

## Formal caregivers' perceptions of everyday interaction with Deaf people with dementia

Minna Rantapää, Ira A. Virtanen & Seija Pekkala

**To cite this article:** Minna Rantapää, Ira A. Virtanen & Seija Pekkala (14 Jan 2023): Formal caregivers' perceptions of everyday interaction with Deaf people with dementia, *Clinical Gerontologist*, DOI: [10.1080/07317115.2023.2167623](https://doi.org/10.1080/07317115.2023.2167623)

**To link to this article:** <https://doi.org/10.1080/07317115.2023.2167623>



© 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.



[View supplementary material](#)



Published online: 14 Jan 2023.



[Submit your article to this journal](#)



Article views: 364



[View related articles](#)



[View Crossmark data](#)

# Formal caregivers' perceptions of everyday interaction with Deaf people with dementia

Minna Rantapää <sup>a</sup>, Ira A. Virtanen<sup>b</sup>, and Seija Pekkala<sup>a</sup>

<sup>a</sup>Department of Psychology and Logopedics, Faculty of Medicine, University of Helsinki, Helsinki, Sieppijärvi, Finland; <sup>b</sup>Doctoral School, Tampere University, Tampere, Finland

## ABSTRACT

**Objectives:** Deteriorating interactive ability of people with dementia challenges formal caregivers. In Finland, Deaf people with advanced dementia may live in a nursing home designed for their care where the staff use Finnish Sign Language (FiSL). This study describes the perceptions of formal caregivers, focusing on the challenges, how they solve the challenges, and what support they need to improve interaction with Deaf residents.

**Methods:** Semi-structured interviews with 13 formal caregivers who work with Deaf people with dementia were conducted and analyzed using qualitative content analysis. A purposive sampling was used.

**Results:** Three key themes were challenges in interaction, strategies in supporting interaction, and support for coping. Caregivers perceived challenges in interaction caused by linguistic changes, deteriorating physical mobility and memory, and Deaf residents' behavioral challenges. Caregivers supported Deaf residents by learning to know them and using personal and linguistic strategies. Support for coping comprised supporting family members and other caregivers.

**Conclusions:** Efficient skills in sign language (SL) and knowledge of dementia are essential in interacting with Deaf residents and to build interpersonal relationships for care.

**Clinical implications:** Supporting Deaf residents requires learning the way they interact which can be achieved over time.

## KEYWORDS



Deaf; dementia; formal caregivers; interaction; sign language

## Introduction


Dementia is a syndrome impacting the brain due to various diseases, such as Alzheimer's Disease (AD). Already in 2012, WHO (World Health Organization) stated that AD is becoming a major reason for older people needing residential care (World Health Organization & Alzheimer's Disease International, 2012). Dementia causes marked changes in cognitive functions (i.e., processing information; McKhann et al., 2011). Psychosocial changes are common in dementia affecting behavior, such as mood swings and increased agitation (Huis in het Veld et al., 2018; Leung et al., 2021; Reeve et al., 2017; Wolf et al., 2018). Dementia is also a significant communication disorder (Bayles et al., 2020; Dijkstra et al., 2004, 2002) and it impacts the everyday interaction with people living with dementia (Kindell et al., 2013). Language

functions, particularly semantic processing, such as finding the right words and relating the word we just heard to other words with similar meanings, seem to impair early in dementia (see Bayles et al., 2020). Therefore, a person's ability to use language for perceiving the world and encoding the meaning of words deteriorates. In addition, repetition and use of empty words increase in dementia (Bayles et al., 2020). However, in the continuum of dementia among those who use spoken language, the ability to produce sound patterns (i.e., phonology) does not appear to deteriorate (Sandler, 2012; Szatloczki et al., 2015).

In Finland, the estimated number of people living with dementia is over 190,000 out of the total population of 5.6 million. It is estimated that annually, 14,500 people are diagnosed with dementia and the majority are over 80 years-of-age

**CONTACT** Minna Rantapää  [minna.rantapaa@helsinki.fi](mailto:minna.rantapaa@helsinki.fi)  Department of Psychology and Logopedics, Faculty of Medicine, University of Helsinki, Kaivajantie10, Helsinki, Sieppijärvi 95800, Finland

Note: "Deaf" with capital "D" in this study refers to people identifying with the Deaf Community, a minority population with its own language and culture (Sheppard & Badger, 2010), and "deaf" refers to people with a hearing loss. Also, "Sign Language" with initial capital letters refers to national languages, such as Finnish Sign Language, and "sign language" refers to sign languages in general.

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/07317115.2023.2167623>

© 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

(Finnish institute for health and welfare, 2022). Among those living with dementia are also members of the Deaf community. Unfortunately, there are no global statistics on how many Deaf people live with dementia. What we do know is that in Finland, approximately 4000–5000 people are Deaf Finnish Sign Language (FiSL) users. If we use the national incidence rate (ca. 3.4%), we can approximate the number to be 165 for Deaf people with dementia in Finland.

In this study, deafness is defined as people identifying with the Deaf community, a minority population with its own language and culture (Sheppard & Badger, 2010) rather than a medical condition of hearing loss. Among deaf people, there are those who experience age-related hearing loss and persons who have become deaf after learning a spoken language. However, the focus of the study is on people for whom Sign Language is their first and thus, native language. There are various Sign Languages (SL) in the world and even though they share some structural features, they are different. SLs are visuospatial languages, which means that they are produced by hands, mimes, and body, and received by vision (Fischer & van der Hulst, 2011).

Research on minority populations living with dementia has thus far concerned mainly the speaking and hearing people (Czapka & Sagbakken, 2020; Hanssen, 2013). Deaf people have only recently been seen as a cultural-linguistic minority (Ladd & Lane, 2013; Young et al., 2014) and been the focus of research (Rantapää & Pekkala, 2016; Rantapää et al., 2021; Young et al., 2016). On many occasions, the methods for investigating dementia in Deaf people have been ill-suited as they are based on tests used with the hearing people (Atkinson et al., 2015; Falchook et al., 2013; Young et al., 2014). For example, spoken language idioms do not occur in SLs, and some words must be fingerspelled since they do not have specific signs. Furthermore, tests that are translated from spoken languages are not sensitive to the declines in a person's SL ability (Falchook et al., 2013). Under- and over-diagnoses may occur because clinicians are unable to communicate directly with Deaf people (Young et al., 2014).

Research on Deaf people with dementia has confirmed that dementia makes one's language skills

deteriorate (Falchook et al., 2013; Hake & Farlow, 2006; Rantapää & Pekkala, 2016). Dementia also impacts the relationships between Deaf people with dementia and their caregivers by changing the relationship and, for example, feelings of burden and distress, respectively (Parker et al., 2010). Similar experiences have been reported by the hearing people with dementia (Eriksen et al., 2016; Mazaheri et al., 2013). In the seminal study on the experiences of Deaf people with dementia, Young et al. (2014) reported how dementia makes their SL poorer. For a Deaf person with dementia, living in an environment with non-signing caregivers confuses, frustrates, and saddens them (Parker et al., 2010).

Good resident–staff communication is related to the high quality of life for hearing people living with dementia (Zimmermann et al., 2005a). Caregivers' person-centered approach to care has been found to support the hearing people with dementia in both their relationships with caregivers (Lanzi et al., 2017; Savundranayagam & Moore-Nielsen, 2015; Wilson et al., 2013) and by enhancing their communication skills in interaction and keeping with the conversation topics (Dijkstra et al., 2004, 2002; Jones, 2015; Wilson et al., 2012). Yet, little is known about the everyday interaction between Deaf residents with dementia and staff in care homes.

In a recent study, Rantapää et al. (2021) used video-recorded everyday interactions between Deaf people with dementia and their formal caregivers. The results revealed that the caregivers used supportive strategies, such as enhancing interaction by initiating topics, providing emotional support (e.g., being empathetic), instrumental support (e.g., assisting with medication), informational support (e.g., giving information on what was agreed with one's family), and memory support (e.g., what day it is and what happens next) to enhance interactions with Deaf people with dementia. However, linguistic challenges and dismissal of difficult topics caused confusion and resulted in unsuccessful interaction. Previous studies on interaction between the hearing people with dementia and their caregivers have shown that the caregivers attempt to overcome the linguistic challenges with person-centered communication (Lanzi et al., 2017; Webb, 2017). Caregivers aim for conversations

**Table 1.** Demographics of the participants.

Demographics		N = 13
Age in years	~20–30	5
	31–40	4
	41–	4
Qualification	Nurse (practical or registered)	10
	Other	3
Dementia-nurse-training or similar	Yes	9
	No	4
Work experience in years	< 3 y	3
	3–8 y	4
	> 9 y	6
Work experience with hearing people with dementia	None	4
	< 1 y	7
	1–3 y	1
	> 3 y	1

which include and show value to the person with dementia by communicating on the person's own terms and according to their remaining communication abilities (Söderlund et al., 2016). Furthermore, Savundranayagam and Moore-Nielsen (2015) showed that diverse language strategies can elucidate how “relational” support is enacted in practice. To our knowledge, there is no previous research on how the level of disability of deafness or dementia affects the used supportive interaction strategies.

Interaction of Deaf people (i.e., users of SL) per se seems to go through similar changes as those using spoken language. However, when interacting with Deaf people, caregivers, doctors, and SL interpreters do not always understand Deaf people who experience changes in interaction (Parker et al., 2010; Rantapää & Pekkala, 2016). Altogether, the number of people who specialize in dementia care of Deaf people is small. And what is more, the dementia care education is concentrated on interaction and care for hearing people, and it can rarely be directly adapted to the care of Deaf people.

This study explores the formal caregivers' perceptions of their everyday interaction with Deaf people with dementia (hereafter Deaf residents), and what they perceive helpful in improving the interaction with those whose native language is SL. The aim of the study is to investigate the specific challenges experienced by caregivers in interaction with Deaf residents. We explore the factors that they consider helpful in and for the interaction as well as the support the caregivers need to improve the interaction.

## Methods

### Qualitative approach

The study uses a qualitative approach to fulfill the stated research purpose. The material for the study comprises of interviews with caregivers. We followed the principles of qualitative research based on Guba's (1981, as cited in Krefting, 1991). The following strategies were used to enhance rigor. To enhance applicability, the demographics of the caregivers are shown in Table 1 (Krefting, 1991). A qualitative content analysis was conducted by the first author following Elo and Kyngäs (2008) and Vaismoradi et al. (2013). The consolidated criteria for reporting qualitative research (COREQ; Tong et al., 2007) was utilized in reporting this study.

### Context

In Finland, dementia care in FiSL is provided by the Service Foundation for the Deaf in total of three nursing homes for older Deaf people. The staff in the homes are required to know or to learn FiSL. The pioneer home of dementia care for Deaf people (hereafter Home) has operated since 2007, and it has approximately 20 residents and 12 caregivers. The Home was chosen for the study, since it is the largest, it specializes in memory care for Deaf people who identify with the Deaf community, they use FiSL and operate with the intent to appreciate the Deaf culture.

The caregivers in this study cared for Deaf residents who had been clinically diagnosed with dementia, mostly with moderate to severe Alzheimer's disease. The residents have been Deaf

since childhood, they attended a school for the Deaf, and used FiSL as their mother tongue throughout their lives. The residents' vision or the stage of dementia was not controlled for this study. The residents ranged in age from 81 to 92 years and the length of their formal education varied from 6 to 8 years (see also, Rantapää et al., 2021). In Finland, the education of the deaf people during most of the 20<sup>th</sup> century used to take place in separate schools for the deaf. Education was based on forcing the children to talk (use speech) whereas learning academic skills was less important (Salmi, 2010). In the study, we have focused on Deaf people with a capital 'D' which means that they identify with the Deaf community using FiSL no matter their hearing status.

### **Sampling strategy of research participants**

Purposive sampling (Elo et al., 2014) of participants (hereafter caregivers) was used. The caregivers were invited to participate in the study during the first author's fieldwork. According to the inclusion criteria, the Deaf or the hearing caregiver had to (1) be involved with the day-to-day care in the Home at the time of the study, and (2) be able to communicate in FiSL. In addition, two dementia specialists working with the Deaf community at the Home were invited to participate. We refer to all of them as caregivers in the study. All 13 participants with diverse ages, clinical experience, and skills in FiSL consented to the study. The demographics of the caregivers are shown in Table 1. The number of participants was considered adequate, as the number of Deaf residents and their caregivers in Finland is small (see also, Cleary et al., 2014). No one withdrew from the study.

### **Researcher characteristics and reflexivity**

The first author is native in FiSL, which provides valuable insight into Deaf people and SL that is often lacking among researchers. The first author was independent of the organization in which the data were gathered. To enhance the truth value of the data, she spent two months in fieldwork in the Home gathering data for this study. Information about the study and the first author's role was introduced to the caregivers at the

beginning of the fieldwork. During the fieldwork, the first author spent time in getting to know the Home, the caregivers, and their work (e.g., daily routines). To prevent bias (Ashton, 2014), the first author (also a registered nurse), kept a personal diary during the fieldwork and data gathering to reflect on her observations and interpretations.

### **Data collection methods**

Individual semi-structured interviews were conducted in 2016–2017 by the first author. The previous research and the notes from fieldwork guided the design of the interview questions. The interviews focused on the work with Deaf residents, the experienced challenges and solutions, and the social support. Examples of interview questions are shown in Appendix. The interviews were one-on-one and lasted 27–63 minutes (9 hours 41 minutes in total). Ten interviews were conducted in person at the Home in a quiet room, two via Skype calls, and one interview took place at the participant's own home. The interviews were transcribed verbatim (123 pages, single-spaced, font Times New Roman size 12).

First, a pilot interview was conducted to enhance neutrality and test the questions. No major changes were made. The first author is native in FiSL, yet a hearing person. Thus, no interpreter was needed. Interviews in Finnish were audio recorded and interviews in FiSL were video recorded with the permission of the participants. According to preliminary analysis during the data gathering, the interview data began to saturate approximately by the 9<sup>th</sup> interview, after which no new themes were initiated by the caregivers. The 13 interviews were considered adequate for the validity of the study.

### **Ethical issues pertaining to human subjects and data protection**

This study was approved by the University of Helsinki Ethical review board of the Humanities and Social and Behavioral Sciences (30/2016). The secure data protection measures are in place for the digitally stored interview data.

## Data analysis

First, the transcriptions were read through methodically. Second, significant words and expressions that recurred in the transcripts were chosen as the meaning units, then searched line by line and for their synonymous expressions and labeled with codes using the qualitative content analysis software ATLAS.ti. Altogether 355 codes were achieved. The codes were evaluated for their occurrence, then grouped and renamed if deemed appropriate. Lastly, the codes were combined to form the main categories. For example, Caregiver 4 described a resident's communication as follows: "When she gets angry, she looks away and does not want to take eye contact." The expression was condensed into a meaning unit "When getting angry, she turns away and avoids eye contact." It was then coded as "no eye contact." Subsequently, all meaning units given the code "no eye contact" were placed in the category of "behavioral factors impacting interaction." In the process of data reduction, 20 such subcategories were achieved.

All subcategories were carefully reviewed. They were grouped based on the themes initiated by the research questions. Hence, the following three main categories were created and they represent the main results of the study: (1) Challenges in interaction (4 subcategories), (2) strategies in supporting interaction (3 subcategories), and (3) support for coping (2 subcategories).

## Results

### Challenges in interaction

According to the caregivers, the challenges in interaction comprised (a) linguistic changes that were experienced by the Deaf residents, as well as (b) deteriorating physical mobility of residents' hands and fingers. Other factors that hindered interaction were (c) deteriorating memory and (d) behavioral challenges of Deaf residents.

*Linguistic changes.* The caregivers had noticed the Deaf residents' linguistic changes by their lesser use of FiSL and increased use of spoken words, although their speech was often unclear. Some added that it became more difficult to understand Deaf residents when they spoke rather than signed. The residents were all taught to speak in formal

education in their youth even when they could not hear spoken language themselves. The residents' sign and word vocabulary decreased, and some signs were unclear or incorrect (paraphasia):

*They sign 'table' when they mean 'floor' ... or they sign 'go to sleep' when they mean 'go to the shower'.  
(Caregiver 4)*

The caregivers noted that Deaf residents did not understand complicated sentences, instructions, or hypernyms (linguistic term for superordinate, e.g., "outerwear" for coat, hat or gloves, and "means of transportation" for bus and train). The caregivers had also observed that Deaf residents sometimes struggled to understand the jargon used by doctors or had trouble comprehending SL interpreters and the FiSL fingerspelling. When Deaf residents became confused, they tended not to ask for clarification:

*For example, 'Parkinson's', when a neurologist uses such phrases, and an interpreter should know how to sign but still it isn't clear for persons with dementia. Especially persons with advanced dementia don't ask for clarifications but appear confused. They don't understand what is happening but still they don't ask for what it means.  
(Caregiver 2)*

According to the caregivers, Deaf residents often chose their language depending on whether the caregiver was hearing or Deaf:

*If a Deaf person [caregiver] is present, they don't use voice but sign. I think people with dementia recognize who is Deaf and who is hearing. At the same time, they often ask whether you can hear. (Caregiver 10)*

Even when the caregivers were native in FiSL, they still had experiences of misunderstanding or challenges in interaction. For example, when they met the resident for the first time and their physical illness had impacted hands and fingers, which made it difficult for a person to sign. Many interviewees disclosed challenges that concerned themselves as FiSL users. They did not always understand the FiSL style of older Deaf residents or all FiSL in general. Furthermore, the caregivers depicted it was challenging to use sign language at the same time as attending to the Deaf resident because both, signing and physical treatment, require hands.

*Deteriorating physical mobility of hands and fingers.* The caregivers reported that the clarity of signs was impacted by the deteriorating physical mobility of the upper extremities of Deaf residents. For example, the signs became smaller and unclear, and the space of signs altered. What should have been signed in upper space was signed in lower space instead. Moreover, the residents' fingerspelling became unclear.

*Deteriorating memory.* The caregivers noted that challenges in memory involved forgetfulness and repetition of the same topics during a conversation. They reported that some Deaf residents would tell them the same story repeatedly, and it was particularly challenging to listen when the story contained sad or distressing memories from the past. The caregivers pursued to change the topic when Deaf residents became anxious, upset, or tearful.

*It depends, if [name] talks about her children or something that is important to her, I do listen to her. But if it's something more negative she keeps repeating I may change topic. I'll lead the conversation to something else to help her forget the negative memory. (Caregiver 6)*

*Behavioral challenges.* The caregivers considered the tendency of the Deaf residents to turn their head away during a conflict challenging. Behavioral challenges could result from mood changes of Deaf residents or arguments between residents. Conflicts could mean someone getting angry or disagreeing strongly about something. When they could not hold gaze it disrupted the communication, and their attempts to solve the conflict without eye contact became a challenge. In the caregivers' experiences, it was easier to continue the interaction with the hearing people with dementia without eye contact. What they found useful in solving disagreements between residents was timing: If the caregiver had witnessed the incident from the beginning, it was easier for them to solve it.

*Especially, when we see the whole situation from the beginning and know who started it, we say 'hey you cannot behave like that'. . . . If they boss others around, talk rudely, push or slap someone, we have to intervene. Then they get furious, sometimes very easily. Then they may leave or stay and calm down. Sometimes it helps when we do not talk about it anymore. (Caregiver 5)*

## **Strategies in supporting interaction**

The data showed that the caregivers' strategies in supporting interaction consisted of (a) learning to know the person with dementia, (b) personal strategies, and (c) linguistic strategies.

*Learning to know the person with dementia.* The caregivers attempted to get to know the person with dementia and their life history by interviewing the resident and their family members when the person first moved to the Home. They would write the most important things on a board and place the board on the wall of the resident's room. In doing so, all the caregivers had the opportunity to learn about the residents' personal history and what they liked and disliked. The caregivers had detected that the overall surroundings were important in supporting Deaf residents.

*[The ward] is smaller and well planned with two short corridors. And they can walk around through the kitchen and the living-room. But it's not too big, and the caregivers are in sight almost all the time. It's calming when they [the residents] can spot a caregiver whenever they feel they must see one. (Caregiver 1)*

*Personal strategies.* The caregivers described using their personality and creativity in interaction with the residents. The caregivers described themselves at work as attentive, calm, empathetic, persistent, tolerant, and as someone who gives time to the residents. They aimed at using FiSL in a clear manner and maintaining eye contact with the Deaf residents. They would try to find other ways to express themselves when a Deaf resident did not respond to their requests and would split a complicated instruction into smaller segments. They also felt that they needed to be patient and make the Deaf residents feel that they have been seen.

*When the illness [dementia] progresses, they don't like if you sign quickly. [. . .] It's important to sign in a calm and clear manner. (Caregiver 12)*

*Linguistic strategies.* The caregivers aimed at finding out what a Deaf resident tried to express by asking more questions and suggesting words for them to use. They also interpreted residents' non-verbal gestures and used some themselves, such as pointing with a finger as well as guided touch. The caregivers disclosed that when some Deaf residents

became confused, they sought confirmation by asking:

*I think you may not have understood, am I right?*  
(Caregiver 2)

The caregivers depicted using touch to calm or guide a resident or to pay their attention to something as part of interaction. They also used touch to communicate when a resident had no language skills:

*Well, if they are not interacting with FiSL or speech anymore and you cannot use them then it's mainly touch and facial expressions and gestures.* (Caregiver 6)

However, the caregivers pointed out that using touch could provoke aggression in some residents and was thus not used with everyone.

The caregivers used repetition and tangible communication when interacting with the residents. For example, they lead a person to the place they had referred to and showed them the object they had talked about. They also suggested words or signs when Deaf residents did not remember, for example, when a doctor asked them how they felt or what symptoms they had. The caregivers considered themselves as second interpreters who function in between the Deaf residents, the SL interpreter, and the doctor. In general, interpreters are seldom used in dementia care for hearing people. Furthermore, unlike for hearing residents with dementia, interpreters are used when going to the doctor's appointment. The caregivers reported that they often had to interpret the Deaf resident's communication to the interpreter, and then mediate between the interpreter and the physician because the resident's signing was unclear. The caregivers felt they understood the resident better than the interpreter.

### **Support for coping**

The data showed that support for coping comprised (a) support for family members and (b) support for caregivers.

*Support for family members.* The caregivers talked about family members who had been accustomed to mouthing and lip-reading before in life to interpret the resident's communication. Now they asked the caregivers for support when they no

longer could understand their loved one. The caregivers depicted using FiSL and sometimes acted as interpreters between family members and Deaf residents. In addition, they gave family members information about dementia and its effects on a person.

*Some family members talk about how the language [of their family member] disappears. They tell us about their problems when they do not understand what their parent wants. Sometimes they come and ask for help because we are there every day. [...] I have told the family members how dementia impacts and that is why the language deteriorates. [...] Sometimes we may go and help them in the situation.* (Caregiver 1)

*Support for caregivers.* The caregivers who were non-natives in FiSL shared that they had either studied FiSL before or when starting to work with Deaf residents. They expressed their desire to continuously learn FiSL, especially the style used by older Deaf people. The caregivers sometimes asked colleagues for help in FiSL—both how to sign and what a Deaf person with dementia meant with a sign. Misunderstandings could result in further challenges in interaction, e.g., when a resident got restless when taken to bed, or refused medical treatment which purpose they did not understand or got upset or angry.

The caregivers said they discussed among coworkers and tried to find solutions together to better understand the residents and their problematic behavior. They also depicted that they regularly met with a professional counseling group to discuss challenges at work. Additionally, one caregiver described what it meant to work in a small unit, as it can be both a challenge and a resource for support:

*Working in a small group is very intensive and it can get under your skin. And then all that happens becomes commonplace. You kind of forget that they have the special features. [...] The most important interaction should be done by the person who knows the Deaf person with dementia best. You should do it peacefully. And you should consider also that you may misunderstand.* (Caregiver 8)

The caregivers disclosed that even though they had attended a special education in dementia care, they had little practical use of it because the methods that were taught were based on hearing, such as using music and singing. They wished for special



education and care practices particularly for dementia care of Deaf people.

## Discussion

The aim of this study was to explore formal caregivers' perceptions of their everyday interaction with Deaf people with dementia. The interviews with the caregivers in a Finnish nursing home for the Deaf focused on the challenges in interaction with the residents, the caregivers' strategies in supporting interaction and support for their coping. Communication, among hearing people with dementia, has been investigated in clinical or experimental settings, whereas research that focuses on everyday interaction has been scarce (Kindell et al., 2013).

This study shows that there are specific linguistic challenges in everyday interaction because of the changes in signed sentence structures and utterances of Deaf people with dementia. Signs or mouthed words may become difficult to produce. The findings of the study are supported by research containing interaction data, which show that sentence construction decreases, and utterances become shorter for Deaf people with dementia (Rantapää & Pekkala, 2016). Words or signs tend to be difficult to find, and Deaf with dementia have challenges in staying on topic and maintaining coherence in their narration (Rantapää et al., 2021.) The difficulties appear similar to those of the hearing individuals with dementia, i.e., struggle with speaking and finding words (Bayles et al., 2020; Dijkstra et al., 2004, 2002). More research is needed on how dementia impacts SL abilities in Deaf signers.

This study presents a unique finding concerning Deaf people with dementia. The caregivers experience challenges in interaction with Deaf residents who have deteriorating physical mobility. They have difficulties in producing and comprehending fingerspelling as well as in the comprehension of complex sentences (Falchok et al., 2013; Rantapää et al., 2021). Since hands and fingers are crucial in producing signs in SL, the deteriorating physical mobility for the Deaf individual with dementia has a great impact on interaction. However, the caregivers testified that they could learn to understand such individuals over time. Because deafness

together with dementia increases the complexity of the care process, it is vital that the person can remain in their familiar Home where the caregivers learn to know them well (see also, Parker et al., 2010; Rantapää & Pekkala, 2016).

According to the caregivers, the Deaf residents alternate between FiSL and spoken Finnish depending on with whom they interact. This can be an indication of Deaf people with dementia being at least to some extent bilingual. Those born in the 1940's or before were forced to use speech at school even if Deaf, and therefore, dementia may cause the confusion about which language to use with caregivers and family members. Spanjer et al. (2014) also reported that choosing a language according to the conversation partner is typical for bilingual people, and that bilingual people with Alzheimer's disease have problems with language choice. The caregivers had detected attempts from the residents to recognize the language that the caregiver would be native to. Thus, clear and calm communication about the language preference in initiating interaction would support the Deaf residents' choice. Although it is typical for Deaf adults to use bimodal mixing (i.e., use both spoken words and SL signs) in their communication even without dementia, we suggest more research particularly on the aspect of bilingualism in Deaf people with dementia.

Quinto-Pozos (2014) argues that iconicity in SLs may support comprehension, and manually produced signs may be perceivable due to their size and visibility. Iconicity means that the linguistic form of a sign resembles its meaning in FiSL, e.g., "a ball" and "a house." The caregivers in this study depicted that the Deaf residents have difficulties in comprehending fast signing. Thus, adjusting the speed of signing by slowing down may enhance their ability to encode the message. Hence, Deaf residents benefit from interacting in SL in which visuality is the basic element.

Furthermore, a repeated practice of enactment (i.e., to illustrate with gestures, movement, and posture) in interaction helps a person with dementia to perform what they want to say, leading to a meaningful interaction compared to what a person with limited vocabulary would achieve (Kindell et al., 2013). Importantly, notwithstanding the notable losses that Deaf people with dementia experience, they may still have partially undiscovered resources of visuo-spatial

(i.e., processes involving visual and spatial awareness) language unavailable in spoken languages (Rantapää & Pekkala, 2016; Young et al., 2014).

In this study, the caregivers depicted behavioral challenges that the Deaf residents have, such as mood changes, getting confused or angry, and repetition. Alike psychosocial changes are common in dementia (Huis in het Veld et al., 2018; Leung et al., 2021; Reeve et al., 2017; Wolf et al., 2018). However, the findings of this study recognize a unique challenge in interaction with Deaf people with dementia: It is impossible to engage in interaction when a Deaf person turns to look away, since SL requires eye contact. The caregivers struggled to interact when they lost eye contact with the Deaf resident. Future studies should investigate ways to counter the loss of connection with a Deaf person with dementia.

The fundamental difference between the Deaf and the hearing people with or without dementia is the language (signed vs. spoken). The visible versus audial modality of Sign Language makes eye contact vital in its interaction. Spoken languages can be used simultaneously with care tasks, that is, when the caregivers' hands are occupied, with those who can hear. With Deaf people, caregivers interact and conduct care tasks consecutively.

There were several ways in which the caregivers supported Deaf residents in interaction. First, they put effort into knowing well the person with dementia. Second, they used personal strategies such as communicating FiSL in a calm and clear manner, showing empathy, giving time, and actively interpreting nonverbal behavior. The strategies they described are person-centered strategies (e.g., Wilson et al., 2013). Person-centered communication has been shown to be an efficient way to improve interaction between caregivers and residents with dementia, as it invites them to socialize and contribute to conversations, such as maintaining the relationship with caregivers (Savundranayagam & Moore-Nielsen, 2015). Additionally, a person-centered approach has been found to increase satisfaction and experienced competence in caregivers who work with people with dementia (Zimmermann et al., 2005b). Person-centered communication behaviors are, for example, encouraging the residents to make choices and decisions about their clothing, food, and activities (Lanzi et al., 2017). Furthermore, being patient and focusing

on the resident's needs were perceived important and caregivers described doing just that (see, also Wilson et al., 2013). Our study used a self-report method of interviews, which can evoke socially acceptable answers. However, a study using video-recorded interaction data between Deaf residents and their caregivers supports these findings (Rantapää et al., 2021).

Previous research has focused on language disorders of people with dementia which highlights their limitations. Yet, recent research has brought attention to the importance of interaction (Jones, 2015; Rantapää & Pekkala, 2016). Jones (2015) found that individuals with dementia continue being socially active and cooperative despite linguistic challenges imposed by dementia. Hence, dementia care education for caregivers of Deaf people should receive more attention. As the caregivers in this study reported, they had little use for dementia specified education which based its rehabilitation and daily activities on music and singing. Thus, the whole thinking of dementia rehabilitation should be revolutionized and it should utilize more diverse and multimodal ways in supporting interaction of people with dementia.

While this study does not extensively describe phonology<sup>1</sup> changes in SL used by Deaf people with dementia, research on hearing people with dementia shows that sound patterns tend to remain relatively spared whereas changes in speech tempo may occur (Szatloczki et al., 2015). In our study and that of Young et al. (2014), the caregivers described grammatical changes in the use of space, location, hand shapes and movement, which are in fact components of phonology in SL (Sandler, 2012)□the language used by the Deaf people with dementia. Such changes can be considered as signs of impaired phonological processing, and the deterioration of fine motor skills are a symptom of dementia (Sandler, 2012). Dementia impacts the physical mobility of hands and fingers, especially in its moderate and severe stages (Liou et al., 2020), and thus renders the interaction with Deaf people with dementia as challenging. The results of this study confirm that physical deterioration makes it difficult for the caregivers to comprehend the communication of Deaf residents. Hence, more research is needed to explore the role of phonological and physical deterioration in SL of Deaf

people with dementia to increase our understanding and to improve SL education of the caregivers.

Finally, dual sensory loss, i.e., losing both hearing and vision, and their impact on the interaction with a person with dementia is further an unknown area. Although the residents that the study's caregivers were caring for were still able to see, using touch is certainly one important way to connect when having dual sensory loss. As the results showed, the caregivers used touch cautiously when for example, guiding or calming the resident but, at the same time, they avoided possible conflicts when touch could irritate or provoke the resident. Other fundamental ways of using touch in interaction need to be explored by future research.

### Limitations

This qualitative study adds to the limited knowledge of support for interaction with Deaf people with dementia and highlights the unique features of those belonging in the community. The study has some limitations. There were only 13 interviewees, yet the participants adequately represent the population, since the number of Deaf residents and their caregivers in Finland is small (see, e.g., Cleary et al., 2014).

In this study, the caregivers expressed their need for more dementia-focused education and training even when some of them had attended a one-year-course in dementia care. To our knowledge, there is no training available in Finland or elsewhere, which would be focused on Deaf people with dementia and the features specific to Deaf culture and SL. Older people in Finland and in other European countries went to school at the time when SLs were not allowed even in schools for the Deaf (Baynton, 1996; Fleurion et al., 2020; Salmi, 2010; Van Cleve, 1993). Education was based on forcing the children to talk (use speech) whereas learning academic skills was less important. For example, children, no matter of their hearing status, were forced to, e.g., mimic their teachers' mouth movements for articulation and practice articulation with the help of spoons and mirrors (Salmi, 2010). In the future, Deaf-specific dementia-focused education and training should be developed and offered to all caregivers working with Deaf people with dementia.

### Conclusions

Our study describes the challenges perceived by caregivers in interaction with Deaf residents and the strategies used to overcome the challenges. Caregivers can support the communication of people with dementia by getting to know them, their life history, their likes and dislikes, and their capabilities. It is essential for caregivers to have efficient communication competence to interact in everyday tasks with the residents and to recognize individual differences in residents when interacting with them. To improve communication competence and using the person-centered approach, caregivers benefit from further education in FiSL, especially the style used by older Deaf people.

### Clinical implications

- Deaf-specific and dementia-focused education and training should be developed and offered to all caregivers working with Deaf people with dementia.
- Deaf people with dementia should have access to long-term-care in their national sign language.
- Caregivers adjust their communicative strategies to support interaction with Deaf residents and their enjoyment of everyday experiences. This requires learning to know the person with dementia and the way they communicate over time.

### Note

1. Phonology in SL means a grammatical part where structural units are combined to create meaningful utterances. The SL signal is shaped by the hands, face, and body. SL phonology is categorized by hand configuration, location, and movement. This means that signs vary by the shape of hand, where it is in space (usually in front of the signer), and how the hand moves (Sandler, 2012). For more information about structures and grammar of SLs, see, e.g., William Stokoe.

### Acknowledgments

We thank all the formal caregivers who participated in the study. We are grateful to the Finnish Service Foundation for the Deaf for helping in the data acquiring.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

This study was supported by Finnish Brain Foundation (grant number 20210078).

## ORCID

Minna Rantapää  <http://orcid.org/0000-0002-6848-5468>

## Author contributions

Author 1, author 2, and author 3 designed the study. Author 1 collected and analyzed the data. Author 2 and author 3 participated in the interpretation of analyses. All authors contributed to the manuscript and have read and approved the final manuscript.

## References

- Ashton, S. (2014). Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse Researcher*, 22(1), 27–31. <https://doi.org/10.7748/nr.22.1.27.e1255>
- 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>
- Bayles, K., McCullough, K., & Tomoeda, C. (2020). *Cognitive-communication disorders of MCI and dementia: Definition, assessment, and clinical management* (3rd ed.). Plural Publishing.
- Baynton, D. C. (1996). *Forbidden signs: American culture and the campaign against sign language*. University of Chicago Press.
- 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>
- Czapka, E. A., & Sagbakken, M. (2020). “It is always me against the Norwegian system.” Barriers and facilitators in accessing and using dementia care by minority ethnic groups in Norway: Qualitative study. *BMC Health Services Research*, 20(954), 1–15. <https://doi.org/10.1186/s12913-020-05801-6>
- Dijkstra, K., Bourgeois, M. S., Allen, R. S., & Burgio, L. D. (2004). Conversational coherence: Discourse analysis of older adults with and without dementia. *Journal of Neurolinguistics*, 17(4), 263–283. [https://doi.org/10.1016/S0911-6044\(03\)00000-0](https://doi.org/10.1016/S0911-6044(03)00000-0)
- 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), 53–74. [https://doi.org/10.1207/S15326950DP3301\\_03](https://doi.org/10.1207/S15326950DP3301_03)
- 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>
- 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>
- Eriksen, S., Helvik, A.-S., Juvet, L. K., Skovdahl, K., Førsvund, L. H., & Grov, E. K. (2016). The experience of relations in persons with dementia: A systematic meta-synthesis. *Dementia and Geriatric Cognitive Disorders*, 42(5–6), 342–368. <https://doi.org/10.1159/000452404>
- Falchook, A. D., Mayberry, R. I., Poizner, H., Brandon Burtis, D., Doty, L., & Heilman, K. M. (2013). Sign language aphasia from a neurodegenerative disease. *Neurocase: The Neural Basis of Cognition*, 19(5), 434–444. <https://doi.org/10.1080/13554794.2012.690427>
- Finnish institute for health and welfare. (2022, January 21). *Chronic diseases: Memory disorders*. <https://thl.fi/en/web/chronic-diseases/memory-disorders>
- Fischer, S. D., & Van der Hulst, H. (2011). Sign language structures. In J. F. Andrews (Ed.), *The Oxford handbook of deaf studies, language, and education* (Vol. 2, pp. 336–360). Oxford: Oxford University Press. <https://www.proquest.com/trade-journals/oxford-handbook-deaf-studies-language-education-v/docview/835079798/se-2?accountid=11365>
- Fleurion, V. S., Ridoux, I., Scemama, C., Bouillevaux, I., Ciosi, A., & Drion, B. (2020). 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/acia125>
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Resources Information Center Annual Review Paper*, 29(2), 75–91. <https://doi.org/10.1007/BF02766777>
- Hake, A. M., & Farlow, M. R. (2006). American sign language aphasia in Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 2(3), S394–S394. <https://doi.org/10.1016/j.jalz.2006.05.1340>
- Hanssen, I. (2013). The influence of cultural background in intercultural dementia care: Exemplified by Sami patients. *Scandinavian Journal of Caring Sciences*, 27(2), 231–237. <https://doi.org/10.1111/j.1471-6712.2012.01021.x>
- Huis in het Veld, J. G., Verkaik, R., Van Meijel, B., Verkade, P.-J., Werkman, W., Hertogh, C. M. P. M., & Francke, A. L. (2018). Self-management support and eHealth when managing changes in behavior and mood of a relative with dementia: An asynchronous online focus group study of family caregivers' needs. *Research in Gerontological Nursing*, 11(3), 151–159. <https://doi.org/10.3928/19404921-20180216-01>

- Jones, D. (2015). A family living with Alzheimer's disease: The communicative challenges. *Dementia*, 14(5), 555–573. <https://doi.org/10.1177/1471301213502213>
- Kindell, J., Sage, K., Keady, J., & Wilkinson, R. (2013). Adapting to conversation with semantic dementia: Using enactment as a compensatory strategy in everyday social interaction. *International Journal of Language & Communication Disorders*, 48(5), 497–507. <https://doi.org/10.1111/1460-6984.12023>
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 214–222. <https://doi.org/10.5014/ajot.45.3.214>
- 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>
- Lanzi, A., Burshnic, V., & Bourgeois, M. S. (2017). Person-centered memory and communication strategies for adults with dementia. *Topics of Language Disorders*, 37(4), 361–374. <https://doi.org/10.1097/TLD.0000000000000136>
- Leung, M., Wang, C., & Famakin, I. O. (2021). Integrated model for indoor built environment and cognitive functional ability of older residents with dementia in care and attention homes. *Building and Environment*, 195(1), 1–14. <https://doi.org/10.1016/j.buildenv.2021.107734>
- Liou, W., Chan, L., Hong, C., Chi, W., Yen, C., Liao, H., Chen, J., & Liou, T. (2020). Hand fine motor skill disability correlates with dementia severity. *Archives of Gerontology and Geriatrics*, 90(1), 104168. <https://doi.org/10.1016/j.archger.2020.104168>
- 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>
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Jr., Kawas, C. H., Phelps, C. H., Koroshetz, W. J., Manly, J. J., Mayeux, R., Mohs, R. C., Morris, J. C., Rossor, M. N., Scheltens, P., Carrillo, M. C., Thies, B., Weintraub, S., & Phelps, C. H. (2011). The diagnosis of dementia due to *Alzheimer's* disease: Recommendations from the national institute on aging-*Alzheimer's* Association workgroups on diagnostic guidelines for *Alzheimer's* disease. *Alzheimer's & Dementia*, 7, 263–269. <https://doi.org/10.1016/j.jalz.2011.03.005>
- 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>
- 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.
- 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>
- Rantapää, M., Virtanen, I. A., & Pekkala, S. (2021). Supportive interaction between formal caregivers and Deaf people with dementia. *Educational Gerontology*, 47(8), 369–382. <https://doi.org/10.1080/03601277.2021.1988447>
- Reeve, E., Molin, P., Hui, A., & Rockwood, K. (2017). Exploration of verbal repetition in people with dementia using an online symptom-tracking tool. *International Psychogeriatrics*, 29(6), 959–966. <https://doi.org/10.1017/S1041610216002180>
- Salmi, E. (2010). *Linguistic turns in teaching of the deaf in Finland*. HUMAK University of Applied Sciences.
- Sandler, W. (2012). The phonological organization of sign languages. *Language and Linguistics Compass*, 6(3), 162–182. <https://doi.org/10.1002/lnc3.326>
- 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>
- 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>
- Söderlund, M., Cronqvist, A., Norberg, A., Ternstedt, B. M., & 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>
- 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.
- 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>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15(1), 398–405. <https://doi.org/10.1111/nhs.12048>
- van Cleve, J. V. (Ed.). (1993). *Deaf history unveiled: Interpretations from the new scholarship*. Gallaudet University Press.
- 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>
- Wilson, R., Rochon, E., Leonard, C., & Mihailidis, A. (2013). Formal caregivers' perceptions of effective communication strategies while assisting residents with Alzheimer's disease during activities of daily living. *Canadian Journal of Speech-Language Pathology and Audiology*, 36(4), 314–331. [https://cjslpa.ca/files/2012\\_CJSLPA\\_Vol\\_36/No\\_04\\_264\\_355/Wilson-Rochon-Leonard-Mihailidis\\_CJSLPA.pdf](https://cjslpa.ca/files/2012_CJSLPA_Vol_36/No_04_264_355/Wilson-Rochon-Leonard-Mihailidis_CJSLPA.pdf)
- 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](https://doi.org/10.1044/1092-4388(2011/10-0206)
- Wolf, M. U., Goldberg, Y., & Freedman, M. (2018). Aggression and agitation in dementia. *Behavioral Neurology and Psychiatry*, 24(3), 783–803. <https://doi.org/10.1212/CON.0000000000000605>
- World Health Organization & Alzheimer's Disease International. (2012). *Dementia: A public health priority*. [http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/)
- 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. (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>
- Zimmermann, S., Sloane, P. D., Williams, C. S., Reed, P. S., Preisser, J. S., Eckert, J. K., Boustani, M., & Dobbs, D. (2005a). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45(1), 133–146. [https://doi.org/10.1093/geront/45.suppl\\_1.133](https://doi.org/10.1093/geront/45.suppl_1.133)
- Zimmermann, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005b). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45(1), 96–105. [https://doi.org/10.1093/geront/45.suppl\\_1.96](https://doi.org/10.1093/geront/45.suppl_1.96)

## Appendix. Interview guide

Theme	Examples of questions
Background	Tell me about yourself and your work
Education in dementia	Tell me about your education in dementia
Work with Deaf people with dementia	Tell me about your work with Deaf people with dementia
Experiences of interaction with Deaf people with dementia	Tell about your experience of interaction with Deaf people with dementia. What language do you use? How do you communicate? What are conversations like? Give examples. What do you talk about? Who makes initiative? How does conversation go on? Tell about greetings, how does it go? When you meet family members, what do you talk about with them?
Challenges in interaction	What kind of challenges have you met? Tell some examples. What are difficult situations like? What happens during them? What makes them difficult? How do you feel then?
Solving challenges in interaction	If you face challenges, how do you react? How do you solve them? What works best? Why? What happens then? What does not work? Why? How does it go then? If there's been a third person involved, what has she/he done?
Support in interaction	What kind of support have you offered to a Deaf person with dementia or to their family members? What kind of support have you hoped for yourself? What kind of support helps you the best? Why? Who do you get support from or wish getting support from? What do you hope for the support? What helps you to carry on with your work
"Free word"	Is there something I have not asked but you want to tell?
Questions for those who participated in video-data-study (Rantapää, Virtanen & Pekkala, 2021)	Tell about your experience of videoed interactions. Who did you have most challenges with? Why? Who was the easiest to interact with? Why? What kind of challenges there were in the interactions? How did you solve them?