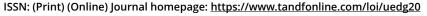# Supportive interaction between formal caregivers and Deaf people with dementia

Minna Rantapää, Ira A. Virtanen & Seija Pekkala

Published online: 12 Oct 2021.

Submit your article to this journal

Article views: 170

View related articles

View Crossmark data

Routledge
Taylor & Francis Group

ARTICLE

Supportive interaction between formal caregivers and Deaf people with dementia

Minna Rantapää [ID][a], Ira A. Virtanen[b], and Seija Pekkala[a]

[a]Department of Psychology and Logopedics, Faculty of Medicine, University of Helsinki, Helsinki, Finland; [b]Doctoral School, Tampere University, Tampere, Finland

ABSTRACT

This qualitative study explores the supportive strategies used by formal caregivers when interacting with Deaf people with dementia. The data consist of video-recorded interactions between dyads of nine caregivers and five Deaf participants in a nursing home for the Deaf in Finland. We analyzed 21 interactions (5 hours and 25 minutes in total), using two methods: inductive content analysis and the Interactive Coping Behavior Coding System. The study found that the formal caregivers used a wide range of supportive strategies. We identified five strategies: (1) interaction maintenance, (2) emotional support, (3) instrumental support, (4) informational support, and (5) memory support. The formal caregivers also used dismiss and avoidance behaviors when the interaction became challenging. Non-proficiency in sign language hindered support. In the future, attention should be paid to teaching formal caregivers national sign language and supportive communication competence for working with Deaf people with dementia.

Dementia and social interaction

Dementia is an umbrella term for illnesses that cause decline in memory and other cognitive abilities, which affect individuals' daily abilities (American Psychiatric Association, 2013). People living with dementia can maintain their communicative abilities during mild to moderate stages of dementia, although linguistic changes can emerge in the early stages of dementia (Calzà et al., 2021; Pekkala et al., 2013). Dementia affects word finding and paraphrasing, which results in problems with verbal communication and interaction, such as difficulties understanding and producing words and sentences (Tsantali et al., 2013). Thus, the ability to initiate and maintain interactions with other people declines as dementia progresses (Evans et al., 2007). Eventually, these problems may lead to the inability to use speech and language (Ellis & Astell, 2017). Increasing challenges in language and interaction create social deprivation and reduce the quality of life for people with dementia and their caregivers (Saunders et al., 2011). Reduced social participation is associated with the risk of dementia (Rafnsson et al., 2020). Consequently, the need for social support among people with dementia increases.

Interaction in one's own language is particularly important for Deaf [1] people with dementia using Sign Language (SL) (Parker et al., 2010). Unfortunately, little scientific attention has been paid to (a) the community, and (b) the similarities and differences between those who can hear and those who cannot. The few studies conducted on Deaf people with dementia have highlighted the linguistic challenges that interfere with interaction, such as difficulties finding signs and challenges in comprehension (Rantapää & Pekkala, 2016). Additional difficulties include

impaired repetition and naming, a reduced ability to produce and comprehend fingerspelled words, and a tendency to produce short simple sentences (Falchook et al., 2013). To our knowledge, no research exists on social support for Deaf people with dementia. This qualitative study explores the supportive strategies formal caregivers use when interacting with Deaf people with dementia.

Social support for people with dementia in the Deaf community

In this study, we define deafness not by the loss of hearing but through language. In Finland, approximately 4000–5000 people out of a total population of 5.5 million are Deaf Finnish Sign Language (hereafter FiSL) users. Most older FiSL users in Finland attended governmental boarding schools for the deaf. From the late 19th century to the 1970's the students were taught orally, and the schools concentrated strongly on teaching the deaf children to speak (Salmi & Laakso, 2005). Using FiSL was forbidden, and children were even physically punished if teachers found them using FiSL. However, as the younger children lived together with older children in the dormitories, they learnt FiSL informally. Those who used FiSL were stigmatized. The older Deaf people still tend to speak rather than sign to hearing people.

There is no statistical information on Deaf people with dementia in Finland. When Deaf people develop dementia, the time from the first signs to diagnosis, treatment and support may be long (Young et al., 2016). They face challenges, as care in SL is uncommon, and the options of nursing homes that use SL are limited (Parker et al., 2010; Rogers et al., 2018). Communicative isolation and deprivation of social stimulation decrease the interaction skills of Deaf people with dementia, which inevitably has a negative impact on their quality of life (Parker et al., 2010). The specific challenges that the Deaf individuals with dementia face are, for example, the lack of common language with their caregivers or the use of sign language interpreters with doctors and nurses when diagnosing. This may result in misunderstandings and misinterpretations. In Finland, there is a shortage of nursing homes or communal care units where Deaf individuals with dementia receive care in FiSL and live with their peers.

The focus in dementia research has evolved from language deficits caused by dementia to pragmatic interaction challenges (D. Jones, 2015). These challenges not only hinder the interaction partners' comprehension of each other; they are also sources of various emotional reactions to interaction. Kitwood's (1997) person-centered communication approach recognizes an individual as someone who responds to another's feelings, preferences and needs. A person-centered approach to care involves positive interaction that consists of five key elements: recognition, negotiation, validation, collaboration, and facilitation (Ryan et al., 2005). This study is interested in how support is communicated, i.e., which behaviors caregivers use as their supportive strategies in interaction with the Deaf people with dementia.

Supportive interaction, the process of exchanging messages to seek and provide support, is complex (Virtanen, 2015). For example, S. Jones (2011) has described supportive interactions as something during which the support-giver listens, interprets and emotionally engages while verbally and nonverbally responding to the emotions of the support-seeker. In the context of living with dementia, we focus on coping with the illness with the support of another, a formal caregiver. According to Barbee and Cunningham (1995, p. 386), 'interactive coping' is defined as 'a dynamic behavioral process in which one individual responds verbally and nonverbally, in either helpful or unhelpful ways, to another individual's problem or emotion.' In other words, not all attempts at support meet the coping needs of the recipient. 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, 2009).

Methods

Research objective

This qualitative study examines the supportive interaction between formal caregivers and Deaf people with dementia (hereafter Deaf participants). First, the study asks what type of support needs do Deaf participants communicate to caregivers? Second, what type of support do formal caregivers provide for Deaf participants in response to their needs? Third, how do Deaf participants respond to the support provided?

Data and participants

In Finland, there are five Homes for the Deaf with various special needs, and in three of the Homes some residents have dementia. The authors co-operated with one of these Homes. The authors set the following criteria for participation: being a Deaf sign language user with symptoms of dementia but diagnosis was not compulsory. The head of staff considered eight possible Deaf participants based on the criteria.

Next, an information sheet about the research along with a consent form were sent to those six individuals who had a family member as a trustee. The last two candidates were approached by the first author during her two-month participant observation period. The first author spent the first two weeks getting to know the residents and the staff. Upon the arrival, only one written consent had been returned. A reminder letter was sent to the family members of the candidate participants. One family member did not reply and one individual refused to participate. Initially, six written consents were returned. Before the data collection, the Deaf participants were always asked about their willingness to participate. After one of the six participants withdrew, five Deaf individuals with dementia participated in this study.

Twelve caregivers worked in the Home where the study took place, and they were all welcome to participate. Three declined the request. The formal caregivers were approximately 20–50 years of age and had been working at the Home from under three months to over 20 years. The participants were informed that the participation was voluntary, anonymous, and confidential, and that they could withdraw from the study at any time without consequences.

Finally, 21 interactions were videoed. ELAN-software was used for handling the data. The five Deaf participants interacted with nine formal caregivers (from here on CG1–9) one-on-one, for approximately 15 minutes per each interaction. The data amounted to 5 hours and 25 minutes. The video-recordings were transcribed in detail in Finnish amounting to 106 pages (single-spaced, font Times New Roman, size 12). All identifiable information such as names, locations, specific ages, and detailed diagnosis were removed. The first author conducted the analysis. Data saturation was controlled during the data collection to guarantee the sufficiency of the data.

Table 1 shows the demographics of the Deaf participants (pseudonyms Ann, Elsa, Inga, Rose and Sue) and a summary of interaction topics which covered a wide range of topics from childhood to the present day. All the Deaf participants were over 80 years of age, and clinically diagnosed with Alzheimer's Dementia (AD). Some also had other diagnoses which affected their FiSL when, for example, they produced hand shapes.

Analysis

Triangulation (e.g., Moon, 2019) was used in the data analysis. The study applied both inductive content analysis (Elo & Kyngäs, 2008) and the Interactive Coping Behavior Coding System (ICBCS, see Table 2) (Barbee & Cunningham, 1995, pp. 381–413). ICBCS (Barbee & Cunningham, 1995) was chosen as it is one of the most comprehensive coding schemes on social support strategies, and has been used in studies of supportive communication (e.g., Virtanen et al., 2014). First, the transcripts were read repeatedly to become familiar with the data and to reduce the units of analysis. The

Table 1. Demographics of Deaf participants and Topics of Conversations.

DEMOGRAPHICS	TOPICS OF CONVERSATIONS				
SUE	CG1	CG3	CG4	CG6	
Late eighties	Childhood	Knee	Birthday	Potted flower	
Alzheimer's Disease,	Birthday	Photos	Country life	Winter	
Other diagnosis	Baking	Nails	Christmas	Birthday	
ELSA	CG1	CG3	CG4	CG6	
Mid-eighties	Childhood	Grandchildren	Life history	Grandchildren	
Alzheimer's Disease	Jobs	WW2	Christmas	Flowers	
	Knitting	Schooltime	Grandchildren	Husband	
ANN	CG2	CG5	CG7	CG9	
Early eighties	Room furniture	Hairdresser	Work	Husband	
Alzheimer's Disease	Chores	Christmas	Husband	Chores	
	Husband	Farm life memories	Schooltime	Room	
INGA	CG1	CG4	CG7	CG8	
Early nineties	Childhood	Daughter	Age	Autumn	
Alzheimer's Disease	Family	Age	Photos	Walking	
	Siblings	Dementia	Family	The Home	
ROSE	CG1	CG3	CG4	CG6	CG7
Early eighties	Life before the Home	Occupation	Christmas baking	Walking	Childhood
Alzheimer's Disease, Other diagnosis	Hobbies	Family	Childhood	Occupation	School
	Sauna	The Home	Pets	Favorite food	Bakery

Table 2. Interactive Coping Behavior Coding System (ICBCS) (Barbee & Cunningham, 1995).

	Approach	Avoidance
Problem-focused	Solve Behaviors: • Asks questions to get more information • Gives perspective, reframes situation, provides insight, clarifies event • Makes suggestions on how to solve the problem, suggests resources, recommends help • Gives information to solve problem, explains how situation can be changed, looks for solutions • Does something active or physical to help, offers help	Dismiss Behaviors: • Avoids problem • Shows disinterest • Criticizes • Minimizes • Sarcasm • Pollyanna, feigns to look on the bright side
Emotion-focused	Solace Behaviors: • Affection, hugs, touches on the shoulders, verbal affection • Shows understanding, makes emphatic remarks ("uh-uh, ooh") • Compliments the conversation partner's looks/abilities • Is available, leans forward, does not interrupt • Reassures, tells them that they are a good person • Shows shock/sorrow at hearing the problem • Agrees • Lifts mood • Offers confidentiality • Addresses feelings, asks how they feel	Escape Behaviors: • Avoids verbally • Distracts, turns on TV, ignores • Nonverbal escape, avoids eye contact • Encourages escape, changes activity • Aggressive joke, makes fun of conversation partner • Shows irritation • Is mean • Suppresses emotion

analysis of the transcribed interaction followed the process of inductive content analysis described by Elo and Kyngäs (2008). The units that were selected were interaction sequences in which a distinguishable topic was discussed. For example, one participant expressed her need for a new carpet and the caregiver responded. A total of 479 sequences were found, and they varied from two to multiple turns. The sequences were then examined and broken down to the dyadic partners' utterances. An utterance was defined as a reaction that had an independent meaning. A total of 1936 utterances were found. They were first coded openly, and then condensed and placed in categories with similar codes. Lastly, the codes were grouped into main categories (see Appendix for an example).

Table 3. Process Analysis of ICBCS (Barbee & Cunningham, 1995).

Utterance from Deaf participant	Utterance from CG	Code/Code Group	Supportive strategy
(nods) Yes. I don't remember anything.	Yes, but before then, when you lived in [name of town], what did you do?	Question/Solve Behavior	Interaction maintenance support
I meet people here.	Yes. How do you feel about going to that Singing with signs-group?	Feelings	Emotional support
I also need some toilet paper.	You get it from here [nursing home], you don't have to buy it yourself.	Solution/Solve Behavior	Informational support
Sauna would be nice too.	I'll have to tell [responsible CG's name] that you'd like to go to sauna. It can be arranged.	Tangible	Instrumental support
I used to remember well but now that I'm [age] I can't anymore.	Let's count how old you are. What month you were born?	Suggestion +Question	Memory support

Following the inductive content analysis, the caregiver's communicative behavior was further analyzed using ICBCS (see Table 3). Each utterance was assigned a code from ICBCS. These codes were assigned in relation to the interactional sequences in which they were uttered and interpreted, based on which expression of need they followed and what the utterance accomplished in the sequence. For example, 'Would you like me to paint your nails?' was coded as Suggestion, one of the problem-focused approach behaviors of the Solve category in ICBCS. After careful analysis, the coded utterances were tested in their respective categories, and recoded if needed. Eighteen of the 28 categories in ICBCS were utilized.

Finally, the codes were examined in their sequential context, which indicated supportive strategies. In the example above, the caregiver showed readiness to help the Deaf participant in a tangible way, and consequently, Suggestion was classified as Instrumental support. Five strategies were distinguished: (1) interaction maintenance, (2) emotional support, (3) instrumental support, (4) informational support, and (5) memory support.

Results

Supportive strategies used by caregivers

The interactions revealed that the caregivers communicated support in several ways. The Deaf participants seemed happy to interact with the caregivers but they rarely introduced a new topic. Therefore, the caregivers attempted to maintain the interaction by asking questions when the Deaf participants took no initiative. When the caregivers tolerated more silence, the Deaf participants began to disclose their emotional needs such as memories or sadness about aging. The dyads discussed the everyday life at the Home, and some practical needs emerged. The Deaf participants needed information on, for example, the services provided at the Home. The data showed that the Deaf participants were not always aware of time and could not remember all the details discussed during the interaction. To support them, the caregivers used different strategies, which we discuss next.

Interaction maintenance

The most common behaviors used to maintain interaction were problem-focused solve behaviors. The caregivers asked questions to determine the cause of the problem and to gain perspective by providing insights into the situation when the Deaf participants struggled to answer. They also made suggestions and offered the Deaf participants information to solve problems. However, on occasion the caregivers used dismiss behaviors to avoid the problem. Such behaviors were, for example, changing the subject, minimizing, or feigning sympathy by being overly optimistic.

First, when initiating the interaction, the caregivers typically asked wide-ranging, open-ended questions. When they did not get an answer, the caregivers specified their questions to which they finally got answers.

Second, the caregivers supported interaction by asking the Deaf participants' opinions and how they felt about something, such as whether they preferred winter to summer. For example, a caregiver named a reason why the Deaf participant preferred summer and supported them when they talked about their fear of winter. Some caregivers paraphrased in FiSL what the Deaf participants had expressed.

Third, the caregivers supported interaction by using visual props (photos) or shifting a topic about the past to one in the present. When the interaction slowed down, the caregivers pointed at photos in the room to discuss them. The Deaf participants seemed happy to converse about the people in the photos and often started to share some memories. When the Deaf participants seemed to repeat their memories, the caregivers introduced a topic of the present. During the interaction, the caregivers used relational knowledge when they asked about the Deaf participant's life history and about living at the Home. The caregivers asked about wishes and preferences, what the Deaf participant had done during the day, and what they wanted to do. Many of the interactions followed a chronological life story.

The Deaf participants participated in the interaction both verbally and nonverbally, by answering questions, initiating new topics, changing subjects, ignoring, smiling, laughing and touching the caregiver. Their answers to questions varied from short one-word or signed replies, nodds or head-shakings to long narratives about their youth. Sometimes the Deaf participants dismissed the question or changed the topic.

Reciprocal comprehension difficulties led to unsuccessful sequences. The caregivers did not under-stand some of the Deaf participants' signs most likely because of other diagnoses that made their hand shapes and fingerspelling unclear. Some of the Deaf used their voice along with FiSL and sometimes spoke words in Finnish with or without signing. Ann tended to repeat stories. Rose answered questions briefly, often using speech without FiSL or without voice, even when she was repeatedly requested to sign. Inga, on the other hand, used FiSL with speech, and repeatedly talked about death and dying. Most of the caregivers were not native signers, which caused occasional difficulties of understanding. Similarities between certain signs also caused misunderstandings and resulted in prolonged pauses, which discontinued some sequences.

In Example 1, Sue talks to CG4 about her childhood in the countryside. Sue felt lonely when no one else signed and all others talked. CG4 misinterpreted the signs SIGN as WORK and BABBLE as CHICKEN (words in capital letters refer here to the signs in FiSL).

Example 1.
   Sue: Nobody could SIGN in the country.
  CG4: No, it's true, there's no WORK in the country.
   Sue: They just opened their mouths, talked, BABBLED.
  CG4: No CHICKEN, no.
   Sue: Yes, they did talk.
  CG4: Was there? Mm. Yes. (3.0) Now everything's changed.
   Sue: Yes.
  CG4: All the machinery does everything, you don't have to do it yourself.

Emotional support

The most common emotional support strategies were emotion-focused solace behaviors. The care-givers used alleviation of stress, comfort, interactional warmth, and humor with laughter. The function of emotional support was typically to help the Deaf participants express their opinions. The caregivers

who were native in FiSL used fluent FiSL and often repeated what the Deaf participants signed. For example, CG7 made Ann's memories positive by saying 'It was nice when . . . ' and smiled to indicate that her intent was positive.

The caregivers communicated alleviation of stress by focusing on the positive in the Deaf participants' situation and used solve behaviors such as giving perspective. For example, Inga repeatedly said that she had dementia and could not remember. CG4 supported Inga by focusing on her current capabilities. The caregivers also supported the Deaf participants by reassuring them when they expressed longing for their families or former homes. When they received emotional support, some Deaf participants showed satisfaction by nodding or smiling.

Comfort was communicated with empathy and touch. For example, Sue had a chronic illness which caused a great deal of pain. The caregivers communicated empathy when they noticed the pain, and CG1 even touched Sue's knee. Interactional warmth was also communicated verbally and nonverbally. When the Deaf participants talked about their memories or opinions, the caregivers showed empathy and encouragement with verbal comments, such as complimenting the Deaf participants. For example, the caregivers praised the Deaf participants for keeping healthy, fit, and being hardworking.

Example 2.
    CG9: you do the dishes diligently
    Ann: *((smiles and touches CG's arm))*
    CG9: *((touches Ann's arm))*
    Ann: nice
    CG9: *((nods))* it's nice (2.0) do you like doing the dishes?
    Ann: *((nods))* yes I used to always do it a bit like work *((grins))* but it's nice to dosomething
    CG9: you keep fit
    Ann: good

The caregivers also communicated emotional support through humor and laughter. The Deaf participants had vivid memories of their youth and meeting their spouses for the first time. Such memories revived positive nonverbal reactions, such as smiles and laughter. Humor was used when talking about sign names that had a humoristic history or appeared to be funny. A sign name is a sign used when referring to a person instead of fingerspelling the name.

Equality was communicated when the caregivers actively listened to the Deaf participants and elaborated on the Deaf participants' turns. The features typical to such successful sequences involved the dyads sitting face-to-face, listening in an active manner, and tolerating silence in the interaction. Equality was also communicated as reciprocity in self-disclosure when the caregivers told the participant something about themselves instead of only asking questions.

However, when the caregivers minimized or were over-optimistic, the Deaf participants communicated dissatisfaction. For example, when the caregivers did not communicate empathy and instead used dismiss behaviors, saying things such as 'well, everybody gets old' or 'you don't have to remember everything', the Deaf participants responded with experiential authority: 'You'll be the same later.'

Instrumental support

Instrumental support was mostly communicated using problem-focused solve behaviors. Instrumental support was expressed practically by doing something for someone, whereby the caregivers made concrete suggestions regarding actions. For example, Sue had a potted plant which was no longer blooming. CG6 offered to throw the plant away, to which Sue agreed.

When the caregivers communicated instrumental support by offering help or promising to organize something for the Deaf participant, such strategies were met with happy, satisfied smiles or responses. The Deaf participants became excited and positive about the near future when they realized something nice would happen or that they would get the help they needed.

Informational support

Informational support was also communicated using problem-focused solve behaviors, of which the most common were asking questions, giving information and perspectives, and making suggestions as to how to solve the problem. Typically, the information consisted of the date, the weather, upcoming events, and the services offered at the Home. When the Deaf participants were reminded of their relatives' visits, the interaction became positive. For example, when Ann expressed that she wanted a new carpet, CG2 informed her that her son was aware of it.

The advice the caregivers gave to the Deaf participants consisted of suggestions such as 'ask a caregiver to walk with you' or 'ask for more help.' The caregivers also offered to inform other caregivers about the Deaf participants' wishes, such as going to sauna.

Caregivers provided informational support by making suggestions to solve a problem, which is shown in the interaction between CG7 and Inga when they discussed Inga's age:

Example 3.
    CG7: Let's count how old you are. What month were you born?
    Inga: [year].
    CG7: Yes, but what month?
    Inga: [month]
    CG7: In [month], so last [month] you've turned, now it's 2016, so it means that you turned [age].

When the caregivers gave informational support, the Deaf participants appeared grateful and satisfied with their responses but if the caregivers simultaneously pointed out that the Deaf participants should know something that had been discussed before, they appeared confused, annoyed or changed the subject. However, some Deaf participants responded by saying: 'Well, you may have said it, but I've forgotten.'

Memory support

The Deaf participants had difficulties remembering recent events, as well as some details about the past. The caregivers' most common strategies for supporting the Deaf participants' memory were problem-focused solve behaviors: asking questions, probing with options, and providing verbal clues. When talking about the past appeared challenging for the Deaf participants, the caregivers addressed the photos in the room and led the conversation to the present. The caregivers provided the Deaf participants with verbal clues when they did not remember what had happened. Verbal clues seemed to help the Deaf participants to remember details, such as names of their family members.

The Deaf participants were not fully oriented to time and place, so the caregivers supported their memory by offering information about the date, month and year. The Deaf participants' repetition seemed to trigger dismissing behaviors among the caregivers. The Deaf participants tended to repeat their childhood memories, complain about pain and loneliness, or even expressed a wish to die. The caregivers first listened empathetically but later showed disinterest or changed the topic in an attempt to move the interaction forward.

Discussion

This study examined supportive interaction between formal caregivers and Deaf people coping with dementia. The supportive strategies that the caregivers used were interaction maintenance, emotional support, instrumental support, informational support, and memory support. The results show that formal caregivers are often responsible for maintaining interaction. When doing so, we advise considering (1) topic selection and (2) emotion regulation.

The topics of the interaction were predominantly chosen by the caregivers instead of letting the Deaf individuals make the initiative. Similar findings have been made concerning family members, who tend to increase their role in initiating conversation with their Deaf parent with dementia (Rantapää & Pekkala, 2016). The caregivers asked the Deaf individuals many questions about their childhood, family, and other memories. Questions were posed particularly when the Deaf individuals showed little or no initiative (see also a study on hearing people with dementia by Söderlund et al., 2016). Some of the topics were familiar to the caregivers as they had a shared history at the Home. Yet they often seemed to expect the Deaf individuals to have preserved episodic memory capabilities and to be able to tell the caregivers what they expected to hear. When the caregivers asked numerous questions about the Deaf individuals' pasts, the interaction failed. Thus, asking specific questions from a person with dementia with a declining episodic memory is problematic and unsupportive (see also Seixas-Lima et al., 2020).

There were several ways that the caregivers used to regulate the Deaf individuals' emotions. Interaction maintenance, emotional support and memory support were the most common strategies. According to Kitwood (1997), caring for people living with dementia requires closeness and warmth, which in turn may create interpersonal relationships. The results showed that when the caregivers provided emotional support it was communicated with empathy and being actively present: They listened carefully to what the Deaf individuals had to say and were polite and reciprocal. Furthermore, the tone of the interaction was warm and the pace was calm. The solace strategies (Barbee & Cunningham, 1995; Virtanen et al., 2014) and person-centeredness (Burleson, 2009) are considered sensitive and effective means of providing emotional support to a person.

Listening is communicated both verbally and nonverbally both with the hearing and the Deaf people. Bodie et al. (2013, p. 46) define supportive listeners as 'other-focused, involved, friendly, understanding, and engaged in appropriate verbal responding.' The aim of listening during supportive interaction is to understand how others feel to facilitate emotional connection. It can be achieved with active-empathic listening (AEL) – the acts of sensing, processing, and responding (Gearhart & Bodie, 2011). Gazes, smiles, direct body orientation, hugs, and comfort-providing touch create nonverbal immediacy (Bodie & Jones, 2012). In this study, the participants sat close or facing each other, smiled from time to time, and occasionally touched one another. Nonverbal immediacy is a meaningful, supportive interaction strategy because it can result in positive impact, increased liking, connection, interpersonal intimacy, and feelings of being cared for and loved (S. Jones, 2004).

This study shows that the caregiver's use of positive feedback can facilitate engagement and topic maintenance during interaction (also Dijkstra et al., 2002), and it can even be utilized during the later stages of dementia. The caregivers in this study helped the Deaf individuals remember their close relationships by, for example, talking about photos of their family members. The particular communicative strategy added positivity to the interaction.

This study suggests that caregivers can establish relationships with people with moderate to severe dementia by taking the initiative and showing people with dementia that the caregivers have time for them (also Ericsson et al., 2011). Another way to strengthen a relationship is to make people with dementia feel secure and equal during interaction, which can help them share their experience and build trust. This can be achieved with physical proximity of the Deaf individuals and caregivers, friendly gestures, and compliments instead of frequent questions. According to our study, successful interaction is a shared experience of a calm and pleasant atmosphere and the dyadic partners appearing equal. Such interactions seemed to produce positive feelings in both the Deaf individuals and the caregivers.

The Deaf individuals responded to the support provided by the caregivers in various positive ways. For example, they smiled and showed excitement. Thus, giving time and listening actively to the Deaf individual seems to help the caregiver comprehend their needs and to create reciprocal interaction, as well as to provide the right support for coping.

The results showed that unsuccessful sequences between dyads emerged when Deaf individuals repeated themselves or brought up difficult or unpleasant topics. Dismissing feelings or redirecting the Deaf person's attention from sad events to the present, for example, the weather, were unempathetic.

Talking about one's past can bring back sad memories. The Deaf individuals expressed their longing for family and home, and they were sad about their deteriorating health. They showed the ability to experience and nonverbally express diverse needs and feelings, which appear to remain even in the later stages of dementia (Bucks & Radford, 2004). When the caregivers dismiss the Deaf individuals' needs, the communication lacks person-centeredness. The caregivers' dismissive behaviors were changing the topic, minimizing, feigning sympathy, or over-optimistic. Following Burleson's (e.g., Burleson, 2009) person-centered approach to supportive communication, a caregiver with high person-centeredness would recognize and validate the person's feelings and would help them express those emotions. A support provider with a person-centered approach also discusses the reasons for the particular feelings and helps the other see the issue in a broader context. The challenge lies in the latter: What is the context – time, place, relationship – that can be utilized for supportive purposes in the everyday experience of dementia?

The impact that dementia has on the interaction skills of Deaf people with dementia (Parker et al., 2010; Rantapää & Pekkala, 2016) challenges their interaction partners. The results showed that the dyads sometimes had difficulties understanding each other. Most caregivers were novice non-native signers of FiSL. However, a person's language skills do not necessarily correlate with unsupportive interaction with Deaf people with dementia. Along with the ability to use FiSL, an equally important factor is the caregiver's communication competence, which in this study was shown by the caregivers and the Deaf individuals reciprocal self-disclosure.

As regards to the Deaf individuals, they were older adults who had gone to school during an era when it was important to learn to speak Finnish. At times it was challenging for the caregivers to comprehend the Deaf people when they spoke without signing. Sometimes the caregivers were unsure if they had understood their message. The caregivers responded by asking the Deaf person to repeat, sign or confirm that they had comprehended correctly. Caregivers who are novice FiSL signers understandably have not mastered profound interaction with elderly Deaf people with dementia. Unsuccessful interaction sequences involving misunderstandings and the caregivers dismissing the Deaf individuals' support needs suggest that caregivers could benefit not only from further FiSL training but also from comprehensive education on Deaf people with dementia.

Strengths, limitations, and future directions

This study is one of the first to explore supportive interaction between formal caregivers and Deaf people with dementia. The data consisted of 21 video-recordings, which was considered sufficient for the study's purposes. The data were collected and initially analyzed by the first author. She is a registered nurse and native in FiSL, which increases the reliability of authentic insight. Although insight may cause bias (Ashton, 2014), using a video camera rather than participant observation assisted in maintaining neutrality. To our knowledge, no other research has applied the ICBCS to analyze the interaction of Deaf people with dementia and their caregivers. ICBCS was purposeful for the study, since it allowed a systematic and transparent analysis. To account for the limitations of structured approaches, we applied inductive content analysis for the data as well. We encourage researchers to develop a method, which encaptures the specific features of interactions in Sign Languages for future research.

The authors have expertise in the field of dementia, supportive interaction, and qualitative content analysis. Multidisciplinary collaboration of authors helped challenge and minimize bias, as all the authors participated in the analysis and debated the results. The analysis was carefully conducted along the guidelines for content analysis by Elo and Kyngäs (2008), and issues of trustworthiness were considered according to the criteria of Graneheim and Lundman (2004). To achieve credibility, dependability and transferability, careful steps were taken throughout the research process.

Formal caregivers face many challenges in their work with people with dementia, and benefit from education which uses monitoring of one's work as a training method. More research is needed to investigate video-recorded interactions between Deaf people with dementia and their caregivers to increase the knowledge specific to Deaf people and their social support needs. Video recordings authenticate both successful and unsuccessful SL interactions, which should be analyzed and practiced for functional supportive interaction with Deaf people with dementia. In addition to video-recordings, mixed methods approaches could be implemented to investigate more comprehensively the interaction between Deaf people with dementia and their caregivers. Above all, more education – and research-based education – is needed as well as continuous FiSL training. The caregivers need education on interaction in general and on the effects of dementia and other diagnosis on interaction in sign language.

Practical implications for formal caregivers and nursing home staff

(1) Learn to know the individual living with dementia by also reciprocating self-disclosure.
(2) Communicate calmly and with open posture, gestures and facial expressions such as smiles.
(3) Do not rush to fill the silence during the interaction.
(4) Listen actively to the individual with dementia.
(5) Elaborate on the topic the individual with dementia initiates.
(6) Make use of photos and other personal items in conversation.
(7) Gather more knowledge about dementia and how to support people with dementia.
(8) Use the language the individual with dementia prefers, e.g., Sign Language, with a Deaf individual.

Note

1. 'Deaf with a capital 'D' refers to people identified with the Deaf Community, a minority with its own language and culture (Sheppard & Badger, 2010) and 'deaf' refers to people with a hearing loss. 'Sign Language' with initial capital letters refers to various national languages, and 'sign language' in lower-case initial letters refers to sign languages in general. Sign languages (SL) are visuo-spatial languages that are produced using the hands and body and received by vision. (Fischer & van der Hulst, 2011).

Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethical consideration

This research carefully followed the appropriate ethical research conduct proposed in the Declaration of Helsinki (World Medical Association, 2013). The study was approved by the University of Helsinki Ethical review board of the Humanities and Social and Behavioral Sciences (30/2016).

ORCID

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

References

American Psychiatric Association. (2013). *American psychiatric association: Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C. : American Psychiatric Association

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

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* (Vol. 18, p. 381–413). Sage.

Bodie, G., & Jones, S. (2012). The nature of supportive listening II: The role of verbal person centeredness and nonverbal immediacy. *Western Journal of Communication*, 76(3), 250–269. https://doi.org/10.1080/10570314.2011.651255

Bodie, G., Vickery, A., & Gearhart, C. (2013). The nature of supportive listening, I: Exploring the relation between supportive listeners and supportive people. *International Journal of Listening*, 27(1), 39–49. https://doi.org/10.1080/10904018.2013.732408

Bucks, R. S., & Radford, S. A. (2004). Emotion processing in Alzheimer's disease. *Aging & Mental Health*, 8(3), 222–232. https://doi.org/10.1080/13607860410001669750

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

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), 101113. https://doi.org/10.1016/j.csl.2020.101113

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

Ellis, M., & Astell, A. (2017). Communicating with people living with dementia who are nonverbal: The creation of adaptive interaction. *PLoS ONE*, 12(8), e0180395–e0180395. https://doi.org/10.1371/journal.pone.018039

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

Ericsson, I., Kjellström, S., & Hellström, I. (2011). Creating relationships with persons with moderate to severe dementia. *Dementia*, 12(1), 63–79. https://doi.org/10.1177/1471301211418161

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

Fischer, S. D., & van der Hulst, H. (2011). Sign language structures. In *The Oxford handbook of Deaf studies, language, and education* (Vol. 1, 2nd ed.), 336–47. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199750986.013.0024

Gearhart, C. G., & Bodie, G. D. (2011). Active-empathic listening as a general social skill: Evidence from bivariate and canonical correlations. *Communication Reports*, 24(2), 86–98. https://doi.org/10.1080/08934215.2011.610731

Graneheim, U., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

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. (2004). Putting the person into person-centered and immediate emotional support: Emotional change and perceived helper competence as outcomes of comforting in helping situations. *Communication Research*, 31(3), 338–360. https://doi.org/10.1177/0093650204263436

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

Kitwood, T. (1997). *Dementia reconsidered*. Open University Press.

Moon, M. (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

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

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

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

Rogers, K., Rogers, K., Ferguson-Coleman, E., Ferguson-Coleman, E., Young, A., & Young, A. (2018). 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

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

Salmi, E., & Laakso, M. (2005). *Maahan lämpimään. Suomen viittomakielisten historia*. Kuurojen Liitto ry. [To the land of warmth. History of the Deaf in Finland. Helsinki, the Finnish Association of the Deaf.].

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

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

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., 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

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

Virtanen, I. (2015). *Supportive communication in Finnish men's friendships*. Tampere University Press.

Virtanen, I. A., Isotalus, P., & Keaton, S. A. (2014). "Offer no readymade solutions": Men's support provision in specific episodes with an upset friend. *Studies in Communication Sciences*, 14(1), 54–60. https://doi.org/10.1016/j.scoms.2014.03.010

World Medical Association. (2013). Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Journal of American Medical Association*, 310(20), 2191–2194. https://doi.org/10.1001/jama.2013.281053

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

Appendix

Example of Process of Inductive Content Analysis (Elo & Kyngäs, 2008)

Sequences	Categories of Deaf participant's expression / reaction	Categories of CG's expression / reaction	Outcome / Abstraction
CG1: What did you buy on board?		Question	Memory support Successful Equality
Sue: I don't know. I've forgotten. I can't remember anymore.	Answer		
CG1: Candies? *(smiles)*		Suggestion/Smile	
Sue: Well, candies *(with a laugh)*. Two choc bars I bought, I wanted to. One for me, one for you.	Answer Laughter		
Ann: I've been waiting for my son to come. I'd like a carpet on the floor. I need one.	Instrumental need		
CG2: Yes, your son, last time he visited here I met him and he said he'd get one.		Gives information	Informational support Successful
Ann: That's nice. It'd be nice to have the same colors on all the carpets. I'd be happy.	Pleased Expressing feelings		
CG2: What color would you like?		Question	
CG8: Have you been outside for a walk around the Home?		Question	
Inga: No, I haven't.	Answer		
CG8: You haven't?		Parrot	

(Continued)

(Continued).

Inga: I'd like to yes. I've always walked around the Home.	Expressing feelings		
CG8: You should ask some cg to walk with you because [daughter's name] is afraid that you might fall.		Advice/Perspective	Instrumental support
Inga: *(laughs)* That's nice. Do you know her?	Laughter/Expressing feelings/Question		
CG8: [daughter's sign name]? Sure I know her. I've met her many times.		Answer	Informational support
CG4: Do you like warmth?		Question	
Rose: Yes.	Answer		
CG4: I myself enjoy the cold. I enjoy the cold winter.		Talks about herself	Equality Successful
Rose: Yes.			
CG4: But you freeze. *(laughs)*		Humor	
Rose: *(nods)*			
CG4: You're a cold-sensitive cat.			
Rose: Yes.	Agrees with CG		
CG6: It'll be Christmas soon. Do you like Christmas?		Gives information about time / Asks about feelings	
Elsa: Is it November now?	Question		
CG6: It's November now.			Informational support
Elsa: And then it'll be December. My sons always come with their families but I don't have the strength to organize Christmas.	Talks about her family traditions		
CG6: You don't have to.		Reassures Shows understanding	Emotional support
Elsa: Yes, [son's name] or [other son's name] can organize our Christmas party. We'll be together.			
CG1: Do you like any hobbies?		Question	Unsuccessful CG points out Deaf person with dementia's disorientation
Elsa: I'll knit some socks ready for Christmas presents for the children.	Answer		
CG1: Well, have you knitted already?		Question	
Elsa: Not yet, later. Not yet in the summer, but then in August I'll start.	Answer		
CG1: Well listen, it's already November.		Gives information about time	
Elsa: Yes, in August I'll start little by little, not yet. Yes November, Nov-, December.	Gets confused about time		
CG1: Yes.			
Elsa: Well, what are you doing?	Changing topic		
CG1: You're still up to knitting?			
Elsa: What do you do for work?	Changing topic		
CG1: I work here.		Answer	