early stage dementia: An updated scoping review. *Molecular Aspects of Medicine, 43–44*, 38–53. https://doi.org/10.1016/j.mam.2015.06.003

Rogers, K. D., Dodds, C., Campbell, M., & Young, A. (2018). The validation of the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) with deaf British sign language users in the UK. *Health and Quality of Life Outcomes, 16*(1), 145–145. https://doi.org/10.1186/s12955-018-0976-x

Rogers, K., Ferguson-Coleman, E., & Young, A. (2018b). Challenges of realising patient-centred outcomes for Deaf patients. *The Patient: Patient-Centered Outcomes Research, 11*(1), 9–16. https://doi.org/10.1007/s40271-017-0260-x

Ruben, B. D. (2016). Communication theory and health communication practice: The more things change, the more they stay the same. *Health Communication, 31*(1), 1–11. https://doi.org/10.1080/10410236.2014.923086

Ryan, E. B., Byrne, K., Spykerman, H., & Orange, J. B. (2005). Evidencing Kitwood's personhood strategies: Conversation as care in dementia. In B. H. Davis (Ed.), *Alzheimer talk, text and context*, (pp. 18–36). Palgrave Macmillan. https://doi.org/10.1057/9780230502024_2

Saga, S., Blekken, L. E., Nakrem, S., & Sandmoe, A. (2021). Relatives' experiences with abuse and neglect in Norwegian nursing homes. A qualitative study. *BMC Health Services Research*, *21*(1), 1–684. https://doi.org/10.1186/s12913-021-06713-9

Salmi, E., & Laakso, M. (2005). *Maahan lämpimään. Suomen viittomakielisten historia*. Kuurojen Liitto ry.

Samtani, S., Stevens, A., Lipnicki, D. M., Sachdev, P. S., & Brodaty, H. (2021). Social health and reserve in the dementia patient journey (SHARED): The role of social interactions in the clinical phase of dementia. *Alzheimer's & Dementia*, *17*(S10), 1–1. https://doi.org/10.1002/alz.053227

Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing & Health*, *23*(4), 334–340. https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, *33*(1), 77–84. https://doi.org/10.1002/nur.20362

Sano, M., Zhu, C. W., Neugroschl, J., Grossman, H. T., Schimming, C., & Aloysi, A. (2022). Agitation in cognitive disorders: Use of the national Alzheimer's coordinating center uniform data set (NACC-UDS) to evaluate international psychogeriatric association definition. *American Journal of Geriatric Psychiatry*, *30*(11), 1198–1208. https://doi.org/10.1016/j.jagp.2022.03.008

Saunders, P., de Medeiros, K., & Bartell, A. (2011). "Oh he was forgettable": Construction of self identity through use of communicative coping behaviors in the discourse of persons with cognitive impairment. *Dementia, 10*(3), 341–359. https://doi.org/10.1177/1471301211407805

Savundranayagam, M. Y. (2014). Missed opportunities for person-centered communication: implications for staff-resident interactions in long-term care. *International Psychogeriatrics, 26*(4), 645–655. https://doi.org/10.1017/S1041610213002093

Savundranayagam, M.Y., & Moore-Nielsen, K. (2015). Language-based communication strategies that support person-centered communication with persons with dementia. *International Psychogeriatrics, 27*(10), 1707–1718. https://doi.org/10.1017/S1041610215000903

Savundranayagam, M.Y., & Orange, J.P. 2014. Matched and mismatched appraisals of the effectiveness of communication strategies by family caregivers of persons with Alzheimer's disease. *International Journal of Language & Communication Disorders, 49*(1), 49–59. https://doi.org.10.1111/1460-6984.12043

Savundranayagam, M. Y., Ryan, E. B., Anas, A. P., & Orange, J. B. (2007). Communication and dementia: staff perceptions of conversational strategies. *Clinical Gerontologist, 31*(2), 47–63. https://doi.org/10.1300/J018v31n02_04

Savundranayagam, M. Y., Sibalija, J., & Scotchmer, E. (2016). Resident reactions to person- centered communication by long-term care staff. *American*

Journal of Alzheimer's Disease & Other Dementias, 31(6), 530–537. https://doi.org/10.1177/1533317515622291

Schwandt, T. A. (2015). *The SAGE Dictionary of Qualitative Inquiry* (4th ed.). SAGE. https://doi.org/10.4135/9781412986281

Seixas-Lima, B., Murphy, K., Troyer, A., Levine, B., Graham, N., Leonard, C., & Rochon, E. (2020). Episodic memory decline is associated with deficits in coherence of discourse. *Cognitive Neuropsychology, 37*(7–8), 511–522. https://doi.org/10.1080/02643294.2020.1770207

The Service Foundation for the Deaf. (2018). *Sign language services for deaf and deafblind people*. Retrieved March 19, 2023, from https://kpsaatio.fi/homepage/the-service-foundation-for-the-deaf/

Setién-Suero, E., Murillo-García, N., Sevilla-Ramos, M., Abreu-Fernández, G., Pozueta, A., & Ayesa-Arriola, R. (2022). Exploring the relationship between deficits in social cognition and neurodegenerative dementia: A systematic review. *Frontiers in Aging Neuroscience*, *14*, 1–21. https://doi.org/10.3389/fnagi.2022.778093

Sheppard, K., & Badger, T. (2010). The lived experience of depression among culturally Deaf adults: Depression among Deaf adults. *Journal of Psychiatric and Mental Health Nursing*, *17*(9), 783–789. https://doi.org/10.1111/j.1365-2850. 2010.01606.x

Sign Language Act 2015 (359).

Small, J. A., Perry, J., & Lewis, J. (2005). Perceptions of family caregivers' psychosocial behavior when communicating with spouses who have Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, *20*(5), 281–289. https://doi.org/10.1177/153331750502000510

Smeijers, A., Bogaerde, B., Ens-Dokkum, M., & Oudesluys-Murphy, A. M. (2020). Specialized outpatient clinic for deaf and hard-of-hearing patients in the Netherlands: Lessons learned in an attempt to improve health care. *Journal of Evaluation in Clinical Practice, 26*(6), 1588–1591. https://doi.org/10.1111/jep.13369

Smith, G., & Rodham, K. (2022). Supporting and sustaining care at home: Experiences of adult daughters who support a parent with dementia to remain in their own home. *Health & Social Care in the Community*, *30*(1), 81–90. https://doi.org/10.1111/hsc.13373

Snyder, L. (2006). Personhood and interpersonal communication in dementia. In J., Hughes, S., Louw, & S. R., Sabat (Eds.), *Dementia: Mind, Meaning, and the Person* (pp. 259–276). Oxford University Press.

Spanjer, P., Fieret, M., & Baker, A. (2014). The influence of dementia on language in a signing population. In D., Quinto-Pozos (Ed.), *Multilingual Aspects of Signed Language Communication and Disorder* (1st ed., pp. 186–208). Channel View Publications, Multilingual Matters.

Spector, A., Gardner, C., & Orrell, M. (2011). The impact of cognitive stimulation therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Aging & Mental Health*, *15*(8), 945–949. https://doi.org/10.1080/13607863.2011.586622

Steinberg, J. R., Turner, B. E., Weeks, B. T., Magnani, C. J., Wong, B. O., Rodriguez, F., Yee, L. M., & Cullen, M. R. (2021). Analysis of female enrollment and participant sex by burden of disease in us clinical trials between 2000 and 2020. *JAMA Network Open*, *4*(6), 1–13. https://doi.org/10.1001/jamanetworkopen.2021.13749

Suzumura, S., Osawa, A., Maeda, N., Sano, Y., Kandori, A., Mizuguchi, T., et al. (2018). Differences among patients with Alzheimer's disease, older adults with mild cognitive impairment and healthy older adults in finger dexterity: Finger skills of AD and MCI patients. *Geriatrics & Gerontology International, 18*, 907–914. https://doi.org/10.1111/ggi.13277

Szatloczki, G., Hoffmann, I., Vincze, V., Kalman, J., & Pakaski, M. (2015). Speaking in Alzheimer's disease, is that an early sign? Importance of changes in language abilities in Alzheimer's disease. *Frontiers in Aging Neuroscience*, *7*(1), 1–7. https://doi.org/10.3389/fnagi.2015.00195

Söderlund, M., Cronqvist, A., Norberg, A., Ternestedt, B., & Hansebo, G. (2016). Conversations between persons with dementia disease living in nursing homes and nurses – qualitative evaluation of an intervention with the validation method. *Scandinavian Journal of Caring Sciences*, *30*(1), 37–47. https://doi.org/10.1111/scs.12219

Tappen, R. M., Williams-Burgess, C., Edelstein, J., Touhy, T., & Fishman, S. (1997). Communicating with individuals with Alzheimer's disease: Examination of recommended strategies. *Archives of Psychiatric Nursing*, *11*(5), 249–256. https://doi.org/10.1016/S0883-9417(97)80015-5

Taylor, S. J., Bogdan, R., & DeVault, M. (2015). *Introduction to qualitative research methods: a guidebook and resource* (4th ed). Wiley.

Thoft, D. S., & Ward, A. (2022). "Just ask me what it means to live with dementia" – people with mild dementia's strategies and techniques shared through in-depth qualitative interviews. *Journal of Clinical Nursing*, *31*(13–14), 1725–1737. https://doi.org/10.1111/jocn.15596

Thompson, T. L., Robinson, J. D. & Brashers, D. E. (2011). Interpersonal communication and health care. In J. A., Daly, & M. L., Knapp (Eds.), *The Sage handbook of interpersonal communication* (4th ed., pp. 633–678). SAGE.

Thorpe, R., Hawkes, G., Dune, T., Fileborn, B., Pitts, M., & Minichiello, V. (2018). Hidden boundaries and shared meanings: the roles of researcher characteristics and cultural norms in shaping understandings of sexuality in the unstructured interview setting. *International Journal of Social Research Methodology*, *21*(2), 205–217. https://doi.org/10.1080/13645579.2017.1350016

Tippett, W. J., Sergio, L. E., & Black, S. E. (2012). Compromised visually guided motor control in individuals with Alzheimer's disease: Can reliable distinctions be observed? *Journal of Clinical Neuroscience*, *19*(5), 655–660. https://doi.org/10.1016/j.jocn.2011.09.013

Tsantali, E., Economidis, D., & Tsolaki, M. (2013). Could language deficits really differentiate Mild cognitive impairment (MCI) from mild Alzheimer's disease? *Archives of Gerontology and Geriatrics, 57*(3), 263–270. https://doi.org/10.1016/j.archger.2013.03.011

Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science*, *4*(3), 236–255. https://doi.org/10.1111/j.1745-6924.2009.01122.x

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, *15*(3), 398–405. https://doi.org/10.1111/nhs.12048

Viljanen, A., Törmäkangas, T., Vestergaard, S., & Andersen-Ranberg, K. (2014). Dual sensory loss and social participation in older Europeans. *European Journal of Ageing*, *11*(2), 155–167. https://doi.org/10.1007/s10433-013-0291-7

Virtanen, I. A. (2015). *Supportive communication in Finnish men's friendships*. [Doctoral dissertation, Tampere University]. Tampere University Press.

Volkmer, A., Spector, A., Warren, J. D., & Beeke, S. (2020). Speech and language therapy for primary progressive aphasia: Referral patterns and barriers to service provision across the UK. *Dementia*, *19*(5), 1349–1363. https://doi.org/10.1177/1471301218797240

de Vries, K., & Drury-Ruddlesden, J. (2019). Advance care planning for people with dementia: Ordinary everyday conversations. *Dementia*, *18*(7–8), 3023–3035. https://doi.org/10.1177/1471301218764169

Walker, J. M., Gonzales, M. M., Goette, W., Farrell, K., White III, C. L., Crary, J. F., & Richardson, T. E. (2023). Cognitive and neuropsychological profiles in Alzheimer's disease and primary age-related tauopathy and the influence of comorbid neuropathologies. *Journal of Alzheimer's Disease*, *92*(3), 1037–1049. https://doi.org/10.3233/JAD-230022

Wallace, L. M. K., Theou, O., Godin, J., Ward, D. D., Andrew, M. K., Bennett, D. A., & Rockwood, K. (2021). 10-year frailty trajectory is associated with Alzheimer's dementia after considering neuropathological burden. *Aging Medicine*, *4*(4), 250–256. https://doi.org/10.1002/agm2.12187

Wang, Q., Sheng, Y., Wu, F., Zhang, Y., & Xu, X. (2019). Effect of different sources support on adaptation in families of patient with moderate-to-severe dementia in China. *American Journal of Alzheimer's Disease & Other Dementias*, *34*(6), 361–375. https://doi.org/10.1177/1533317519855154

Ward, K., Gott, M., & Hoare, K. (2015). Participants' views of telephone interviews within a grounded theory study. *Journal of Advanced Nursing*, *71*(12), 2775–2785. https://doi.org/10.1111/jan.12748

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2008). A different story: exploring patterns of communication in residential dementia care. *Ageing and Society*, *28*(5), 629–651. https://doi.org/10.1017/S0144686X07006927

Watson, J. (2019). Developing the senses framework to support relationship-centred care for people with advanced dementia until the end of life in care homes. *Dementia*, *18*(2), 545–566. https://doi.org/10.1177/1471301216682880

Webb, J. (2017). Conversation takes two: Understanding interactions with people with dementia. *Disability & Society, 32*(7), 1102–1106. https://doi.org/10.1080/09687599.2017.1321225

Werngren-Elgström, M., Iwarsson, S., Elmståhl, S., & Dehlin, O. (2005). ADL dependence and perceived health among elderly Deaf sign-language users: A comparison with a matched group of elderly hearing people. *Scandinavian Journal of Occupational Therapy*, *12*(2), 81–88. https://doi.org/10.1080/11038120510031743

West, J., Birt, L., Wilson, D., Mathie, E., & Poland, F. (2022). A case study of co-production within a mental health recovery college dementia course: Perspectives of a person with dementia, their family supporter and mental health staff. *Frontiers in Rehabilitation Sciences*, *3*, 1–8. https://doi.org/10.3389/fresc.2022.920496

Wiechula, R., Conroy, T., Kitson, A.L., Marshall, R.J., Whitaker, N., & Rasmussen, P. (2016). Umbrella review of the evidence: what factors influence the caring relationship between a nurse and patient? *Journal of Advanced Nursing, 72*(4), 723–734. https://doi.org/10.1111/jan.12862

van Wijngaarden, E., Alma, M., & The, A.-M. (2019). "The eyes of others" are what really matters: The experience of living with dementia from an insider perspective. *PloS One*, *14*(4), 1–23. https://doi.org/10.1371/journal.pone.0214724

Williams, K. N., Perkhounkova, Y., Jao, Y.-L., Bossen, A., Hein, M., Chung, S., Starykowicz, A., & Turk, M. (2018). Person-centered communication for nursing home residents with dementia: Four communication analysis methods. *Western Journal of Nursing Research*, *40*(7), 1012–1031. https://doi.org/10.1177/0193945917697226

Willis, D. G., Sullivan-Bolyai, S., Knafl, K., & Cohen, M. Z. (2016). Distinguishing features and similarities between descriptive phenomenological and qualitative description research. *Western Journal of Nursing Research*, *38*(9), 1185–1204. https://doi.org/10.1177/0193945916645499

Wilson, R., Rochon, E., Mihailidis, A., & Leonard, C. (2012). Examining success of communication strategies used by formal caregivers assisting individuals with Alzheimer's disease during an activity of daily living. *Journal of Speech, Language, and Hearing Research*, *55*(2), 328–341. https://doi.org/10.1044/1092-4388(2011/10-0206)

de Witt, L., & Ploeg, J. (2016). Caring for older people living alone with dementia: Healthcare professionals' experiences. *Dementia*, *15*(2), 221–238. https://doi.org/10.1177/1471301214523280

World Health Organization. (2023a, February 27). *Deafness and hearing loss*. https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss

World Health Organization. (2023b, March 15). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Xiang, C., & Zhang, Y. (2023). Comparison of cognitive intervention strategies for individuals with Alzheimer's disease: A systematic review and network meta-analysis. *Neuropsychology Review*, 1–15. https://doi.org/10.1007/s11065-023-09584-5

Yamada, Y., Denkinger, M. D., Onder, G., Henrard, J.-C., van der Roest, H. G., Finne-Soveri, H., Richter, T., Vlachova, M., Bernabei, R., & Topinkova, E. (2016). Dual sensory impairment and cognitive decline: The results from the shelter study. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, *71*(1), 117–123. https://doi.org/10.1093/gerona/glv036

Yates, J., Stanyon, M., Samra, R., & Clare, L. (2021). Challenges in disclosing and receiving a diagnosis of dementia: a systematic review of practice from the perspectives of people with dementia, carers, and healthcare professionals. *International Psychogeriatrics*, *33*(11), 1161–1192. https://doi.org/10.1017/S1041610221000119

Young, A., Ferguson-Coleman, E., Keady, J. (2018). Authentic Public and Patient Involvement with Deaf sign language users: it is not just about language access. *Dementia, 17*(8), 1001–1010. https://doi.org/10.1177/1471301218789567

Young, A., Ferguson-Coleman, E., & Keady, J. (2014). Understanding the personhood of Deaf people with dementia: Methodological issues. *Journal of Aging Studies*, *31*, 62–69. https://doi.org/10.1016/j.jaging.2014.08.006

Young, A., Ferguson-Coleman, E., Keady, J. (2020). Sign language communities, neighbourhoods and dementia?: A conceptual thematic review. *Ageing and Society 40*(2), 262–281. https://doi.org/10.1017/S0144686X18000946

Young, A., Ferguson-Coleman, E., & Keady, J. (2016). Understanding dementia: effective information access from the Deaf community's perspective. *Health & Social Care in the Community*, *24*(1), 39–47. https://doi.org/10.1111/hsc.12181

Young, A., & Hunt, R. (2011). *Research with d/Deaf people*. Methods Review 9. National Institute for Health Research. https://sscr.nihr.ac.uk/PDF/MR/MR9.pdf

Young, A., & Temple, B. (2014). *Approaches to social research: the case of deaf studies*. Oxford University Press.

Åhlin, J., Ericson, L. E., & Strandberg, G. (2022). Assessments of stress of conscience, burnout and social support amongst care providers in home care and residential care for older people. *Scandinavian Journal of Caring Sciences*, *36*(1), 131–141. https://doi.org/10.1111/scs.12970

Öhman, A., Josephsson, S., & Nygård, L. (2008). Awareness through interaction in everyday occupations: Experiences of people with Alzheimer's disease. *Scandinavian Journal of Occupational Therapy*, *15*(1), 43–51. https://doi.org/10.1080/11038120701441080

Øksnebjerg, L., Woods, B., Vilsen, C. R., Ruth, K., Gustafsson, M., Ringkøbing, S. P., & Waldemar, G. (2020). Self-management and cognitive rehabilitation in early stage dementia - merging methods to promote coping and adoption of assistive technology. A pilot study. *Aging & Mental Health*, *24*(11), 1894–1903. https://doi.org/10.1080/13607863.2019.1625302