Between body and mind:
diagnosing and caring for deaf people with dementia

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For
Thea and Bruni
my two beloved and graceful grandmothers,
who faced dementia with courage and dignity

The motivation

“Das habe ich noch nie vorher versucht.
Also bin ich völlig sicher, dass ich es schaffe.”
Astrid Lindgren

The position

“Our prime purpose in this life is to help others.
And if you can't help them, at least don't hurt them."
Tenzin Gyatso, 14th Dalai Lama

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PROLOGUE

It is the spirit of starting a PhD, combined with my optimistic and ambitious nature, that makes one embark on the journey even without seeing the entire road ahead. It was during my master's program that I took a lecture with Joanna Atkinson, a deaf clinical psychologist, who developed the first sign-language based and novel cognitive screening in the world to detect dementia in deaf individuals, the British Sign Language Screening Tool (BSL-CST). After her class, I did my research on the situation of deaf people with dementia in Germany and found a lack of and call for an appropriate dementia screening in German Sign Language (DGS) to assess deaf sign language users in Germany. This call was open for over ten years, and was based on the SIGMA Project (Kaul et al., 2009). In this project the situation of deaf people in Germany was explored and it was conducted by researchers at the University of Cologne, Anne Gelhardt and Thomas Kaul, - with whom I would work very closely together one year later. While an initial attempt to close this gap was made by a research group, it was concluded that the heterogeneity of DGS and the deaf population posed significant challenges to the success of a novel screening tool.
At that moment, a determined thought rose within me: that a cognitive assessment for DGS signers is possible. I felt a scientific urge and fire burning inside me. I can only describe it with the words of my former professor Renate Fischer. During a student consultation she asked me: "Where is the burning lava?". Was finding a solution and developing or adapting a cognitive assessment for deaf people in Germany the burning lava? Yes, it definitely was. This question became one of my most guiding principles in doing research so far.

In 2017, Jo and I sat down and she advised me to take the BSL-CST to Germany.
The seed was sown.
Back in Germany in 2018, I've met with groups of deaf older people at senior gatherings, talked to active and former caregivers of deaf people, visited a care home for deaf people, and got the chance to spend some time with the residents. A clinical work shadowing experience at the LWL Clinic in Lengerich with Ulrike Gotthardt and Johanna Tuschmann in late 2018 gave me the chance to get an idea of the clinical challenges faced by psychologists, psychiatrists and neurologists in diagnosing, treating and caring for deaf people in Germany.
When I started out, my access point was the gap of a dementia screening tool in DGS. In academia and from clinicians, I was asked whether deaf people show different patterns of dementia-related cognitive impairment than hearing populations because of their deafness. The argument of the auditory deprivation hypothesis is still dominant in the discourse around

deafness and dementia. But apart from small differences in cognitive functions, which can be explained by language exposure and use, according to a small body of research, the deaf brain does not function differently. It is fundamentally important to interpret the cognitive abilities in the context of normative data from deaf populations and not compare them to the hearing population.

What I have learned at Deaf community gatherings, through exchanges with older deaf signers, but what clinicians never asked me about were the differences shaped by the lived experience of being deaf person in a hearing world. Over the course of my PhD, I therefore expanded the scope from focusing only on dementia diagnostics to consider life with a dementia diagnosis and embodied resources to reflect both medical as well as community concerns.

As a hearing person without deaf relatives, I am aware of the outsider perspective and express my deep gratitude to all the deaf people I have met along the way until this day. To be welcomed and shown the needs and challenges of deaf people with and without dementia and allowing me to contribute scientifically to possibly improve the situation, has been a great honor.

LIST OF ABBREVIATIONS

ACE-R	Addenbrooke's Cognitive Examination-Revised
AD	Alzheimer's disease
ASL	American Sign Language
ATEC	Automated Test of Embodied Cognition
BSL-CST	British Sign Language Cognitive Screening Test
BSL-VLMT	BSL-Verbal Learning and Memory Test
DGS	German Sign Language
DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Classification of Diseases
KoDGS	Kognitionstest Deutsche Gebärdensprache
MMSE	Mini Mental Status Examination
MoCA	Montreal Cognitive Assessment
NGT	Sign Language of the Netherlands
WFD	World Federation of the Deaf
WHO	World Health Organization

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SUMMARY

This dissertation explores the question of what is needed to provide better and urgently needed appropriate healthcare to deaf people with dementia. The current healthcare situation of deaf people in general is insufficient and presents with barriers to receive adequate care, with language barriers being the most robust cause. Dementia is one of the biggest health-related challenges and one of the most feared conditions of our time. In the common cognitivist worldview, the loss of reasoning and memory is closely connected to losing one's identity and selfhood. In this framework, dementia is regarded as a threat for which no cure is currently available. An alternative framework is embodied cognition which acknowledges the central role of the body and the environment to shape the mind. In dementia, body-related implicit memory, proposed as body memory, is retained until late stages of dementia. While the explicit and conscious memory and reasoning diminishes, the person themself maintains selfhood. Therapeutic and care practices that include an embodied framework foster well-being and quality of life for people with dementia. This shift in perspective invites to reconsider dementia prevention, diagnostics, therapy, and care.

Detecting dementia at an early stage, increases the options of treatment and support for the person with the diagnosis and their environment. Most Deaf communities do not have access to diagnostic tools that can detect dementia-related cognitive decline and are linguistically and culturally sensitive for deaf people who communicate in their local sign language.

Study 1 presents the first sign-language based cognitive screening tool for deaf signers of German Sign Language (DGS). The novel screening tool, the *KoDGS* (Kognitionstest Deutsche Gebärdensprache) is based on a comprehensive cultural test adaption paradigm that was developed as part of the study. It was normed with 99 participants and showed reliable distinction between cognitively healthy individuals and individuals with a neurological history or an indicative life profile.

In order to ensure reliability of the *KoDGS* test items and control for underlying mechanisms related to memory processing, the sign frequency and sign iconicity of the test items in DGS were investigated. Study 2, therefore, collected subjective rating data for the psycholinguistic measures of frequency and iconicity of more than 300 DGS signs. The data elaborated on the issue of reliability of these measures and cross-checked with existing subjective rating data, and objective measures from DGS corpus data. A large emphasis on collaborative work between deaf and hearing researchers is discussed to stimulate the methodological normative discourse in the field.

Study 3 presents the shift in perspective in dementia care contextualized for the deaf population. Acknowledging the embodied nature of deaf persons, therapeutic and care practices that include the embodied framework provide deaf persons with dementia with a sense of continuity.

The results of all three studies are discussed in the context of bridging theory and practice. Aspects related to reducing current disparities in healthcare for deaf people, the impact of physical, social, and historical environments on deaf individuals (with dementia), and the importance of practitioner awareness are examined. Additionally, memory processes and potential future applications that incorporate the embodied framework into dementia care practices are proposed.

This dissertation argues that appropriate therapeutic and care practices and assessment tools offer a step towards higher-quality, reliable, and culturally and linguistically sensitive healthcare for deaf people.

Methodological aspects are reflected and the role of collaboration discussed. At the end of this dissertation, a phenomenological description of three scenes calls for action on the reviewed insufficient situation of deaf people, before concluding the pooled presented evidence.

1 INTRODUCTION

Dementia is a major challenge of our times. Worldwide approximately 55.2 million people were living with a form of dementia in 2019 (WHO, 2021), with estimated 14.1 million for Europe. Dementia is a condition related to aging, which – with improved life expectancy – has become a matter of growing urgency in the Global North. In a report of the global situation by the World Health Organization (WHO (2017), the global costs for governments, communities, people with dementia and their families were estimated 818 billion U.S. Dollars, and according to the WHO and World Bank, 40 million new jobs in the health and social care sector will be needed globally by 2030.

In Germany in 2023, approximately 1.8 million people were living with dementia, with a yearly increase of around 400,000 people with a diagnosis (Blotenberg et al., 2023). The numbers can be overwhelming with the awareness of currently no available cure. The large numbers, costs and prevalence data call for coordinated action at global, national and local levels, and have been the cause for strategical actions, such as the German national dementia strategy (BMFSFJ & BMG, 2020).

It seems that the economic arguments, e.g., arguments of high costs for economies, jobs and "loss in productivity of economies" (WHO, 2017, p.3), overshadow the quieter and less reflected side of dementia. The personal and interpersonal dimensions of living with dementia or caring for someone with dementia include perspectives proposed and contextualized by Fuchs (2020) and Kontos (2003, 2004, 2005). Their embodied approach to dementia centers the person's bodily lived experience with dementia. The embodiment approach as a theoretical framework, facilitates to see beyond the deficits that arise when focusing only on the brain and cognitive decline in people with dementia like it is understood in the classic cognitivism. The lived experience of the world through the bodily senses impacts the brain and cognition, consequently, it influences constructs like memory. Embodiment, in the context of this work, is the interaction between the brain, the body and the environment (Gallagher, 2005, 2023), with 'environment' referring to the physical, the historical and the social environment of the person living with dementia.

This dissertation adopts a broad approach, requiring adequate awareness of a person's functional deficits to diagnose appropriately, while the person's resources and remaining abilities are acknowledged. Regarding persons with dementia in their environment and from an embodied perspective in their lifeworld (Dzwiza-Ohlsen, 2021), preserves the sense of continuity of self of the person with dementia (Fuchs, 2020; Kontos, 2003, 2004). This way,

neuropsychological assessment meets socio-epistemological consideration of embodied cognition.

The provision of adequate and sufficient healthcare services for persons with dementia in society, communities, and families challenges politics and societies. Especially smaller populations, minoritized in the system, are at risk of receiving less appropriate services and barriers to existing ones. There are globally approximately 430 million people living with some form of "hearing loss" (WHO[1]). Among them is the deaf population, whose language is a sign language, for whom signing is the preferred and most secure mode of communication, and who identify culturally with the Deaf community. This population encompasses worldwide 70 million people (WFD[2]).

In Germany, the total number of estimated 235,000 (Rannefeldt et al., 2023), included people who are deaf and use sign language, who are hard-of-hearing and use spoken language or continue to use speech after their partial loss of hearing, and people with presbycusis, an age-related hearing impairment. Deaf sign language users in Germany, are approximately 80,000 people, but exact numbers are not recorded. Deaf sign language users rely on sign language to communicate, to inform and to be informed, to access healthcare services, to get examined, assessed, diagnosed and treated. Services accessible for deaf sign language users are very limited, which reveals the lack of appropriate healthcare for the underserved population of deaf signers. This situation tightens even more for deaf people living with dementia and their families. This dissertation focuses on the situation of deaf sign language users with dementia and explores the question of what is needed to provide not only better but also urgently required dementia-related healthcare for the deaf population. The focus is particularly on the diagnosis and therapy and care of deaf signers, and has evolved from a Germany-based perspective.

To set the frame, chapter 2 introduces the main constructs of this research, dementia and memory, as well as the theoretical framework, embodiment. This chapter sets the frame and opens the discourse. Chapter 3 then portrays the population of deaf sign language users in old age, presents the current evidence on healthcare services for deaf signers from an international to a Germany-focused perspective, and demonstrates the barriers for deaf people with dementia in obtaining an appropriate diagnosis, therapy and care. Both chapter 2 and 3 are literature reviews that form the basis of the original scientific contributions of this research (chapter 4) and lead to the final discussion (chapter 5).

[1] https://www.who.int/health-topics/hearing-loss#tab=tab_2, accessed 05.09.2025
[2] www.wfdeaf.org, accessed 05.09.2025

With three research papers presented in chapter 4, this dissertation contributes to the field of human sciences in a broader sense.

Study 1 contributes to the field of neuropsychology as a novel neurocognitive screening that has been adapted for users of German Sign Language (DGS) to assess cognitive functions of deaf individuals. The adapted screening KoDGS (Kognitionstest Deutsche Gebärdensprache) is the first sign language-based cognitive screening for dementia in Germany to improve diagnostics. Study 1 also encompasses a step-by-step adaptation paradigm for cultural test adaptions between sign languages which aims to stimulate the scientific discourse.

Study 2 investigates reliability in psycholinguistic norming data of sign iconicity and sign frequency for DGS. Choosing reliable language items in scientific experiments, in clinical settings and test adaptations, such as in study 1, is highly important. Study 2, therefore, contributes to the discourse in psycholinguistic research and broadened the available DGS norming data.

Study 3 takes a theoretical approach of conceptual transfer to reflect the question of what remains in the body of a deaf person when the cognitive control is fading. Zooming in on the remaining abilities of body memory in persons with dementia facilitates ethical considerations and the discussion of dementia care in the deaf population. Study 3 is based on philosophical discourse and re-contextualizes theory of how experiences are stored and retrieved from a type of implicit memory in the context of deaf persons. It proposes the concept of Deaf body memory for deaf people with dementia and discusses the importance of 'intercorporeality' in this context. Implications that are rooted in an embodied, phenomenological perspective on dementia care, are presented to enrich the discussion of ethical dementia care of deaf people.

In chapter 5, the results of Study 1 – 3 are critically discussed in the context of healthcare services for the deaf population. Challenges of the studies are identified and a call for action is presented. In this section, aspects of collaboration in deaf-related fields of research are reflected. The original papers of this dissertation are attached and are referred to as stated.

"Between body and mind", as the title of this dissertation says, is the position of this dissertation within the overall discourse. Approaching dementia only from either one, body or mind, limits the impact of the argument and restricts the possible changes in how society handles the immense challenge of dementia in our times. This research was motivated by bringing human expertise, theoretical constructs and disciplines together in order to offer a complex contribution to a complex challenge.

2 DEMENTIA, MEMORY AND EMBODIMENT

This chapter provides a multidisciplinary review of the literature on the constructs of dementia and memory, considering not only the cognitive perspective, but also embodiment as a conceptual framework. These constructs and the embodied framework set the foundation for the discussion of cognitive assessments, reliable and valid testing, as well as therapy and care for people with dementia.

2.1 Dementia: the challenge

By global average, 80% of the population believed that dementia is a normal part of aging, with 58% believing that an unhealthy lifestyle, and 43% believing that lack of family support are causes of dementia (Alzheimer's Disease International, 2024). Misinformation about dementia is a worldwide challenge and influences how dementia is dealt with. The access point of this dissertation to the discourse is by decoding the label 'dementia' and uncover the symptoms, the detection and possible therapy and care.

Dementia is a Latin term, with its etymological roots 'de' (= lack of) and 'mens' (= mind, ability to think) translating to "without mind", meaning madness or insanity. Over the years, authors have proposed to remove the term, arguing that 'dementia' refers to a syndrome and not a single condition, and thus, the term does not appropriately cover the scope of the syndrome. The current term stigmatizes the complex and heterogeneous conditions that are all under the label 'dementia', and the term itself carries a stigmatizing connotation (Behuniak, 2011; Jellinger, 2010; Sachdev, 2000). In the year 2025, 'dementia' is far from being removed as a term, but academic disciplines have made efforts to broaden the understanding of dementia, such as the anthropology, sociology and epistemology. In this dissertation, the construct dementia refers to the complex conditions, including Alzheimer's Disease, Lewy-Body dementia, frontotemporal dementia, semantic dementia, vascular dementia, primary progressive aphasia. However, Alzheimer's disease (AD) is likely to be overrepresented due to its high prevalence of around 60%-80% among dementia-related conditions ("2024 Alzheimer's Disease Facts and Figures", 2024[3]), the current state of scientific evidence in the literature with a bias on AD, and a focus

[3] No named authors

on memory and memory-related symptoms which are looked at in particular within the scope of this research.

2.1.1 Symptoms

According to the WHO (2017), dementia "is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behavior, and that interfere significantly with a person's ability to maintain the activities of daily living." (p. 2). Depending on the underlying form of dementia, the symptoms vary. In AD, the first symptoms generally show 10 to 20 years after the onset. This preclinical stage is the focus of much research since it indicates a stage in which future treatments may change the outcome of e.g., AD pathology (Braak et al., 2011; Jack et al., 2013; Jessen et al., 2014). Early symptoms of AD are subsequent changes to memory, usually short-term memory. Other symptoms affect spatial and temporal orientation, word-finding difficulties and verbal fluency, as well as visual-spatial and perceptual abilities, such as recognizing and drawing shapes and figures. As the condition progresses, problems with planning and carrying out complex tasks become apparent (see exemplary studies on dementia symptoms: Chen et al., 2019; Cummings et al., 2015; Liou et al., 2020; McKinnon et al., 2008; Reilly et al., 2010; Rohrer et al., 2008; for a recent overview, see "2024 Alzheimer's Disease Facts and Figures"). The retrieval of stored information as memories can no longer be recalled. In the late stages of dementia, language is severely affected, so are short-term and working memory, and even most parts of declarative memory. Compared to symptoms of AD, however, in forms of frontotemporal dementia, semantic dementia and primary progressive aphasia, language disorders or changes in behavior can be reported as early symptoms (Mesulam, 2007; Reilly et al., 2010), while memory remains largely intact (McKinnon et al., 2008).

In addition to cognitive symptoms, people with dementia show changes in personality and behavior over the course of the disease. Agitation, apathy, lack of initiative behavior, irritability and depression have been described as symptoms of every second or third person with dementia (Seidl et al., 2007). Increased frailty, which is associated with old age, becomes evident in the form of increased mental, physical and cognitive vulnerability (Fried et al., 2001).

2.1.2 Diagnosing dementia

Diagnosing a condition that presents as a memory disorder in old age was already known in ancient Egypt (Boller & Forbes, 1998; Signoret & Hauw, 1991). But our modern system to

diagnose psychiatric and mental disorders has been based on the precursor of the International Classification of Diseases (ICD) system (first list of classification from 1893), which became the official classification of the WHO in 1948[4] (WHO, 2025), as well as the Diagnostic and Statistical Manual of Mental Disorders (DSM) (with its first publication in 1952; American Psychiatric Association, 1952).

In the German context, the S3-Guideline 'Dementias', a living guideline published by the German Society of Psychiatry and Psychotherapy, Psychosomatics and Neurology (DGPPN) and the German Society of Neurology (DGN), presents the gold standard to diagnose, treat and care for individuals with dementia in Germany (DGPPN & DGN, 2025). Apart from biomarkers such as blood or liquor diagnostics and brain scans, neuropsychological assessments that focus on cognitive functions are still among the first diagnostic steps to assess an individual who presents with dementia worries or even symptoms. Getting a medical dementia diagnosis, is, despite the challenges, perceived as valuable by 96% of the general public on global average (Alzheimer's Disease International, 2024). Sensitive and specific neuropsychological screening tests (so-called short tests) can be conducted by the GP or in memory clinics to test cognitive performance.

In Germany, the Mini-Mental Status Examination (MMSE) (Folstein et al., 1975), the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) and the DemTect (Kessler et al., 2000) are standard instruments, that can be combined with additional and more function-specific assessments. The initial neurocognitive examination plays an important role in differential diagnosis, ruling out other conditions, such as delirium and clinical depression, and guides follow-up examinations.

2.1.3 Therapy and care: Psychosocial interventions for dementia

The lack of cure and – to this day – very limited treatment, emphasizes the need for sensitive care for the person with dementia, as well as support for the family caregivers. A dementia diagnosis has a destabilizing effect on mental health as a consequence. Knowing that you will have difficulties orienting yourself in the future, consciously remembering and recognizing your friends and family and, ultimately, yourself, is a heavy burden on the psyche. People at an earlier stage of dementia in particular are often very aware of the impact that the progression of the neurodegenerative disease has and will have on their lives (Steeman et al., 2006; Villarejo-Galende et al., 2022).

[4] https://www.who.int/standards/classifications/classification-of-diseases, accessed 01.09.2025

Non-pharmacological forms of treatment, such as psychosocial interventions, can be a valuable resource for empowering those who have been diagnosed with dementia. The S3-Guideline "Dementias" (DGPPN & DGN, 2025), which was developed by experts with the involvement of patient and family representatives, refers to the importance of using psychosocial interventions. Interventions include cognitively stimulating methods, such as cognitive training and biography work, as well as physically activating methods, such as occupational therapy, massages, music and dance therapy. Psychotherapy and the method of validation can support with behavior and emotion regulation (Saragih et al., 2025; Sukhawathanakul et al., 2021). This enables people with dementia to learn how to cope with the changes at an early stage. Teaching coping strategies to relatives is also an important resource in stabilizing the affected person and their environment (Liddle et al., 2012). In Germany, however, in order to be eligible for such psychotherapeutic treatment, a primary diagnosis must be made that is not dementia (G-BA, 2024). As a result, people with dementia must first have an acute psychiatrically relevant illness, such as depression, in order to be approved for psychotherapeutic treatment (Kessler & Tegeler, 2018). This practice runs counter to the S3 guidelines "Dementias", according to which "all applicable psychosocial interventions should be exhausted before a pharmacological intervention is considered" (Kessler & Tegeler, 2018, p. 6).

In addition to the psychosocial treatment spectrum, people with dementia and their relatives in this situation also need sufficient information on the course of the disease, counseling services and self-help groups, as well as on the topic of care. This becomes particularly urgent with 86% of the care in Germany, being provided by family caregivers (Brandt et al., 2025).

As shown, these recommendations for providing appropriate therapy and care to the general population are not easy to implement. These dementia-related services and interventions are regulated and present barriers which may be difficult to overcome, especially, if additional language and cultural barriers are present.

2.1.4 Fearing dementia

The fear around dementia is documented in the World Alzheimer Report 2024 (Alzheimer's Disease International, 2024). The stigma around personally developing dementia and how it affects the search for medical advice and social support is a global issue. Avoiding behavior towards healthcare services can be the result and may worsen insufficient provision of services. In a research report by Alzheimer's Research UK (2023) the health condition that was feared the most, was dementia for 49% (n = 1,232) of their sample. A study within the social sciences investigated fear and anxiety in the context of memory clinics (Swallow & Hillman, 2019).

Their data revealed how the "horror of Alzheimer's" (ibid, p.234) impacted the setting in memory clinics where people were assessed and diagnosed with dementia, family members got informed about the diagnoses, and the clinical staff was required to balance their work between accurate assessment and treatment and work efficiency. Handling this sensitive situation and moment of change for many people asked for special care practices, which were adapted in the moment to adjust for fearful behavior (ibid). The study clearly demonstrated the challenges of providing cognitive assessment in a situation filled with fear and anxiety, and showed the different perspectives of all involved individuals and professional groups. Offering an assessment which may lead to a dementia diagnosis is in itself a highly sensitive act. The fear surrounding the diagnosis can be grasped through associations and comparisons of people with dementia as "the living dead" (Behuniak, 2011). A change so radical, that a person with dementia mutates into a zombie, naturally evokes fear and anxiety. Part of the common perception of this radical change in a person is due to the term, which is even used as a synonym of dementia: memory loss. This piece of research argues that the fear of memory loss is the foundation of the fear surrounding dementia. Changes in orientation, in perception, in circadian rhythm, and even in language do not threaten human identity as profoundly as, changes in memory do.

2.2 Memory: the mechanism

> *"Life without memory is no life at all […] Our memory is our coherence, our reason, our feeling, even our action. Without it, we are nothing" Buñuel, 1985, p. 4f*

Dementia is still mainly understood as having predominantly memory loss. Even though memory loss is not a primary symptom in many forms of dementia, e.g., semantic dementia, frontotemporal dementia, for the predominant form, AD, changes to the memory system are reported as early symptoms (see for an overview "2024 Alzheimer's Disease Facts and Figures", 2024). In general, however, the emphasis on the loss of memory, even to the state of using dementia and memory loss synonymously, is scientifically incorrect.

This chapter will review literature on the construct of memory, the link between memory and identity, and will shift to a more fundamental perspective on memory systems and the theory behind memory in the context of cognitive assessment and therapeutic and care-related use of memory. It therefore lays the foundation for understanding how memories are retrieved and what may influence that process.

2.2.1 Memory = Identity?

The initial quote of this chapter by Buñuel (1985) emphasizes the supposed importance of memory for identity and builds the equation 'memory = identity'. In this thinking pattern, with the loss of a person's reasoning and coherence, the person's memory and whole being are lost. In other words, what a person thinks, is who the person is. The emphasis on the mind and reasoning can be directly linked to Cartesianism, the tradition of rational philosophy, which was most famously shaped by Descartes, Kant and Hegel. Descartes' dictum "Cogito ergo sum ('I think, therefore I am) (Descartes, 1894) demonstrated the role of the mind and its connection to identity. This tradition was at the core of classical cognitive sciences, which has merged different traditions and emerged in the late 1950s (Smith, 2015). Classical cognitivism assumes a body-mind dualism and regards the mind as a computer. The important role of the mind to process information, as well as the dominance of the brain over the body are emphasized (Gupta, 2021). This view has spread across disciplines, it evolved, but Descartes' dictum still dominates our world today. If memory is regarded as cerebrocentric processing of information, a neurocentric approach to the mind and memory, parts of human memory are completely disregarded. Therefore, the following section will outline the basic understanding of memory systems, before introducing the embodied perspective into the scope of this dissertation.

2.2.2 Memory systems and dementia

The first classic book studies on the science of memory by Ebbinghaus in 1885 demonstrated the ability to study memory through experiments. Cognitive psychology could from then on interpret their behavioral observations and experimental results in terms of their assumed associations (McGeoch & Irion, 1952). The case of H.M. (Henry Molaison) revolutionized cognitive psychology, neuroscience and the understanding of memory (Scoville and Milner, 1957; Squire, 2009). H.M. presented with strong and regular epileptic seizures. As a consequence, his medial temporal lobes were bilaterally removed in surgery, including large parts of the hippocampus and the amygdala. While the seizures were almost gone after the surgery, so was his ability to consolidate new memories. The mechanism of forming long-term memories was damaged and could not be reinstalled (Dittrich, 2016). This taught neuroscience about the role of the limbic system, the subcortical areas of the brain, in memory, and it clearly demonstrated the existence of more than one memory. Over the decades, neuropsychology became aware of the distinct forms: short-term memory, working memory and long-term

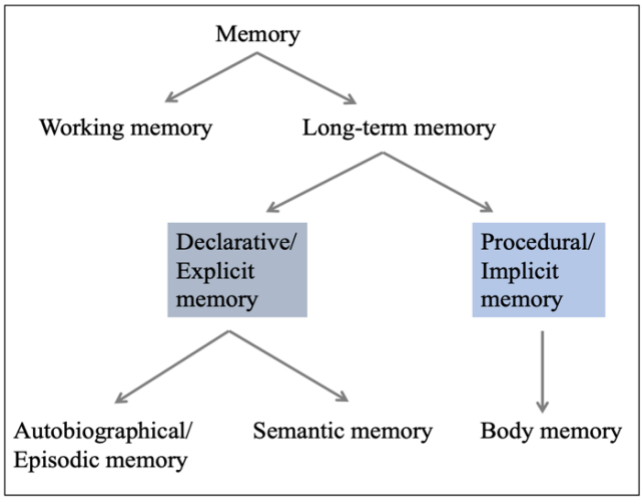

Figure 1: Memory systems

memory (Baddeley et al., 2015). The latter stores both (i) explicit memory and (ii) implicit memory: (i) declarative memory, such as episodic memory (consisting of autobiographical knowledge) and semantic memory (factual knowledge); (ii) non-declarative memory or procedural memory ('automated' and embodied skills), see Figure 1. Dementia-related memory changes impact short-term memory and explicit memory first (Braak et al., 2011), information and experienced episodes may no longer be consciously retrieved or recollected from memory. This makes explicit memory, especially semantic knowledge highly reliable for dementia assessments (Spaan et al., 2005).

2.2.3 Assessing memory

Memory can be tested directly and indirectly. A direct memory test is either a free or cued recall, or a recognition task: free recall refers to the retrieval of, for example, an encoded list of words on any order; cued recall uses, for example, a word or a letter as a cue to recall the target memory; and recognition task requires a decision whether a stimulus was encountered before. Generally used tests for free or cued recall are 10-word list-learning task (encoding and recall of the learned words), digit span task (recalling the digits in the correct order - forward or backward), category fluency task (naming as many exemplars belonging to one category such as 'animals' in 60 seconds), and many more. A task that tests recognition is the word-recognition test (10-word learning-task followed by recognition task with added distractor items on the list). Indirect memory tests make use of the influence of prior experience without the task to recall or recognize it (Schacter, 1987). A task may be a word-stem completion task (adding a letter to complete a word stem to a word, words are related to items from earlier tasks).

Neuropsychological screenings mostly use direct memory tests in the form of recall to test declarative memory. Numerous examples can be found: Mini Mental Status Examination (MMSE) (Folstein et al., 1975), Montreal Cognitive Assessment (MoCA) (Nasreddine et al. 2005), DemTect (Kessler et al., 2000), Addenbrooke's Cognitive Examination-Revised (ACE-R) (Mioshi et al., 2006) and British Sign Language Cognitive Screening Test (BSL-CST)

(Atkinson et al., 2015), all use memory items in which the person is asked to retrieve information from memory. One standard item is the three-word immediate recall and delayed recall of the MMSE. Another form of memory test item is the anterograde memory recall of a profile of a fictive Deaf man, an item developed by Atkinson and colleagues (2015) for the BSL-CST, the first cognitive screening tool to assess a deaf population. Semantic memory, like knowledge of historical events, is usually assessed with recall items as well, testing declarative memory using cues to retrieve the correct answer. One example is the BSL-CST (Atkinson et al., 2015) item which asked for the name of the royal family member who died in a car crash. The correct retrieval would lead to the answer "Princess Diana" or "Lady Di(ana)" or equivalents. Another item to test memory is the word list recall, often combined with an encoding, a learning phase. The DemTect (Kessler et al., 2000) asks a list of ten words for free recall. The BSL-Verbal Learning and Memory Test (BSL-VSMT) (Denmark et al. 2016) used a word-list as well, giving three rounds of immediate recall and stimuli repetitions for encoding. A delayed recall is given as well.

Implicit memory is less frequently tested in neuropsychological assessments for acquired cognitive impairment and dementia, even though evidence showed sensitivity for early changes in people who developed AD (Spaan et al., 2005).

Apart from classical memory tasks, even language tasks such as picture naming and language comprehension tasks also require certain memory activity that are recall processes, including working memory resources, of the earlier task instruction, as well as retrieval of the matching word to the picture and recognition of a presented word.

It is therefore essential to understand the aspect of memory retrieval/recollection by reflecting the underlying mechanism.

2.2.4 Theory of memory

This section will briefly introduce the dominating models of memory theory that are used in psychology to explain recollective and recognition memory.

Memory comprises of three steps: encoding, consolidation and retrieval/recollection (see Baddeley et al., 2015). When an information is processed, the system learns or encodes the information. This is followed by memory consolidation, in which the memory is stabilized and strengthened into long-term memory - the processing part that the before mentioned patient H.M. was impaired in doing due to the surgical removal of the medial temporal lobe, hippocampus and parts of the amygdala. The retrieval from long-term memory uses internal cues and activates working memory resources, to bring back target memories into awareness.

Different retrieval theories and approaches to explain processing of memory were discussed. For example, Tulving (1983) proposed autonoetic awareness, as a form of mental time travel that brings the person back to the originally encoded event.

Retrieval is the process of recovering a target memory, such as remembering the name of a person that one has encountered. The retrieval may be a recalled memory or a recognition. The exact mechanism underlying the recollection of memory is still an unsolved research objective (Audrain et al., 2022; Roy et al., 2017; Tulving, 1983; Watkins & Gardiner, 1979).

With the search for a match, recall is much more complex than recognition. With both mechanisms requiring a recognition (of the searched memory for recall or for the previously encountered item that is now recognized) and both occupying hippocampal brain regions (Audrain et al., 2022; Roy et al., 2017; Wixted, 2007), there is an overlap in both functions. Recognition memory has a history of two seemingly conflicting theories: the dual processing theory (Atkinson & Juola, 1973; Bellini-Leite, 2022; Mandler, 1980) and the signal-detection theory (Ratcliff et al., 1992). A reconciling approach is a combination of the two theories into one model (Rotello et al., 2004; Wixted & Stretch, 2004; Yonelinas, 1994), which was reviewed in detail across empirical studies and showed robustness and strong reliability (Wixted, 2007). According to the model, memories are conceptualized to have an internal state of memory strength that contributes to its accessibility. The higher the memory strength, the easier to access is the target memory. In the model, the memory strength is modulated by the criterion of familiarity. When the memory strength rises above the threshold of the criterion of familiarity, it signals that it was previously encountered.

To break it down with an example: one may imagine the word-recognition task, in which words that have been previously learned, are presented and to be recognized. To the list, additional distractor words are added to make the judgement task of familiarity more demanding. If a previously learned word is presented, the memory strength connected to that word is supposed to be higher, meaning more familiar, and therefore, evokes the response that the item is familiar/known. If the presented word is an additional distractor item, the memory strength is conceptualized to be low, requiring additional activation of working memory resources to process recognition.

The theories suggest that every memory has the attribute ‘familiarity’ by which it can be ascertained. Words which are familiar to the person will be recognized more likely than less familiar words that the person has rarely or never encountered before.

Those two mechanisms describe how information are retrieved/recollected and can reveal memory patterns of different dementia conditions. For example, the mechanism was observed

in studies that investigated recall and recognition in people with AD and FTD (Caruso et al., 2020). The data showed that people with AD had more difficulties in the delayed recall task, compared to the people with the behavioral variant of FTD. Following dual processing theory, this meant that people with AD had more difficulties if they had to rely on working memory and explicit recollection. Familiarity, however, showed no significant difference between the groups (ibid.).

There has been research looking at word frequency and its effect on memory and language processing. Recall of high-frequency words was better compared to low-frequency words in pure word lists and equal in alternating lists (Hulme et al., 2003). Recognition performance, on the other hand, was found to be better with low-frequency words. Malmberg et al. (2003), demonstrated that recall performance of low-frequency words was better when the encoding time was very short. This was interpreted as an effect of attention since the same effect was not found for late phase encoding. In recognition, low-frequency words seem to be only better recognized if they are studied (the "mirror-effect", see Malmberg et al., 2002). While frequency has been a widely studied feature that influences memory and processing, but is not yet fully understood (see Hulme et al., 2003 for a review), other features have been studied less. A more recent neuroscientific study came to the conclusion that the memorability of certain words is associated with the frequency with which the brain utilizes them as semantic connectors between other memories, making them often-visited hubs in individuals' memory networks (Xie et al., 2020). Iconicity (Perniss et al., 2010) has been studied in relation to memory processing as well. Sidhu et al. (2023) investigated the effect of word iconicity in spoken language on recognition memory in a recognition task. They found that words were recognized better when the words were more iconic. However, false alarm rate was higher for more iconic words as well. Earlier studies on sign language presented no effect of iconicity on memory processing for American Sign Language (ASL) in a memorizing task (Klima & Bellugi, 1979; Meier, 2002). Similarly, Bosworth & Emmorey (2010) could not find a facilitating effect of iconicity on a sign recognition task. Thompson et al. (2009), however, studied reaction time and lexical retrieval and showed a facilitating effect of iconicity in ASL for native signers. A similar effect was presented by NGT (Sign Language of the Netherlands) data from Ormel et al. (2009) in a sign-picture matching task. Higher iconicity facilitated faster sign recognition. The same was found for DGS (German Sign Language) (Grote & Linz, 2003). The conflicting evidence lacks agreement on how iconicity influences memory, but it indicates an impacting role.

To conclude, there is much evidence in the literature indicating an effect of frequency on the recollection of memory. Other features such as memorability and iconicity may also have an effect on the retrieval performance. What all this research has shown is the link between language features and memory processing. Considering and controlling for these psycholinguistic features is therefore of high importance for reliable and valid memory testing.

2.2.5 Apart from neuroprocessing

Theories and empirical work have pointed to the complex interaction that is happening during memory processing, also in memory testing. During cognitive screening, individuals constantly use memory processing to navigate and give their responses. The multitude of item inherent characteristics (e.g., familiarity, frequency, iconicity etc.), have a direct connection to the individual's test outcome, thus, playing a role in the test reliability and validity. The reviewed mechanisms of memory so far focused on the brain and its computer-like functioning. How does a theory include the body and the environment into the discourse around memory?

The psychologist Glenberg (1997) raised the question "what memory is for" and contributed to the discourse with a publication in which he proposed an embodied account, saying "retrieval processes appear to be sensitive to how we use our bodies" (Glenberg, 1997, p. 5). The review of the human memory has pointed many times towards a more conclusive approach that takes the body and embodied memories into consideration (e.g., Schacter, 1987). Regarding memories as lived experiences, those "established processes of movement are merged "into our flesh and blood"" as "our lived past" (Fuchs, 2020, p. 668).

The following chapter will shift the perspective and will introduce embodied cognition to the discussion, hence, will open new perspectives on the matter of dementia, memory assessment and dementia care.

2.3 Embodiment: The shift in perspective

> *"Undoubtedly what is thus palpitating in the depths of my being must be the image, the visual memory which, being linked to that taste, is trying to follow it into my conscious mind (...) Will it ultimately reach the clear surface of my consciousness…?" Proust, 1992, p. 62*

Besides neurocentric classic cognitivism, which is the dominant framework in many fields, the embodied cognition paradigm offers an alternative, or the way I interpret it, a shift in perspective. This section introduces the framework of embodied cognition to this dissertation and presents body memory as the core concept of embodied memory in relation to dementia. Recent developments in trying to assess embodied cognition are reviewed to widen the lens for more inclusive and appropriate screening tools.

2.3.1 Embodied cognition

The embodied paradigm encompasses different principles or goals (Shapiro, 2007; Wilson, 2002) which are also discussed as 4E cognition (Menary (2010), and which impacted various disciplines (reviewed in Gallagher, 2023). The 4E's relate to cognition being embodied, embedded, extended and enactive. The understanding of embodiment that is used in the scope of this dissertation is grounded in the 4E cognition and discusses mostly the embodied cognition as well as the embedded cognition. Embodied cognition according to Gallagher (2005) encompasses the understanding that "extraneural structural features of the body shape our cognitive experience" (Gallagher, 2023, p. 11), and that brain and body coevolve. The anatomy and perception are the foundation of what the brain processes. From a phenomenological standpoint, one makes sense of the world through one's body, through the lived bodily experience. Like a crocodile that perceives the world differently from humans with its morphology, such as formation of the eyes, its shell and earth- and water-bound ecology. Or a blind person who perceives the world through the bodily experiences without relying on vision. The brain-body-environment axis is the core of the embodied framework.

Affordances are a key element of the ecological approach within embodied cognition. Based on Husserl and influenced by Merleau-Ponty (1962) - the concept of "affordances" has been developed by Gibson (1979). 'Affordances' offer interaction with the environment, including objects and beings. It is "the idea that we experience the world perceptually in pragmatic terms of what we can do with the objects that surround us." (Gallagher, 2023, p. 17).

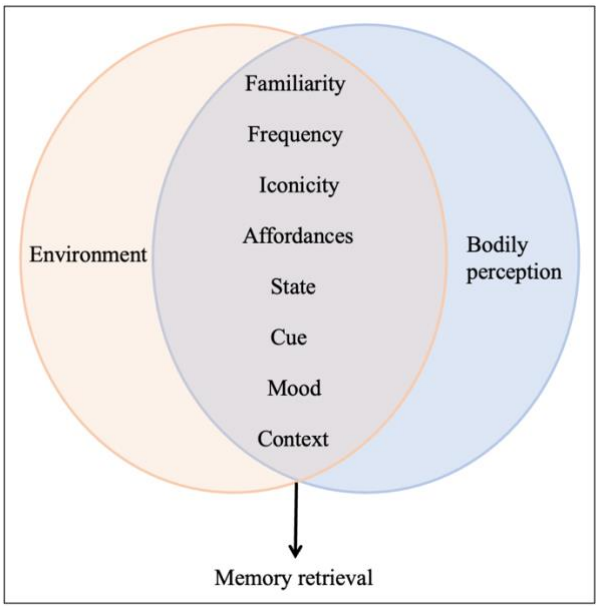

Figure 2: Embodied model of memory retrieval

2.3.2 Embodied memory

Within the embodiment paradigm, the body plays a crucial role in memory processing. Information in the form of situations, events, interactions etc., is bodily experienced and creates stored sediments in the body (Fuchs, 2012). The importance of the embedding environment, the situation, the context, the state, and even the language are supported by early memory research, which found a strong relationship between the environment of information encoding and consolidation, and the environment of information retrieval (Baddeley et al., 2015): environmental context-dependency (Godden & Baddeley, 1975; Smith & Vela, 2001), state-dependency (Eich, 1980; Goodwin et al., 1969; Miles & Hardman,1998), mood-dependency (Clark & Teasdale, 1982; Eich et al., 1994; Teasdale & Fogarty, 1979), and language-dependency (Marian & Fausey, 2006; Marian & Neisser, 2000). All studies showed a facilitating effect of memory when the environment during encoding and retrieval were the same. This research was grounded in classic cognitivist research, but supports indirectly the idea of embedded cognition. The personal mood (feeling depressed or well), the sensual environment (being under water diving or sitting in a noisy and crowded urban space), the bodily state (having a high heart rate during sportive activity or feeling calm and relaxed sitting on a couch) impacts memory processing. The research findings gave profound evidence that memory processing depends strongly on the body and the environment, and that this form of memory is less conscious and indirect.

A cultural-historic reference in classic literature whose author gave his name to, the Proust-effect, goes back to Proust's madeleine memory in "À la recherche du temps perdu" (1913/1992). In short, the protagonist dips a French bakery madeleine into a lime blossom tea and as he tastes it, long-buried memories that he could not access consciously and through thinking and reasoning rise to the surface of his consciousness. The close connection between smell and taste and the limbic system, the steering system of human emotions and memories, was depicted in Proust's novel (in seven volumes). Not long after, Maine de Biran articulated the first scheme of what Graf and Schacter (1985) later defined as implicit memory. De Biran (1929) described habits to be executed automatically and unconsciously, and distinguished

memory into mechanical memory and sensitive memory for implicit memory and representative memory for explicit memory. Earlier philosophers and scholars did not distinctively describe the difference between the two forms of memory (see a review in Schacter, 1987). According to de Biran (1929), repeated movements and sensual, feeling-related experiences are stored in and retrieved from implicit memory.

Therefore, extending the idea of retrieving memories through neurocognitive processes to a more bodily centered approach is not new. However, introducing the concept of body memory into the academic and scientific discourse around memory and even dementia, is a more recent development. Fuchs (2008, 2012) distinguished six forms of body memory which cannot be strictly separated, as he emphasized himself:

(a) the procedural memory encompasses "patterned sequences of movement, well-practiced habits, skillful handling of instruments, as well as familiarity with patterns of perception" (Fuchs, 2012, p. 12).

(b) the situational memory is rooted in bodily, sensory perceptions, including the atmosphere. This form of body memory has a spatial nature and an "atmosphere of familiarity" (ibid, p.13).

(c) the intercorporeal memory refers to the patterns learned during the earliest social encounters in life and are a form of "musical memory for the rhythm, dynamics, and undertones inaudibly present in interactions with others." (ibid, p.15).

(d) the incorporative memory are everyday life's experiences that may include subconscious forms of "socially learned dispositions, skills, styles, tastes, and ways of acting, which are often taken for granted or 'go without saying'" (ibid, p.16). Bourdieu's habitus (1990) is a reference for this form of body memory.

(e) the pain memory describes the inscription of experienced pain into memory which forms behavior and well-being.

(f) the traumatic memory may consist of "bodily sensations, the senses of taste, smell, or hearing, even certain weather conditions may suffice to suddenly revive the past," (Fuchs, 2012, p.18). As trauma is not explicitly present in consciousness, the body stores the experience and re-activates or re-enacts it.

In recent literature, bodily accounts to memory have been applied in several studies that revealed strong potential to understand and modify mental health problems, and proposed implications for neurorehabilitation and therapy, as well as a potential for neurophenomenological interventions (Gentsch & Kühn, 2022; Parma et al., 2024; Riva, 2018).

Parma et al. (2024) approached the concept of body memory from a neurorehabilitation perspective and used a multidisciplinary approach to navigate through the terminology of body memory, procedural and implicit memory, which all relate back to the same core (Schacter, 1987). As discussed in section 2.2. on memory, body memory has been overlooked in cognitive psychology due to the dominant cognitivist framework in psychology. Over time, and due to phenomenology, body memory has been described, measured, and is consequently found within the taxonomy of memory under implicit memory or procedural memory (see Figure 1).
The link that inspired Proust's so-called road down memory lane (1913/1992) was confirmed by theories and empirical studies. The limbic system, which includes the hippocampus and the amygdala, is central for the retrieval of bodily encoded and consolidated memories. What was discovered with Henry Molaison (H.M.) with a neurocentric view on memory (Squire, 2009), was empirically supported for body memory in neuroimaging studies (e.g., Bartholomei et al., 2017; Bierbrauer et al., 2021; Stevens et al., 2017). Gentsch & Kühn (2022) reviewed the evidence of clinical outcomes of negative bodily experiences and how they could be identified in memory-related brain regions. The Clinical Body Memory (CBM) mechanism that they presented, has offered implications for clinical interventions to include the body into therapeutic practices. Reconciliation can be observed between cognitive neuroscience, psychology and neurophenomenology about processing brain regions of bodily experiences, which brings the discourse on (psychiatric, neurocognitive and psychological) assessments, therapeutic and care practices forward.

Differences between implicit and explicit memory performances have been described in people with diverse conditions. There is well-founded evidence for intact or less altered implicit memory functioning while explicit memory is altered or disrupted in individuals with changes to memory due to brain lesions, to neurological or psychiatric conditions: the woman with amnesia who was pricked with a pin during a hand shake, but could not explicitly recall that experience, and still refused to shake hands again (Claparède, 1911), or the woman in an amnesic state who knew how to tailor dresses and did so every day without consciously recalling her skills (Dunn, 1845). Similar changes were documented for persons with dementia, which are presented in the following section.

2.3.3 Embodied perspective on dementia

From an embodied perspective on dementia, acknowledging body memory is a key element in maintaining a person's selfhood while living with dementia. As it was presented, memory plays a central role for identity and sustaining continuity in life. This continuity of selfhood is what has been strongly argued to get lost in dementia in cognitivist discourse, represented by Locke and Descartes, and to be preserved through the lived body in embodiment discourse (Fuchs, 2017, 2020; Kontos, 2003, 2004). The continuity becomes apparent in "organic life, which the body establishes even through phases of unconsciousness […]; on the other hand, on bodily subjectivity, which maintains a continuity of selfhood through body memory even when the ability of self-knowledge has been lost" (Fuchs, 2020, p. 673). Selfhood in dementia is maintained through the constant experience of being a body in relation to the environment and to other lived bodies (Kontos, 2003).

Implicit memory remains intact until the very late stages of dementia (Fuchs, 2020) and has been, therefore, the foundation of Fuchs' (ibid) embodied perspective on dementia, which focused on body memory. He argued that "[t]he foundational continuity of a person does not depend on a stock of explicit knowledge and memories or his own biography. It depends […] on a history accumulated, sedimented in the body and, as such, implicitly always present" (Fuchs, 2020, p. 669). The earlier presented typology of body memory (Fuchs, 2008, 2012) is therefore the basis of Fuchs' argumentation.

As dementia progresses, naming objects or remembering the name of a person becomes increasingly difficult. However, familiar faces and the use of certain objects and affordances facilitate recognition and engagement. This example of procedural memory describes "a dissociation of explicit and implicit memory" (Fuchs, 2020, p. 671), which is common in dementia. Changes to the environment of a person with dementia can result in unrest and more severe disorientation. Fuchs (2020) suggested that situational memory supports continuity and therefore retains the self. A familiar surroundings, including the entire atmosphere (smell, taste, lighting, sounds, colors etc.) stabilize the person with dementia due to its bodily accessible continuity of experience. Incorporated activities and behaviors, which have become 'second nature' to a person, shape what Bourdieu (1990) socially contextualized habitus. The way a person with dementia behaves and interacts with others and objects, is rooted in their incorporated memory (Fuchs, 2020[5]). For Fuchs (ibid), intercorporeal memory is "the most

[5] Fuchs (2020, p. 672) gave an example of a case of a man living with dementia at an advanced stage whose incorporative memory of being a young football player became activated and enacted when his grandchildren visited him and played football.

important source" (p. 672) of continuity for a person with dementia. Constantly 'reading the room' to make sense of "the state of a relation (acceptance, evaluation, nearness or distance, etc.) from the intonation, facial expression and gestures of others and react sensitively to social atmospheres, for example to subtle signs of criticism or rejection" (ibid, p. 672), is an embodied perspective on the lived experience of persons with dementia. Embodied memories of habitualized practices, termed embodied habits (Fuchs, 2020), have been discussed by Dzwiza-Ohlsen and Kempermann (2023) to be embodied long-term memory and present in all of the above forms of body memory. They even make an argument for the preventive and therapeutic character of embodied habits as a resource to "bridge any 'subjective gap'" (p.11), which, consequently, fosters embodied selfhood (Kontos, 2005).

The notion of a dementia-sensitive care environment was outlined from a phenomenological viewpoint and included the concept of affordances (Gibson, 1979) to guide future decisions to design appropriate care facilities (Mercieca et al., 2025).

Social care practices have been criticized (Kontos, 2004, 2012; Kontos & Martin, 2013), and (therapeutic) practices for more dignified care to strengthen the self of the person have been proposed (Kontos, 2004, 2005; Kontos et al., 2017; Winniewski, 2022). Promoting the use of creative art-based practices (Kontos, 2003, 2004; Kontos et al., 2017) to enact bodily stored memories, and encouraging spontaneity (Kontos, 2004), as well as playfulness and humor (Kontos et al., 2017) have been consistently demonstrated to foster the continuity of the self. A multimodal approach to autobiographical narratives that includes "gestures, bodily contact, paralinguistic means, laughter, and not least the coordination of all these aspects" (Hydén & Örulv, 2009, p. 213), also support sociability in dementia care (Kontos, 2012) as a counterpoint to social isolation, for example in the form of empathy. An embodied perspective on dementia has evolved, offering a critical rethinking of current practices in dementia care, which still very much focusses on "order and mechanistic efficiency" (Kontos & Martin, 2013, p. 293).

Educating practitioners and caregivers in embodied practices (see Kontos & Naglie, 2009) may also have an impact on how persons with dementia are assessed and diagnosed.

2.3.4 Assessing embodied cognition

The theoretical framework of embodied cognition in combination with recent technological progress has inspired novel approaches of assessment. Classical neurocognitive assessments, such as MMSE (Folstein et al. 1975), MoCA (Nasreddine et al., 2005), ACE-R (Mioshi et al., 2006) have a disembodied perspective and ignore the brain-body-environment axis that is the foundation of embodied cognition (Gallagher, 2005; 2023). Possible explanations are that

embodied and habitualized experience is less affected by MCI- and dementia-related neurological changes. It may be more difficult to control for, and due to its embodied nature and reliance on prior experience, one may raise the question about test reliability. To my best knowledge, very little assessments take on the bodily experience and operationalize embodied cognition. The Automated Test of Embodied Cognition (ATEC) presents a new perspective and has been conceptualized, developed and validated for samples of both children (Bell et al., 2021; Buchanan et al., 2019) and older adults (Bell et al., 2023). The ATEC uses physical activity to test cognitive functioning and encompasses subtasks for several cognitive domains. For the sample of older adults, the mean age was approximately 54 years (range 21 to 89) with a total of 45 participants. Almost half of the sample had a history of substance abuse. The ATEC could differentiate between individuals with and without prior history. This result indicated that early changes due to neurological conditions, even for dementia, may be detected by the ATEC, and may contribute to future assessment protocols. One exemplary task for embodied memory and delayed recall was a movement sequence that the tested individual had to observe and copy (encoding phase), followed by a 20-minutes delayed recall (retrieval). For some embodied cognition researchers, the ATEC may be a tool of "weak EC" (Gallagher, 2023), meaning that the body follows the brain, thus, the brain is still the dominant actor in the ATEC. It still makes a valuable contribution of embodiment to the field of neurocognitive assessments. Other embodied forms include evidence that walking assessments demonstrated a robust effect in distinguishing between groups of people with and without dementia (Hackett et al., 2018; Lee & Park, 2017).

When the gait and memorized body movements already show reliability, validity and robustness in the context of neurological conditions, evidence points towards more elaborate forms of assessment, including the literal embodied into the mere cognitive assessment. A review by Kolovou (2022) showed that assessments tend to use traditional cognitive measures and indicated that future research should develop new metrics to implement the embodied framework. This shift in perspective will even allow for a more diverse account on assessment, thinking about populations besides western, highly educated, industrialized, rich and democratic (WEIRD) populations (Henrich et al., 2010), and populations that use their bodies culturally more, such as those populations that use sign languages.

2.4 Interim summary I

This chapter has introduced the constructs of dementia and memory, and has presented the current practice in diagnosing, treating and caring for people with dementia. Dementia is a complex challenge for societies. It requires multi-sectorial collaboration between professions, up-to-date clinical practices to deliver the best possible healthcare, and sensitive awareness of the massive burden that people with dementia and their families carry. Getting a diagnosis, is a moment filled with anxiety, and ideally, it is the essential gateway to appropriate dementia-related healthcare practices. The construct of memory plays an important role in the discourse around dementia. Dementia screening tools make use of the changes to memory processing that occur with dementia. In order to do that, it is important to understand the mechanisms of memory processing and the influencing features in the process. Knowing all this builds a reliable foundation for memory assessment. With the understanding that memory is not just in the brain, but an embodied form of stored sensory and lived experiences that are remembered bodily long after explicit recall becomes impossible, is a key shift in perspective. Beyond a necessary assessment for diagnosis, which may include embodied (cognition) assessment tools in the future, an embodied perspective on caring for persons with dementia carries ethical value.

3 DEAF SIGN LANGUAGE USERS AND DEMENTIA

So far, the main concepts of this dissertation, dementia and memory, were introduced and the conceptual framework of embodied cognition applied. The challenge of dementia and providing sufficient and appropriate healthcare services for all became clear. This chapter will now introduce the population in focus: deaf sign language users.

The population of deaf signers signifies deaf people who identify with the cultural and linguistic minority of the Deaf community. Deaf signers communicate in one of the many sign languages around the world, which have their own grammar and are distinct from the spoken languages of the surrounding hearing population. This research particularly discusses deaf signers and not hard-of-hearing people who prefer speech/spoken language for communication through the use of hearing aids and cochlear implants. Deaf people identify as “people of the eye” (Veditz, 1912) who rely much more on the visual sense to navigate their lives. Their embodied form of communication is ubiquitous, due to sign languages making use of the space surrounding the signing person, of shared eye gaze and the bodily articulation. With deafness contributing to

human diversity and enriching scientific discourse, sign languages and deafness have been topics of research in neuroscience, education, psychology, and anthropology. Medical sciences and particularly medical practitioners often discuss deafness as a deficit that requires fixing. This dissertation acknowledges the challenges of practitioners to provide services for all amid the current (economic and social) healthcare crises, and emphasizes the need to shift the perspective towards sensitive assessments, resource-oriented therapeutic and care practices for minoritized population to reduce disparities.

Since this work is set in the context of age-related neurocognitive decline due to dementia and discusses possible outcomes on brain-based and body memory for cognitive assessment and dementia care, an introduction on the deaf older population is given. A review of the healthcare situation of deaf signers and the barriers follows, and the current state of evidence related to dementia in deaf signers is presented.

3.1 A psychosocial profile of deaf people (in old age)

A holistic perspective on dementia which encompasses the neurological and the social dimension, requests a multi-dimensional view on environmental factors shaping a person's life. Generally, old age is associated with drastic changes to the individual. Passages between working life and retirement, loss of social partners and multimorbidity are just a few challenges of old age, unspecific of deaf people (Kruse, 2017; Schaeffer et al., 2017). This section portrays deaf older sign language users in the context of their social and historical environment to give background about the target population of this dissertation.

3.1.1 Deafness in the German historical and social context (over the last century)

Zooming in on the current generations of deaf older people in Germany, the group refers to cohorts born between the 1920s and the 1960s with early forming years up to the 1970s and 80s. Deaf people of those cohorts in Germany share specific historical experiences of war, the post-war period, National Socialism, the division of the German states and their reunification.

During the 1930s and 40s Nazi regime, deaf people were targeted strategically and horrifically in various ways. Many deaf individuals experienced forced sterilization with all its consequences, forced abortions, persecution and even killings as part of the so-called eugenic program under the "Law for the Prevention of Hereditarily Diseased Offspring" (1933) (Brockmann & Kozelka, 2021; Vogel, 2015 – Film reference) or euthanasia operationalized via "Action T4" (Klee, 2010). With approximately more than 15,000 deaf individuals forcefully

sterilized by the Nazis (Biesold, 1988) and around 1,600 killed by "Action T4" (Alys, 1989; Büttner, 2005), the individual and collective traumata are immeasurable. From the Nazis and even from within the Deaf community, Deaf Jews were ostracized by those who supported the Nazis, and there were also enthusiastic followers of the Hitler Youth (Biesold, 1988; Muhs, 2002; Mittelstädt & Hosemann, 2020; Scharf, 2006; Zaurov, 2003).

After the war, Germany was divided and the two separate states BRD (German Federal Republic) and the socialist DDR (German Democratic Republic) were founded. While this was a political act, the social impact on the populations has been profound and is evident until today (Werner, 2024). Education and social life of deaf people took place in distinct systems, following their own rules and prohibiting communication between the two Deaf communities. Modern communication technology such as mobile phones or computers were not yet invented and available, leaving limited possibilities for interaction. The two systems dealt differently with the education of deaf children and young adults. Managing life as a deaf person changed again after the reunification of Germany in 1989/1990, particularly for deaf people from the DDR.

3.1.2 Education and profession

Educating deaf people in Germany, following the Milan resolution from 1880, focused on speech and articulation training, regarding hearing and speaking as superior abilities to be human. Audism (Humphries, 1975 in Bauman, 2008) is the ideology that built the so-called oralism, the oralist education of deaf people until the end of the 20th century (Löwe, 1983). Whereas effects of the separation of Germany was limited to Germans, the oralist education for deaf people was in many European countries the system through which schooling occurred. Psychologically and physically abusive and violent experiences and humiliation in schools, homes, and boarding schools causing trauma were documented across Europe (Hoffstadt, 2018; Ladd, 2003; Sullivan et al., 2000). A recent study from Australia presented significant impact of early life experiences on perceived mental health, with higher rates of suicidal ideation of those deaf people who were not socialized and educated in a deaf context (McRae et al., 2025).

The emphasis on oral articulation and speech training impeded crucial learning and possibly cognitive development (Hall et al., 2017). Higher education was not accessible for deaf users of sign language until the end of the 20th century, and barriers remain still today (Poskowsky et al., 2018). So even after leaving school, today's deaf older people had limited access to formal

education and vocational training[6]. This meant and still means limited opportunities for career advancement and pension provision in later life, resulting in lifelong disadvantage.

3.1.3 Communication and socialization

Until its recognition in 2001, German Sign Language (DGS) was pejoratively referred to as 'chatting' (German: Plaudern) and had specifically no official language status. The rise of linguistic research on sign languages (Stokoe, 1960; Stokoe Jr., 2005), with some years later in Germany (Prillwitz et al., 1985), and the cultural renaissance of Deaf culture (Padden & Humphries, 1988), fostered the confidence of the Deaf community as a linguistic and cultural minority. Today's older deaf individuals, however, have lived at least half of their lives without the official language status. The general emphasis on spoken language/speech and articulation training in education of deaf individuals (Löwe, 1983) has formed the communication of many deaf older adults. The language and form of communication depends on the socialization during childhood and adolescence with 90-95% of deaf children being born into hearing families (Mitchell & Karchmer, 2004). The grammar of DGS and spoken German differ, which partly explains the challenges of acquiring written language (e.g., written German), combined with the reduced access to the linguistic structures of German (Fellinger et al., 2012; Traxler, 2000). Compared to hearing individuals, the written language proficiency of deaf individuals is lower (Musselman & Szanto, 1998). Signing DGS or using a mix of DGS and German, referred to as "LBG" (German: Lautsprachbegleitendes Gebärden, literally translated as "signing that is accompanied by speech"), are the common forms of communication. LBG follows German grammar and uses functional signs that are not DGS signs because the grammatical function does not exist in DGS grammar. It is important to make this distinction because deaf older adults tend to use LBG or even speech when communicating with hearing people (Kaul et al., 2009). This internalized pattern can be explained by the oral education and the way deaf people were forced to use speech with hearing people (Ladd & Lane, 2013). Even if a hearing person is a fluent DGS signer, this communicative pattern can often be observed. For Finland, Rantapää (2024) reported the same communication pattern for deaf older signers. Consequently, there is a risk that professionals will underestimate the importance of sign language for deaf older people (Kaul et al., 2009).

[6] See the project „(In)visible Life Stories - Documentation of the Live, Culture and Language of Elderly Deaf People PRO*Niedersachsen" at the University Goettingen, Germany.

To navigate through life in a hearing spoken language environment, interpreting and translations are necessary. The group of deaf older adults spent most of their lives without professional sign language interpreters (first sign language interpreter training in DGS was established in the 1990s). Relatives, neighbors, teachers and trusted persons in the environment took over the role of interpreters. A study by Kaul et al. (2009) described the situation of deaf individuals in old age and found particular deficits in terms of knowledge of legal entitlements, cost coverage and organization in interpreter commission. This leaves some deaf older signers still asking for non-professional interpreters compared to trained and objective professional sign language interpreters. Unqualified hearing people, such as relatives and children of deaf adults (CODAs), may preferably be requested to provide support and assistance with communication. Written language was used for brief communication by the group but not for communicating complex issues (Kaul et al., 2009).

The importance of being amongst other deaf people is described as a feeling of being 'home' (Meek, 2020, p. 1682). For older deaf individuals, regular senior gatherings at Deaf clubs foster social interaction, informal information exchange, as well as offering a sense of belonging and coherence (Kaul et al., 2009). The Deaf community functions as emotional and advisory support for the members of the community who live in what was termed 'the hearing world' (Higgins, 1979), in order to prevent loneliness and isolation, and its impact on psychological well-being. Support from family members such as children or nieces and nephews may be affected by social and historical factors related to sterilization within the family, or by language barriers like having hearing children who do not sign well (Kaul et al., 2009).

3.2 Challenges in healthcare

Access to health treatment depends on having a doctor's appointment at a local GP or a specialist or at a clinic. Wherever a person consults a doctor, an assessment is needed to refer or advise on further steps taken. These steps could include a referral to a neurologist due to dementia-related symptoms or with progression of the condition to an institutional facility for institutionalized dementia care. This chain of services challenges the deaf population due to significant barriers. (Fellinger et al., 2012; Kaul et al., 2009).

What studies indicated is that deaf people generally have a higher health risk. Data from the UK showed a greater risk to suffer from untreated or late diagnosed conditions (Harris et al., 2021). Another UK report estimated costs to the healthcare system of around £30 million per year as a consequence of incorrect diagnosis and inadequate treatment of deaf patients (Sign Health, 2014). Estimations for Germany are not provided. To give comprehensive evidence-

based context, the current healthcare situation for deaf people, including appropriate diagnostics, treatment and care, is reviewed below.

3.2.1 International perspective

Internationally, several studies brought evidence of barriers to access healthcare and clinical services (Kuenburg et al., 2016). McKee et al. (2015) assessed health literacy among US deaf individuals in ASL, and demonstrated that around 43% of the study participants had inadequate health literacy, which increased their risk compared to hearing controls. Poorer health was also associated with less use of technology, such as eHealth services (Ryan & Kushalnagar, 2018), which may be a barrier for older individuals to these healthcare services. A study by Williams & Abeles (2004) revealed barriers to therapy in the US, presenting challenges for both hearing therapists and deaf clients/patients. Miscommunication between deaf individuals and hearing medical staff was revealed to be common in healthcare settings (Yet et al., 2022). Besides the general need of communication in the local sign language, there are challenges due to differences in the use of language amongst deaf populations (Gulati, 2019). For deaf individuals in the UK, studies have repeatedly reported poor access to primary care, to diagnoses and to appropriate care services that include assessment in sign language or medical staff that has received Deaf awareness training (Harris et al., 2021; Reeves et al., 2003; SignHealth, 2014). As presented above, deaf individuals often lack the access to sign language in their earliest years with a resulting impact in cognitive development and possibly challenged mental health or general health literacy (Ricke et al., 2024). On the part of clinicians, misinterpretation may occur due to variability in the deaf population and lack of assessment tools and norming data. This results in an overreliance on qualitative measures, such as behavioral observation, rather than on quantitative measures (Glickman & Gulati, 2003).

In the UK, a specialist cognitive clinic for Deaf people was established in 2011 and made a validated change to health inequality and diagnostic accuracy (Harris et al., 2021). Through the involvement of both deaf and hearing clinical staff that is highly proficient in the local sign language, sensitive and appropriate healthcare was provided.

3.2.2 Healthcare in Germany

The satisfaction with healthcare services among deaf people is generally low. Over the last two decades in Germany, evidence was collected and continued to replicate the significant shortage of healthcare services suitable and adequate for deaf people. A German study by Paulini (2008)

surveyed 246 individuals with a degree of audiological hearing impairment about their experience with the healthcare system. A subsample of 73 deaf individuals reported a significantly lower satisfaction rate than their peers. In a following study of the German Deaf community, Höcker (2010) found that two-thirds of the 831 survey participants, reported time pressure and communication difficulties, over half of the sample reported feelings of dependency and helplessness, and more than 40% assumed a false diagnosis due to problems in communication. One third of the sample was not informed about the current legal status of sign language interpreting services in medical settings. This lack of knowledge was particularly associated with young age, low education and a strong focus on the own family. A decade later, Cüre (2020) looked at the situation of deaf individuals in outpatient healthcare settings, including perspectives from members of the Deaf community and sign language interpreters in a qualitative interview study. The data indicated inadequate services in terms of accessing appropriate services near one's home, difficulties in arranging doctor's appointments and scheduling sign language interpreters. As presented in previous studies on Germany (Höcker, 2010; Kaul et al., 2009; Paulini, 2008), a still ongoing information deficit regarding health literacy was confirmed in the interview study with communication being the largest barrier in the process (Cüre, 2020). In the most recent study by Rannefeldt (2025; Rannefeldt et al., 2023), a sample of 383 deaf study participants was assessed in an online-survey on satisfaction with and access to the German healthcare. Their results could once again underline the previous research findings. While a general avoidance of healthcare services and doctor's visits was reported, the satisfaction with medical help was low. Rannefeldt et al. (2023) found a significant correlation between lower levels of contentment and more worries connected to doctor's visits. Their study sample reported low to medium levels of confidence to receive acute medical help if necessary. Prior experience of miscommunication with the medical (hearing) staff in an acute medical emergency situation was indicated by almost two thirds, with reported feelings of helplessness and dependency – again supporting previous research (Höcker, 2010; Kaul et al., 2009). The survey also replicated Cüre (2020)'s result of more satisfaction when services are nearer located, such as in urban compared to rural areas (Rannefeldt, 2025; Rannefeldt et al., 2023). A novel finding of the study was the avoiding behavior of deaf patients who showed symptoms, but did not seek help due to communication barriers (61%), a feeling of too much effort related to one's hearing disability (44%), and concerns of facing misunderstandings by the doctor (24%). With language being the most dominant factor influencing satisfaction and behavior, meaning consequently language skilled medical staff and/or a shared language between medical staff and patient, Rannefeldt et al. (2023) concluded - in line with Kietzmann

et al. (2016), that ease in communication is more impactful than general sociodemographic-related factors in healthcare settings among minority populations.

3.2.3 Mental health care in Germany

In psychiatric and psychotherapeutic settings, the level of satisfaction was reported similarly (Ricke et al., 2024). A survey study investigated mental health literacy within the German deaf population and could include 390 participants. 86% indicated a poor level of satisfaction with the current mental health services accessible to deaf individuals. As demonstrated by the data from studies on general healthcare (Cüre, 2020; Höcker, 2010; Paulini, 2008; Rannefeldt et al., 2023), Ricke et al. (2024) showed a need in information on mental health issues accessible in sign language. 74% preferred direct communication in sign language for psychotherapy; 44% would prefer a deaf therapist, only 18% preferred a hearing therapist, and for 38% the hearing status did not matter. Interestingly, the survey data could show a correlation between mental health literacy and age of sign language acquisition. Participants who had access to and acquired a sign language before the age of four, reported higher mental health literacy. Ricke et al. (2024) argue that the early access to language may function as a central preventive factor fostering later mental health literacy.

A survey that addressed psychotherapists in a German region (n = 71), revealed common lack of experience with the client population of deaf people (84.5%), and almost two thirds would decline a therapy request from a deaf individual due to assumed communicative difficulties and a lack of prior experience (Schröder & Vereenooghe, 2021). These findings support the conclusion by Rannefeldt et al. (2023) that language is the key factor to appropriate healthcare. While satisfaction level, avoidance and information deficits did not differ between age groups in the previous studies on deaf people, evidence from the general population clearly indicated that healthcare becomes increasingly important in old age for all (Kruse, 2017; Schaeffer et al., 2017). Taking psychiatric and psychotherapeutic services in the general German population, one third of psychiatric diagnoses are made to individuals over the age of 60, however, this age group only accounts for 6% of psychotherapeutic treatments (Melchinger, 2011). People over the age of 80 with a psychiatric diagnosis only account for 1% of psychotherapeutic treatments (Kessler & Tegeler, 2018). This shows a significant discrepancy between need and services in the general (hearing) population in the context of healthcare, leading to the assumption that deaf older adults are likely to receive hardly any psychotherapeutic treatment if needed. The challenges of dementia-related changes require adequate healthcare services and specific treatments and care planning, and often increase the need for psychological and social

interventions (McDermott et al., 2019; Warren, 2023). The presented evidence on the general older population in Germany in relation to the lacking data and the statistical evidence on deaf older people suggests an under-served situation for deaf people who require mental health support.

3.2.4 Accessibility and availability of services in Germany

In terms of cognitive decline and dementia in deaf individuals, the current evidence-based knowledge in Germany is still scarce. Kaul et al. (2009) were the first to study the situation of deaf older adults in Germany. In that study, 113 experts assessed provided services for deaf people in terms of their suitability to deaf older adults; around three quarters of the participants assessed psychological consultations and senior residences/nursing homes as not sufficient, and according to two thirds of the experts, help with dementia to deaf older adults was not sufficiently provided. To this day, there is a body of evidence of the tremendous lack of appropriate and sufficient healthcare of deaf people in Germany - it should be emphasized that these services should also serve age- and dementia-related needs of even more vulnerable individuals with dementia amongst the Deaf community:

Unclear communication has been demonstrated to be a significant reason why services were either not sought by deaf patients (Rannefeldt et al., 2023; Ricke et al., 2024) or not provided and accepted by professionals (Schröder & Vereenooghe, 2021). Communication barriers and lack of Deaf awareness may result in inadequate treatments or treatment discontinuation (Harmer, 1999; Kaul et al., 2009; Steinberg et al., 2006; Ubido, 2002). Facilities specifically designed for deaf individuals require a culturally sensitive approach. Deaf awareness training, social and sign language skills, applying the concept of DeafSpace (Bauman, 2010), and setting quality standards to assure appropriate care to deaf residents, were identified as crucial (Kaul et al., 2018). Apart from institutionalized facilities, there is a great need for 'low-barrier' services that advise, support and accompany deaf people as they cope with the challenges of ageing.

Although there are services generally aimed at older people, such as care offices, memory clinics and outpatient care services, these are not specifically tailored to the needs of deaf people. There are very few services aimed specifically at deaf people in old age. For instance, residential and care services designed specifically for deaf people are rare and mainly exist in larger cities and almost exclusively in the inpatient sector. Outpatient, day-structuring, and counselling services are even rarer. The same applies to voluntary care and visiting services (Kaul et al. 2009).

3.3 Dementia in deaf sign language users

Building on the review of the Deaf community and their healthcare situation, this section will expand the literature review to include dementia: how it presents itself in deaf people, how it is detected, and what barriers are involved.

3.3.1 Dementia-related symptoms

Over the last fifteen years, significant scientific contributions to the understanding of dementia in deaf people was published. In studies on signers of Finish Sign Language, changes in language with family and formal caregivers were reported (Rantapää & Pekkala, 2016; Rantapää et al., 2023). A tendency to speak with hearing and to sign with deaf conversation partners was documented. Rantapää and Pekkala (2016) documented a decline in the ability to interact and a reduced ability to speak, although this is not specific to sign language. Family caregiver, CODAs, described changes in the speech or signing of their deaf parents. Simpler language with shorter sentences and repetition of signs as well as word or sign finding difficulties, semantic errors, changes to the fingerspelling, deteriorating finger dexterity, problems in negating statements and difficulties in telling a coherent story, characterized the language of deaf people with dementia (Falchook et al., 2013; Rantapää & Pekkala, 2016; Rantapää et al., 2021; Rantapää et al., 2023). The studies found patterns of repetitiveness in communication and disengagement from the necessary eye contact in sign language communication, caused by dementia. According to the caregivers' assessment, interaction with sign language interpreters also became more difficult as dementia progressed (Rantapää & Pekkala, 2016). The communication became increasingly challenging because of a decrease in understanding specific concepts, including medical terms around dementia and care (Rantapää et al., 2023). Deaf individuals with dementia showed a general decrease in social activity and appropriate response behavior (Rantapää & Pekkala, 2016; Rantapää et al., 2021). Caregivers observed changes in handling daily living activities, such as managing the household, as well as changes in spatial and temporal orientation (Rantapää et al., 2023).

Being aware of these changes and behavior patterns requires a certain degree of health literacy, which was reported to be lower in the deaf population compared to the hearing population (McKee et al., 2015; Ricke et al., 2024). For the UK, the lack of education in the Deaf community was described, regarding the symptoms and effects of dementia (Ferguson-Coleman et al., 2014; Rogers et al., 2018; Young et al., 2016). There is a risk that people will

be excluded from the Deaf community as a result of dementia-related changes in their behavior, which may be perceived as inappropriate in the community. This unaware ignorance and possible tabooing of dementia may have radical consequences for one's Deaf identity and social integration as a member of the Deaf community. As a result, the networks in which dementia could be recognized as such may be lost and thus also the opportunity to initiate suitable measures for clarification (Kaul et al., 2009).

3.3.2 Through the embodied lens

In a small-scale study by Young et al. (2014), interviews with deaf persons with a formal dementia diagnosis and their caregivers were used for a phenomenological approach to the experience of dementia for deaf persons. The study is unique with its scope and approach and is, therefore, particularly important for this review of existing evidence on healthcare practices. From a standpoint that sign languages are embodied and closely connected to Deaf selfhood and identity, the study analyzed the signed utterances and narratives and found retention of the linguistic non-verbal of signing, i.e., facial expression, while complex syntactic structures were diminished. It has been shown in the literature that non-verbal communication is more salient against the dementia-related changes of language, but these studies have looked at non-verbal as mostly non-linguistic (Hydén & Örulv, 2009; Kontos, 2004). In sign language utterances, non-verbal, e.g., raised eyebrows, tilting of the head etc., are linguistic features, carrying distinct meaning. Young et al. (2014) portrayed the embodied signer with dementia as "he was observing his own expression and this 'thing called signing' had become objectified as he asked me [the interviewer] to look too. His hands were both the expression and the object of that expression seeing sign language as of himself (produced through his body) and about himself (he could comment on his own language)" (p.65). Losing one's ability to express oneself through sign language endangers one's identity and selfhood – revealing a pronounced importance of signing as an expression of embodied selfhood. Retaining one's identity was reported to be challenged as well for the deaf person in the nursing home with hearing non-signing caregivers. The deaf body and the embedding environment are mostly not well coordinated in most caring environments. Caregivers who do not understand sign language cannot interact, exchange information, or establish a trusting relationship with deaf persons with dementia. "The flashing doorbell that has been a part of her life always, still takes her to the door, but when she opens it there are now people who cannot sign, who cannot communicate with her and yet she still must open the door. Where has her native language gone? Why does the flashing doorbell no longer bring signing friends?" (p.67). The flashing doorbell is a visual

doorbell that translates the usual acoustic ringing into a visual flash. Even though the person in the quote had a flashing doorbell, it still did no longer afford interaction. Young et al. (2014) continue by pointing towards existing concepts such as DeafSpace (Bauman, 2010) to promote embodied selfhood for both research and care practices. Environments that consider the body and its implicit memory and foster multimodal expressivity and creativity support the person with dementia in maintaining selfhood (Kontos, 2012; Kontos et al., 2017).

3.3.3 Barriers to diagnosis

Currently used assessment tools were developed and normed with users of spoken languages. Test adaptations have increased the global availability of cognitive assessments. Over the last years, cognitive screening tests which target the population of hard-of-hearing individuals were developed. Specifically for the German context are the DemTect$^{Eye+Ear}$ (Brünecke et al., 2018), the O-Dem (Ballasch et al., 2023) and the German adaptation and validation of the MoCA for hearing impairment, MoCA-HI (Völter et al., 2023). While taking into consideration that test items may need more visual presentation, the studies did not include deaf signers of DGS in the norming samples. For deaf DGS signers, there are currently no quantitative measures to assess acquired cognitive decline and dementia. In the past, translations from the MMSE into American Sign Language (ASL) revealed significant linguistic and cultural issues when tests are only translated and not appropriately adapted (Dean et al., 2009; Taylor, 2017). Invalid and unreliable diagnoses are the result of applying inappropriate screenings to populations which are understudied and often underserved. Without the necessary awareness of the deaf population, hearing clinicians may rely on their clinical knowledge about dementia and established cognitive thresholds as a benchmark for deaf individuals with dementia. This carries a high risk of misinterpreting cognitive performance. It is, therefore, important to assess the patient's etiology of deafness as well as the linguistic, educational and cultural socialization before choosing a screening tool (Hill-Briggs et al., 2007). Simply using sign language interpreting between a hearing clinician and a deaf patient does not facilitate reliable and valid testing, but rather increases the risk of misdiagnosis (Kaul et al., 2009).

Deaf individuals may switch to spoken language articulation in clinical settings due to internalized social behavior or caused by dementia (Rantapää & Pekkala, 2016). Unaware of the cognitive costs (Emmorey et al., 2016; Emmorey et al., 2020) and (negative) impact on the intelligibility and clarity of the utterance, for both sides, for the clinician and the deaf person, reliable and valid testing is at risk. As one result, a high extent of false diagnoses is assumed by the deaf population (Höcker, 2010).

The language used for clinical examination and test administration needs to be the dominant language of bilinguals to ensure reliable testing (Briceño et al., 2021). Even so-called language-free tests, such as the TRAKULA (Kessler et al., 2005), which rely on non-verbal communication, cannot be regarded as reliable test alternatives. Non-verbal communication, gestures and body language interfere with utterances in sign languages because of the common visual-spatial or visual-gestural modality, which can lead to misunderstandings and misinterpretations of test responses. Considering the cognitive domain of language is particularly important for the development of a culturally sensitive diagnostic tool for deaf signers (Atkinson et al., 2015; Denmark et al., 2016).

3.3.4 Language and culturally sensitive dementia diagnostics

In the UK, a dementia screening tool in British Sign Language (BSL) was developed as part of the Deaf with Dementia Project from 2010-2016. The British Sign Language Cognitive Screening Test (BSL-CST) was the first assessment tool to detect acquired cognitive impairment and dementia in deaf sign language users of BSL (Atkinson et al., 2015). It does not rely on spoken or written language, is computer-based, standardized and validated in the UK. The BSL-CST is currently clinically applied in the context of an extensive clinical work-up in a specialist clinic for deaf individuals in London, UK. The test comprises of seven test domains, including memory (mostly recall tasks), orientation, language, executive function, perception and visual-spatial abilities, attention and semantic fluency. Based on the structure of the Addenbrooke's Cognitive Examination – Revised (ACE-R; Mioshi et al., 2006) with additional adapted items of the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), the BSL-CST is culturally and linguistically sensitive to the heterogeneous Deaf signing community in the UK (Atkinson et al., 2015). Over the last years, cognitive assessment tools were adapted and developed, including an additional screening in BSL (Denmark et al., 2016), for French Sign Language (LSF; Fleurion et al., 2021), for American Sign Language (ASL; Timperlake, 2024), and for Finish Sign Language (FinSL; Rainò, 2010). Whether these adaptations have been implemented in the national healthcare's diagnostic protocol and are used in clinical practice, remains unclear. Bridging the gap between clinicians who are unaware of sign language-based assessment tools and who follow their regular protocol, and deaf sign language users who rely on language- and culture-sensitive diagnostic tools to receive reliable and valid diagnoses, is a challenge, and a crucial additional step, beyond test adaptation, towards change.

3.3.5 Services and care for deaf people with dementia

When deaf people need formal care, an important question arises: whether to stay or move into a signing environment (Kaul et al., 2009; Kaul et al., 2010). A signing and culturally appropriate environment activates deaf residents (Rantapää et al., 2023). On the contrary, social isolation and sadness was documented in a caring environment that is not tailored to the needs of deaf individuals (Parker et al., 2010). The solution seems simple, yet difficult to implement in the real world (Kaul et al., 2018). With dementia, barriers for the person with dementia and the caregiver(s) grow and effective communication and interaction become more challenging (Young et al., 2016). The changes to the linguistic expression of deaf people with dementia make understanding and interacting more difficult (Rantapää, 2024). There is a need to express oneself in sign language with one's Deaf identity even in the face of dementia in some deaf sign language users (Rogers et al., 2018; Young et al., 2014). Strategies of family caregivers to support the deaf family member with dementia encompass sign language communication, using nonverbal cues and expression, initiating interaction and being attentive and observing carefully to make the family member be understood (Rantapää & Pekkala, 2016). Reading the nonverbal in an already visual-gestural language like sign language, is particularly challenging, and a strategy that formal caregivers can adapt from. Formal caregivers use the strategies around interaction maintenance, emotional support, instrumental support, informational support, and memory support. It was reported to be key to have sufficient background knowledge of the biography of the deaf person with dementia in order to provide adequate care to the individual (Rantapää et al., 2023).

If family members of deaf people with dementia become the primary caregiver, they often need to educate medical staff about deaf people, which raises the burden and the risk of one's own health (Ammons et al., 2020).

For the German context, limited research is available on services and care for deaf people with dementia (Kaul et al., 2009; Kaul et al., 2018). In general, care facilities that specialize on deaf people which have additional specialized dementia care services are limited. There are some residential and care services for deaf people in old age, however, due to a lack of quality standards, it is not possible to assess the extent to which these services cater to the special needs of deaf people with dementia. What was described for the UK (Young et al., 2016), was also found in Germany (Kaul et al., 2009; Kaul et al., 2018). With regards to services for deaf people with dementia, service providers often lack knowledge about the specific services for deaf people while deaf people lack information about dementia and related services and treatments. General counselling are often the first services which come in contact with deaf people seeking

help in this situation. Social counselling targeted at deaf people is therefore a highly important service, however, in-depth knowledge about dementia often lacks in those facilities.

Psychiatric and psychotherapeutic treatments as inpatient and outpatient services that are tailored to deaf and hard-of-hearing people in Germany are located in Lengerich (LWL-Klinik Lengerich) and Erlangen (Klinikum am Europakanal). In these facilities, examinations, treatments, and therapy are available in DGS and adjustable to different forms of signing thanks to deaf and hearing signing medical doctors, psychologists, therapists and nurses. The lack of standardized assessment tools in DGS, having highly skilled and specialized staff, the heterogeneity of signing styles within the deaf population and necessary long-term financial security to offer these care services, are some of their challenges[7].

3.4 Interim summary II

Providing healthcare for a small population within the general healthcare system is a challenge. The evidence clearly demonstrated that the population of deaf sign language users is faced with high barriers in terms of getting information, getting access to services, getting adequate assessment, as well as sensitive therapy and care. With dementia, deaf older adults face a tremendous lack of appropriate care as long as there is no language- and culture-sensitive screening assessment tool in DGS and no sufficient sensitive dementia care that applies the current state of evidence to activate deaf care home residents.

[7] This was reported to me during some work shadowing days at the clinic in Lengerich in October 2018.

4 SCIENTIFIC CONTRIBUTIONS

Building on the evidence and presented lack of appropriate assessment of deaf DGS signers, and the limited resources to provide deaf-sensitive dementia care, this chapter presents original scientific contributions to the discourse. The following three studies are presented and put into context:

Study 1: Stockleben, L., Woll, B. & J. Atkinson. (2026). Screening for acquired cognitive impairment and dementia in deaf users of German Sign Language: the Cognition Test German Sign Language. *Archives of Clinical Neuropsychology, 41*(2), acaf094. https://doi.org/10.1093/arclin/acaf094

Study 2: Stockleben, L., Straub, A. & L. Klinner. (in revision). How reliable are subjective ratings? The issue of reliability in psycholinguistic measures of sign frequency and iconicity in German Sign Language (DGS).

Study 3: Stockleben, L. & Gelhardt, A. (in revision). Deaf (collective) body memory and intercorporeality: an embodied perspective on deaf persons living with dementia.

The first study is a neuropsychological study that targeted the lack of appropriate screening tools to assess acquired cognitive decline and dementia in deaf signers of DGS, presented in section 4.1. The second study targeted the issue of reliable psycholinguistic norming data to select test items in accordance with the knowledge on memory processing in section 4.2. And the third study discussed the embodied concepts of body memory and intercorporeality for the group of deaf persons with and without dementia in section 4.3.

4.1 Providing cognitive assessment for deaf DGS signers

4.1.1 Dementia diagnosis disparities in minoritized groups

In recent years, many studies have gathered evidence of disparities affecting minoritized populations with dementia. For the US, data showed later dementia diagnoses in ethnic minority populations compared to the general population (Armstrong-Mensah et al., 2024; Co et al., 2021; Lin et al., 2020). The same was found for minoritized groups in the UK (Adelman et al.,

2009). A review focusing on Europe, identified factors influencing the accessibility of healthcare for people with dementia from minoritized populations and their caregivers (Duran-Kiraç et al., 2022). A lack of linguistic and cultural awareness among healthcare professionals and a lack of health literacy in minoritized populations were reported as hindering factors to adequate healthcare. One can observe a growing awareness and willingness to change the disparities in current dementia research (just a look at the conference program of the world's largest forum on dementia research, the annual conference of the Alzheimer's Association International, AAIC25, which I attended in-person). However, there is still a long way to go. Research can function as an inclusive catalysator for underserved populations for change when recruiting strategies are tailored to an inclusive setting (Brijnath et al., 2022*;* Marchant et al., 2025). According to recommendations on including ethnic minoritized populations in dementia research based on review evidence, linguistically and culturally adapted instruments are needed. By using appropriate tools and materials, differences in education and health literacy should be considered (Brijnath et al., 2022).

Deaf people do not identify as an ethnic minority; however, as the research findings presented in chapter 3 demonstrate, the challenges related to accessing healthcare services, obtaining accurate diagnoses, and receiving culturally sensitive care, are comparable. There is evidence of barriers in the healthcare system for deaf individuals (studies only limited to Germany: Cüre, 2020; Höcker, 2010; Rannefeldt et al., 2023; Ricke et al., 2024; Schröder & Vereenooghe, 2021), of assumed misdiagnoses (Höcker, 2010; Kaul et al., 2009) and clinically documented false and/or late diagnoses (for the UK: Harris et al., 2021), and a lack of culturally appropriate screening tools to assess deaf sign language users' cognitive functions. All this leads directly to late dementia diagnoses, which was reported for ethnic minoritized groups (Armstrong-Mensah et al., 2024) and minoritized deaf populations (Ferguson-Coleman et al., 2014). While late diagnosis is often located in the lack of awareness and knowledge of dementia of deaf people, the structural barriers are too often overlooked (ibid.). Late diagnoses delay personal orientation and adjustment for better quality of life, clarification and support to family caregivers, eligibility to healthcare services, therapies and treatment, and access to specialized dementia care. A timely diagnosis is therefore of high importance.

4.1.2 Study 1: The first cognitive screening tool in DGS – the KoDGS

The aim of Study 1 was to address the lack of appropriate diagnostic screening tests and develop a screening tool to detect acquired cognitive impairment and dementia in deaf signers of DGS, the Kognitionstest Deutsche Gebärdensprache – KoDGS (Cognition Test German Sign

Language). The KoDGS was linguistically and culturally adapted from the BSL-CST (Atkinson et al., 2015). With its structure on the ACE-R and selected items from the MoCA and MMSE, the BSL-CST was developed on the basis of validated gold standard cognitive screening tools in the field of neuropsychology. As the BSL-CST was the first screening tool sensitive to Deaf culture and sign language, it was chosen as the source test for the target test KoDGS. A rigorous and comprehensive 15-step test adaption paradigm was developed (see Study 1, Table 1). A collaborative, transdisciplinary and participatory research approach was applied. Reflections regarding the research approach are discussed in 5.2. in detail. For the adaptation, the usual translation and back-translation process of test adaptations (Mirza et al., 2017) was split into four steps, adapting the paradigm to the involved two modalities (signed and spoken) and four languages (DGS, BSL, German and (British) English). Participation of both the deaf focus group and the clinical expert group – whose members convened multiple times throughout the adaptation process, enhanced the test's validity and reliability. Both focus groups helped bridge the gap between theory and practice, while also improving the test's applicability and acceptance among both patients and clinicians. The dynamic iterative process of revising the test is one characteristic of this particular test adaptation.

Test items were chosen based on reliable psycholinguistic norming data of DGS (Study 2). Creating the test instruction videos was a participatory process. In order to meet the communicative needs of the heterogeneous Deaf community, the test administrator was chosen and encouraged to adjust to an inclusive signing style. Test developer involvement scaffolded the whole process and gave orientation and useful insights from years of clinical use of the original BSL-CST in the UK.

The KoDGS was tested with 99 participants, who were assigned to two sample groups depending on their medical history. Of the normative sample of 86 cognitively healthy participants with a mean age of 63.1 (SD = 9.2, min-max =50-92), mean of 13.6 years of education (SD = 2.6, min-max = 6-22), mean age of acquiring DGS of 8.3 (SD = 9.6, min-max = 0-50) KoDGS score (mean = 100.4, SD = 6.4, min-max = 86-109) were collected. Percentiles for two age bands, age 50-64 (n = 50) and 65+ (n = 36), were calculated (Study 1, Table 6). Participants who reported a neurological history (e.g., multiple sclerosis) or indicative life profile (e.g., alcoholism) were assigned to the second sample. For this group of 13 individuals with a mean age of 72.5 (SD = 11, min-max =56-96), mean of 9.9 years of education (SD = 2.7, min-max = 4-13), mean age of acquiring DGS of 7.9 (SD = 3.9, min-max = 0-15) KoDGS score (mean = 69.2, SD = 14.7, min-max = 50-99) were collected. The two samples differed significantly ($t(97) = 13.3$, $p < .001$) and a receiver operating characteristic (ROC) curve

analysis revealed a highly reliable accuracy (.965, p <.001). The Youden's index J indicated a likely cut-off value of 85. KoDGS scores and age negatively correlated (rho = -.56, p <.001) and KoDGS score and years of education showed a positive correlation (rho = .45, p <.001) for the normative but not for the neurological history sample. Correlations with convergent measures supported content validity. The KoDGS is the first cognitive assessment in DGS to detect acquired cognitive impairment and dementia and may improve dementia diagnoses for the deaf population in Germany. The study contributes to the field of disciplines around cognitive assessment of deaf individuals and may enrich future test adaptations for small populations in neuropsychology.

4.2 Ensuring reliable and valid testing

4.2.1 Seeking reliable and valid equivalence

The overarching challenge in adaptation processes is to maintain equivalence between origin/source and target. For the test adaptation of the BSL-CST to the KoDGS, this meant careful replacement of British cultural and BSL test items with German and DGS items. Keeping the validity of the test construct, such as semantic memory, and ensuring the reliability of the item for the target population, were typical challenges of adapting a test. For semantic memory, to take the earlier used example from chapter 2.2.3., the BSL-CST asks for the name of the royal family member who died in a car crash. While the death of Princess Diana was a well-known event in the United Kingdom, in Germany, not many cognitively healthy people could reliably give a correct answer. In order to maintain the validity of testing semantic memory, the item had to be a shared collective (cultural) knowledge of people in Germany. The Fall of the Berlin Wall was chosen for the KoDGS, as it unites collective memory of deaf people from former East and former West Germany.

For testing the cognitive domain language with the object naming task, the KoDGS presents the person with black and white drawings of objects and asks the person to name the equivalent sign to that object. For this task, the BSL-CST based the selection of the language item on psycholinguistic norming data (Vinson et al., 2008) to control for frequency, age of acquisition and iconicity of the chosen BSL signs. These norming data for the selected objects facilitated to control for bias in cognitive processing.

As shown earlier in 2.2.4., there is a close link between psycholinguistic features of language and memory processing. While familiarity is a core attribute of any given information, according to memory theories, low or high frequency showed an influencing effect on whether

or not an information was retrieved more easily. For iconicity, clear evidence is still not provided but studies indicate a facilitating effect of iconicity on memory retrieval.
Seeking reliable and valid testing requires best possible control over the impacting factors of underlying mechanisms, such as memory processing. For test adaptations of cognitive screenings, to control for sign/word frequency and sign/word iconicity are important steps to take. For DGS, psycholinguistic norming data were not provided, which led to Study 2.

4.2.2 Study 2: Providing psycholinguistic norms in DGS

The aim of Study 2 was to collect psycholinguistic norming data for sign frequency and sign iconicity for DGS signs. In a collaboration between hearing and deaf researchers, an online subjective rating study was designed in the footsteps of Vinson et al. (2008). The paper describes transparently and in detail the challenges of adjusting the study during the covid pandemic. Data was collected online from 98 participants of whom a sub-sample of 48 participants rated sign iconicity, while 50 participants rated sign frequency.
For each task, the stimuli items (347 for frequency and 351 for iconicity) were divided into three item lists each to avoid fatigue and dropout, resulting in grand means of frequency 4.5 (SD = 1) and of iconicity 5.8 (SD = 0.7). The mean rating values were calculated and compared to an existing set of subjectively rated norming data from Trettenbrein et al. (2021) with 131 overlapping items to control for reliability. The statistical measure Hedges' *g* indicated general agreement between study data, yet some differences between our data and the existing data by Trettenbrein et al. (2021) on the same lemmas with both the 72 'same' and 59 'different' DGS sign variants. Phonological and morphological similarity analysis between study ratings were discussed as being important for mixing data from different studies.
In addition, both study's norming data on sign frequency were compared to data from the DGS Corpus project (Konrad et al., 2020), as an objective measure of sign frequency. Our data showed a small significant correlation (r = .25, p = .005) with the objective measure of frequency, the DGS corpus data, while the existing subjective rating showed no significant correlation (r = .13, p = .16). The study discusses possible challenges in subjective rating studies to ensure reliability of the norming data, e.g., online study design, task instruction, and participants' representability. In sum, Study 2 contributes to the literature on psycholinguistic measures and the methodology of subjective ratings, as well as on collaborative research, which is discussed in detail in chapter 5.2.

4.3 Using body memory as a resource for dementia therapy and care

> *"All modes in which any body is affected follow from the nature of the body affected, and at the same time from the nature of the affecting body [...] Hence it follows in the first place that the human mind can perceive the nature of many bodies at the same time as the nature of its own body." Spinoza, 1941, p. 53*

4.3.1 Memory-related therapeutic and care practices for dementia

This dissertation focuses on the role of memory in dementia for better and more appropriate healthcare practices for deaf people. For non-pharmacological therapy and care, memory work has been an important element. Multiple studies have demonstrated small to large effects of memory training for persons in the earlier stages of dementia (Camp et al., 1996; Moore et al., 2001; see for a systematic review Gates et al., 2011), with a growing focus on not only explicit but also implicit memory (Harrison et al., 2007; Parahoo et al., 2006; Warren et al., 2023; Zanetti et al., 1997). It seems that preserving function in people living with dementia is the main goal of these implicit memory trainings that include using a toothbrush and learning to use external cues for orientation (e.g., a calendar). However, another observation was that the "ability to drink from a cup, comb their hair and/or brush their teeth was preserved so long as the utensils for these procedures (the primers) were handed to them, and a request was made along with imitative motions" (Parahoo et al., 2006, p. 565). In their study, Parahoo et al. (2006) interviewed nurses in care homes about their use of implicit memory for caring. Their insights highlighted the reliance on personal experience and the experience of others during care practices. But the study pointed clearly towards the limitations of practices that use conscious recall. To be able to use implicit memory-informed care practices, knowing the person's biography, their worldview, preferences, and even their special interests and habits, were presented in the interview data. Having experience was interpreted to be beneficial in the creative use of practices. One experienced nurse observed the memory support practices of the younger colleagues who focused on newspapers and pictures to elicit memory and possibly narrative expression. The experienced nurse, however, took the person with dementia, who was an ex-farmer, out into the garden where he did not have to recall the past from his cognitive memory, but his body remembered. Parahoo et al., (2006) quote the nurse, "'[w]e were able to walk into the grounds of the hospital and we were able to walk on the grass, where it was damp and moist under our feet. We were able to kick leaves, to feel the wind, and the patient began to talk about the weather forecast and the hours of light that were left and about the cold.'" (p. 566f). The bodily experience of the environment enacted past memories of the person with

dementia. This way, he could not only remember the past, but parts of who he was. This practice example of using body memory, without the nurse or the authors framing it within the embodiment framework, shows the potential of care practices that are already installed in many care environments.

General care practices still rely on cued retrieval for memory support. The very limited data on care practices with deaf people living with dementia, supports this view. Rantapää et al. (2021) have investigated practices of formal caregivers with deaf people with dementia. Their data demonstrated memory support, alongside other support strategies through the use of "problem-focused solve behaviors: asking questions, probing with options, and providing verbal clues" (p. 376). Explicit recall was the first strategy, followed by using photos as external cues for conversation. Rantapää et al. (2021) reported that the caregiver mostly relied on explicit cognitive behavior (e.g., supporting with remembering the names of family members or temporal orientation). In conversation with the deaf person with dementia, after listening with empathy first, the caregivers seemed to get triggered to show "dismissing behaviors", presented with "disinterest or change[ed] the topic in an attempt to move the interaction forward" (p. 376). The "art of caring" (Parahoo et al., 2006, p. 568) for another human being, retaining selfhood of the person with dementia, is all but an easy task. The work with embodied practices of implicit memory of people with dementia (Fuchs, 2020; Kontos, 2005; Kontos et al., 2017) is a highly ethical one. "[E]ntering the person's world" (Parahoo et al., 2006, p. 567) to make ethical decisions regarding practices that open up space for creativity and expressivity is an even greater challenge in our multilingual and multicultural world, however, it is essential in order to retain selfhood of the person living with dementia. To bridge this intercultural gap, Rantapää et al. (2021) found that not only a high language competence is necessary, but an "equally important factor is the caregiver's communication competence" (p. 378). This supports findings by Kietzmann et al. (2016) that pointed out the relevance of emotional and social competences in care practices. One may, therefore, acknowledge the importance of the interaction between caregivers and people with dementia as a resource for therapy and care.

4.3.2 Study 3: Proposing resource-oriented concepts for dementia therapy and care of deaf persons with dementia

Study 3 is a conceptual transfer (Hallet, 2012) of the concepts of body memory (Fuchs, 2012) and intercorporeality (Merleau-Ponty, 1962) into the context of deaf persons living with dementia. The narrow focus of the re-contextualization of the existing concepts allows to both illuminate socio-cultural aspects of the Deaf community that have received less attention in the

literature, and outline concrete implications for therapy and care of deaf persons with dementia. The transferred concepts are body memory, collective body memory and intercorporeality, proposed by phenomenologists and integrated into the field of embodied cognition (Gallagher, 2023). The main results of study 3 are, firstly, the applications of Fuchs' (2012) typology of body memory to the population of deaf people: situational, traumatic and intercorporeal memory. In line with existing literature, the study argues that these forms of memory remain accessible even when living with dementia, and that they are a resource for therapeutic and care practices. Secondly, implications related to the physical environment (e.g., DeafSpace (Bauman, 2010) and affordances (Gibson, 1979), to the social interaction and general awareness of Deaf collective body memory provide new impulses to theory-informed practices.

5 DISCUSSION

"You can explain anything to the people,
provided you really want them to understand"
Fanon, 1963/2004, p. 200

This dissertation explored the question of what is needed to provide appropriate dementia-related healthcare for deaf people. This work acknowledges the stretch between the common cognitivist perspective and brain-based assessment in dementia diagnostics and the importance of dignified therapy and care of people living with dementia from an embodied perspective. To the field of neuropsychological assessment, this dissertation presented the first cognitive screening in German Sign Language for deaf DGS signers: the KoDGS (Study 1). A cultural test adaptation paradigm was developed with an emphasis on interdisciplinary collaboration, transdisciplinary participation, and community involvement to strengthen the test applicability and test acceptance. The rigorous approach focused on reliable and valid item selection during test adaptation and required psycholinguistic norming data to control for possible biases. Since no psycholinguistic norms on frequency and iconicity for DGS signs were available at that point, an experimental subjective rating study collected data on psycholinguistic DGS norms (Study 2). The results informed the KoDGS adaptation and will contribute to the field of open data in sign language research.

Having a reliable diagnosis changes a person's life. It is of highest importance/need to make sure that therapeutic and care practices support the person with dementia in coping and

adjusting to the changes. Study 3 discusses an account that regards the body as a resource for continuity on this path of change. The enactment of body memory enables those living with dementia to maintain their selfhood.

5.1 Bridging theory and practice

Theory can inform practice and practice can inform theory. This dissertation made an effort to embrace a wide range of focal points between theory and practice while not refraining from a thorough deep dive into the explicit contexts. To provide not only better but also urgently needed dementia-related healthcare for the deaf population, the following aspects are discussed: (1) *reducing disparities*, (2) *reconsidering the environment in assessment, therapy and care*, (3) *awareness of the practitioner*, (4) *reconsidering memory processes,* and (5) *reconsidering cognitive assessments through an embodied approach*.

5.1.1 Reducing disparities

One overarching theme throughout this dissertation is the lack of awareness of the needs of deaf people. A body of research clearly demonstrated the barriers for deaf people in the healthcare system (Cüre, 2020; Höcker, 2010; Kaul et al., 2009; Rannefeldt et al., 2023; Ricke et al., 2024; Schröder & Vereenooghe, 2021). The KoDGS offers a completely new way of testing and treating deaf individuals with dementia. The described overreliance on behavioral observation in diagnosing deaf people (Glickman & Gulati, 2003) should therefore be obsolete for the German context. Using quantitative measures, like the KoDGS (Study 1), in addition to behavioral observation has the potential to reduce disparities that were reported for minoritized and marginalized populations (Adelman et al., 2009; Armstrong-Mensah et al., 2024; Ferguson-Coleman et al., 2014). It is necessary that both deaf people and healthcare professionals are focused on to change the current desideratum. Reducing linguistic and cultural awareness in healthcare workers and increasing health literacy for deaf people are supposed to facilitate adequate healthcare (Duran-Kiraç et al., 2022). One example is the specialist clinic in the UK, the National Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery in London, which reduced health inequalities and increased diagnostic accuracy (Harris et al., 2021). This demonstrates some key components to reduce disparities. Integrating appropriate assessment into sensitive and Deaf aware contexts promotes better, meaning more equal, appropriate, and sufficient, healthcare (Atkinson et al., 2015; Harris et al., 2021). To my best knowledge, the above mentioned clinic operates mostly in-person, but the BSL-CST has

been conducted successfully in a remote setting as well. A cognitive assessment that has been developed for ASL focused on remote testing only (Timperlake, 2024) to possibly facilitate assessments without local specialist clinics. Future studies will benefit from incorporating remote testing into test norming and validation.

In Germany, the two specialist clinics in Lengerich (LWL-Clinic Lengerich, Treatment Center for the Hearing Impaired) and Erlangen (Department for the Hearing Impaired at the Europakanal Clinic in Erlangen) for deaf individuals are a fruitful ground for the KoDGS to be implemented. However, centralized care through centers rather than decentralized services that serve people in rural areas as well, are problematic for small populations living in scattered locations, such as the deaf population. In Study 1, a strong effort was made to build a heterogeneous sample of study participants from all over Germany to set the foundation for representability of the KoDGS norming data. Implementing the KoDGS as a tool to be accessible throughout Germany, has to be the subject of future research. Study 1 made a first step towards better diagnostic care of deaf sign language users in Germany, but much more work is needed to follow to implement the novel assessment tool into treatment protocols for deaf individuals.

Apart from treating protocols and appropriate and reliable language- and culture-sensitive tests, emotional and social competencies are needed to offer adequate care services (Kietzmann et al., 2016). Intercultural literacy and the openness to "enter[ ] the person's world" (Parahoo et al., 2006, p. 567) to connect in empathy beyond language and cultural barriers is an increasingly challenging task in our world. Interestingly, the openness and respect required to provide dignified care for a minoritized population is similar to the openness and respect that people living with dementia deserve. Making the effort to bridge the gap by being with the person, whether deaf or hearing, communicating through gestures and intercorporeal presence (Kontos et al., 2017) lowers or even eliminates barriers, allowing the person to retain their sense of self.

5.1.2 Reconsidering the environment in assessment, therapy, and care

The term 'environment', as it is used in this dissertation, includes the physical and the social environment of the person with dementia (Study 3). This refers to caregivers, informal and formal, to the social environment having deaf signers or mostly hearing non-signers, to the personalities of the caring persons and their personal openness and willingness to build Deaf awareness. It also refers to diagnosticians and their personalities and sensibility to be informed and aware. Environment is also the actual physical setting in which an assessment is conducted or a person with dementia is cared for: the building, the room, the lighting, the positioning of

the chairs, the visually accessible surrounding. It is crucial to carefully consider these aspects in a hearing-deaf interaction with people with (and even without) dementia (Study 3).

Being aware of the historical and psycho-social context in which deaf persons with dementia lived their earlier years, is critical to appropriate assessment and care. Disregarding the context factors may bias a test result or the interpretation of certain behaviors of deaf persons with dementia, resulting in dismissing reactions of caregivers. In order to be consciously sensitive to the social environment of the person, it is key to have sufficient background knowledge of the deaf person with dementia (Parker et al., 2010; Rantapää et al., 2023). Knowing how the person was educated and having a basic idea of the person's childhood and adolescence will guide the interaction (Rantapää et al., 2023) and determine appropriate selection of a screening test (Hill-Briggs et al., 2007). Intercorporeal memory plays a dominant role here (Study 3) in interactions throughout the lifespan and may even be pronounced with dementia when the socialized behavior diminishes. The high relevance of maintaining continuity for a person with dementia should not be underestimated (Fuchs, 2020). When a deaf person was socialized over years as a child to obey the hearing teachers/nuns and was physically punished for disobeying, this frequent behavior may have sedimented as a memorized pattern. Negative interactions with hearing people who told the deaf person what to do or not to do all shaped the intercorporeal memory over the lifespan. If this person develops dementia and tries to 'read the room' in a nursing home full of hearing people, linguistic communication will be very limited, making oneself understood will be even more difficult, which can lead to loss of control and agency. As a practitioner, reflecting on power differences between deaf patients or residents and hearing clinicians or caregivers, is highly important.

Choosing affordances, such as appropriate and accessible materials in nursing homes (Study 3), information material in sign language, and DGS-based assessment tools (Study 1) in clinics will enable the deaf person to interact and show natural-like behavior. This way, cognitive costs (Emmorey et al., 2016; Emmorey et al., 2020) due to switching between languages (in this context German and DGS) of the deaf person with dementia will be removed and a form of ease in interaction will be made possible. In assessment settings, affordances facilitate recognition and general engagement besides the test situation being already stressful enough. Having no language barrier during the assessment, clear visual fields and a sensitive person as diagnostician afford engagement and elicit cognitive performance without biases.

In care environments, affordances that are not deficit- but resource-oriented will best include embodied habits, arts-based practices, and embodied sensory stimulation in therapeutic and care practices (Dzwiza-Ohlsen & Kempermann, 2023; Kontos, 2003, Kontos et al., 2017;

Winniewski, 2022). This dissertation makes a strong point that positive affordances should best be aligned with the persons' body memory. Keeping the person in their stable and familiar environment maintains the access to familiar affordances and strengthens continuity (Fuchs, 2020). The person who often knows best about appropriate affordances for a person with dementia is mostly a close family member: the partner or a daughter or son. One may pose the question whether this means that caring for a person in their household by a family member should be considered the most appropriate care for people living with dementia. Already 86% of the care in Germany is provided by family caregivers, with 64% being women as primary caregivers, with a mean age of 54 years (for caring outside of one's own household) (Brandt et al., 2025). This increased caregiver burden and responsibility onto a large group of mostly women cannot be the solution.

The current crisis in the German healthcare system is in need of reform. Reconsidering current diagnostic, therapeutic and care practices, applying dementia-sensitive architecture and design, training caregivers and clinicians in dementia-sensitive and intercultural care, which includes Deaf awareness, even when a person has no sign language skills, and creating spaces that foster multimodal interaction and expressivity would all improve the situation of deaf persons with dementia.

5.1.3 Awareness of practitioners

This dissertation reviewed and gathered multidisciplinary evidence on the deaf population to build awareness amongst practitioners. It requires the acknowledgment that deaf people are a cultural and linguistic minority who are visucentric in nature (Ladd, 2003; O'Brien, 2021). As a consequence, culture-specific features should be considered, encompassing preferred visual communication and a community. To offer appropriate healthcare, the following aspects should be recognized: experiences with oralist education and violence and abuse in boarding schools, which have caused trauma (Hoffstadt, 2018; Ladd, 2003; McRae et al., 2025; Sullivan et al., 2000), resulting in an internalized pattern when speaking with hearing people (Kaul et al., 2009; Lane & Ladd, 2013; Rantapää et al., 2024), and that this language switch biases cognitive performance. Practitioners need awareness training that these experiences of deaf people have formed explicit and implicit memory, such as body memory. The increased vulnerability of a deaf person with dementia in 'the hearing world' requires to acknowledge the embodied intercorporeality in interactions. The lack to good quality education and barriers to access health-related information resulted in low health literacy amongst deaf people (Ferguson-Coleman, 2016; Ferguson-Coleman et al., 2014; Rogers et al., 2018; Kaul et al., 2009; Young

et al., 2016). On top, general cultural differences between deaf individuals from former East and West Germany should be kept in mind.

Acknowledging the linguistic character of deaf people means to understand that interaction in the local sign language can be the only secure form of communication. DGS grammar is unequal to German grammar, emphasizing the need to avoid written or spoken language in diagnostic assessments and therapeutic- and care-related affordances.

The reviewed lack of appropriate healthcare and the presented solution-oriented scientific contributions invite future research to elaborate on the topic. Future practice-oriented research may work on awareness for the deaf population within the healthcare system. An addition to the S3-Guideline 'Dementias' (DGPPN & DGN, 2025), comparable to the existing addition on culturally sensitive dementia diagnosis for people with a migrant background[8], could be one reasonable action. A shift towards care practices that incorporate an embodied approach should be applied in practice, with policies that guide caregivers to consider the cognitive, but also the physical, emotional, and sensory needs of individuals.

5.1.4 Reconsidering memory processes

One significant focus of this dissertation is the role of memory in dementia. Memory processing is impacting other cognitive domains, such as language. Distinguishing between explicit and implicit memory and between recall and recognition enriches our understanding of dementia. In diagnostic assessment of dementia, recall tasks targeting explicit memory are still mostly applied. This is probably due to explicit memory being affected at an earlier stage of dementia than implicit memory, i.e., procedural memory. The embodied form of implicit memory, body memory (Fuchs, 2008, 2012), has been acknowledged for therapeutic and care practices (Dzwiza-Ohlsen & Kempermann, 2023).

As reviewed in chapter 2, the underlying processing of information or events is influenced by features like familiarity, frequency, memorability, and iconicity. This has a direct connection to how well the information or event can be recollected. This link was focused on for DGS signs to control for bias in cognitive processing (Study 2). The KoDGS, just as most cognitive assessments, uses recall tasks that require knowledge of the sign frequency and sign iconicity when selecting test items (Study 1). Considering psycholinguistic features in cultural test

[8] Recommendation by DGPPN, DGGPP, DEGAM, and the German Alzheimer's Association. Improving dementia diagnosis for people with a migrant background. Appendix 1: Procedure for culturally sensitive dementia diagnosis based on the S3 guideline on dementia: https://www.dgppn.de/_Resources/Persistent/232f6fb55acd96fba7e50d9ed707ffb2bc9e6569/Anhang%201%20Ablauf%20Demenzdiagnostik.pdf , accessed 15.09.2025

adaptations is crucial and may be overlooked in simple test translations or even some adaptations. During the test development of the original BSL-CST, the researchers (Atkinson et al., 2015) controlled for sign frequency and sign iconicity based on BSL norming data (Vinson et al., 2008). Thus, a rigorous test adaptation should consider underlying cognitive processes (Study 1).

How are frequency and iconicity regarded and experienced through the body, and what could that mean in terms of retrieval performance, when shifting to an embodied approach?

I frame embodied frequency as perceived frequency of using a certain sign or word connected to real lived experience. There is a certain context to a word, a semantic field which cues certain associations to retrieve memory[9]. While the direct relationship between word/sign frequency and memory retrieval is not yet fully clarified, the link has been proven.

Future research may investigate the idea of embodied frequency and embodied iconicity and may look into the relations between embodied repeated movements and activities of the body in the embedding environment to recollect memories. This will inform especially therapeutic and care practices, as it was already reported from practices of experienced nurses (Parahoo et al., 2006) to support embodied memory retrieval. The embodied approach to memory challenges the cognitivist view through which dementia is still perceived (Kontos, 2003, 2004). Understanding the intersection of frequency, iconicity and memory in a deaf person whose embodied being is already pronounced (Study 3) will benefit foundational research on memory and language beyond the deaf population. Future research may challenge the current state of memory theory and the underlying mechanism of recollection memory by testing the theory in empirical studies on body memory and general embodied cognition.

[9] A personal example of this phenomenon, which I could not explain for a long time originated in East Africa, on Zanzibar. During a stay of several months on Zanzibar, I have lived through some time of extreme heat and humidity. The Kiswahili (locally spoken language) word that I probably heard the most every day and used several times a day myself was joto, meaning/signifying extreme heat. Several months later, I was sitting in wintery cold Vienna in a Kiswahili class, and when I was asked the Kiswahili word for 'heat', I could not recall it. Once told the correct word – joto – I was shocked about how I could forget, and I immediately felt thrown back to the lived experience of months ago like a re-enactment of those embodied memories.
Many years later I have learned that this was a context-dependent memory (the context being probably tropical humid heat), which is more difficult to access and retrieve in a different context such as Austrian winter. On top, one can argue that the lived experience of humid heat combined with the natural use of the word several times a day with other persons who shared the environment, created an embodied word frequency, a deeply rooted context-dependent experience of high-frequent word use. In an embodied sense, this example describes situational memory and intercorporeal memory.

5.1.5 Reconsidering cognitive assessments through an embodied approach

The proposal of an embodied cognition framework to dementia-related therapy and care has enriched the discussion around dignified care (Dzwiza-Ohlsen, 2021; Kontos, 2004, 2005, 2012; Kontos & Martin, 2013; Winniewski, 2022). This dissertation contributes to the discussion by presenting the deaf population to the field that has already an increased embodied expression. The concepts of Deaf body memory and Deaf collective body memory can be applied to and implemented into future sensitivity training to foster understanding of deaf people's often unfamiliar cultural aspects. The practice-oriented implications (Study 3) further support future applicability in dementia therapy and care.

The body-environment axis plays a significant role in memory processing as it was reviewed from early research on dependencies of memory retrieval, inspiring the Proust-effect. While concepts such as the Clinical Body Memory mechanism (Gentsch & Kühn, 2022) have been proposed to include the body into therapeutic practices, the question remains: why is it, that embodied cognition is applied so little in clinical assessment practice? I argue that one answer is reliability.

Clinical assessments require quality criteria, such as validity, objectivity, and reliability, to obtain psychometric data. Conceptualizing an embodied cognitive assessment would include to take into account that cognitive processes are rooted in physical actions, bodily sensations, and interactions with the world. The Automated Test of Embodied Cognition (ATEC) (Bell et al., 2023) and the gait analysis are examples of embodied sensorimotor integration to infer cognitive functioning. The use of virtual reality could be applied to include the notion of an embedding environment, and influence possible negative influences of a clinical, and hearing dominated environment. It may be used as well to assess interactions with concrete objects and people. Eye-tracking may also serve as a future method for studying attention and perception during bodily active tasks. All of this will be particularly interesting when comparing hearing non-signers and deaf signers, as their embodied sense of being in the world may affect their embodied cognitive performance. Obtaining psychometric data for the proposed assessments will present another challenge, with reliability likely to be a key issue.

5.2 Constructive collaborations, participation, and community involvement

Study 1 and 2 have emphasized the importance of collaborations and community involvement (Study 1) and problematized participatory research practices (Study 2). This section will briefly

position this dissertation within the field of research on sign languages and on the deaf population.

It is both a personal and professional conviction that hearing researchers have a responsibility to reduce barriers within academia and the sciences for deaf individuals, and to attain fluency in a sign language in order to develop a deeper, more authentic understanding of the community they study. The concept of hearing allies to deaf persons, which was proposed by Paddy Ladd (2003), is still highly relevant. A collegial coexistence and collaborative environment, which truly involves interaction with as little barriers as possible and on an equal footing, is the kind of research ethic that I have tried to live up to, accepting the challenges that come with it and working to become a better researcher, ally and collaborator.

The three collaborations on the three studies presented in this dissertation have demonstrated very different facets. In Study 1, every step of the KoDGS adaptation was in a deaf-hearing collaborative setting, such as the focus groups, the test recording with the co-researcher, publishing with the international co-authors, while I was navigating the entire research process by myself. Study 2 was a far narrower and focused collaboration between deaf and hearing researchers. Reflecting on this experience, it all required adjustments to different degrees on both sides. Distinguishing between a participatory researcher or a collaborator has been a key learning in the process. Defining a collaboration between deaf and hearing researchers on eye level comes with responsibility, willingness, discipline, and the often referenced 'benefit of the doubt' for all collaborating researchers. The effort of making oneself understood both linguistically and cognitively/intellectually is of main importance for a fruitful and respectful collaboration. Becoming a more proficient signer, more skilled in social communication and technical sign vocabulary, was one goal along the way. Another one was respecting the time and patience that the collaborations needed without disregarding the elevated value of the insights and evidence. Most of all, it opened up the prospect of immediate applicability and utilization of the research results. Study 3 was a collaboration with a hearing colleague who has been working in the field in academia and practice with deaf people over 20 years. We have reflected our hearing perspective before and throughout the collaboration, and we are both aware of our hearing perspective and confident of its significance as an ally in the discourse.

In sum, the collaborations enriched the studies and brought joy to the research process, which is a factor that should not be underestimated in doing long-running research.

5.3 Strengths and limitations

This dissertation offers a broad scope on the diagnostics, therapy, and care of dementia in deaf people. With three unique contributions to a multidisciplinary field of (dementia) research, it focuses on the reliability and validity in test adaptations and the embodied memory as a concept to improve dignified dementia care. The rigor of this dissertation is considered through the detailed reports of all methodological decisions and research steps (Study 1 and 2). The common test adaptation steps (see Mirza et al., 2017) were reflected for their applicability to the deaf population and sign language-based tests, resulting in a comprehensive cultural test adaptation paradigm that enriches the field (Study 1). The sample size of 99 study participants in Study 1 who were tested across Germany indicates a rigorous approach to representability and inclusion of the heterogeneous deaf population. The rigor is also evident in the careful and thorough approach to the topics collaboration and participation in deaf-related and sign language research (Study 2, see more details in chapter 5.2.). The explorative work in aiming for highly reliable psycholinguistic norms to be openly used in diverse contexts (Study 2) adds to this. The narrower view on dementia care through the framework of embodied cognition strengthens this dissertation as well. The concrete transfer of the embodied concepts (Hallet et al., 2012) body memory and intercorporeality to the context of the deaf population adds a new approach to the literature around healthcare of deaf people (Study 3).
Four identified and impactful aspects will be discussed within this scope: (1) *collective or individual,* (2) *being deaf or hearing*, (3) *cross-language and cross-cultural processes*, and (4) *in-person or online*.

5.3.1 Collective or individual

A community as small as the Deaf community is referred to as a collective community (Padden & Humphries, 1988). While the collective may be emphasized to strengthen the personal identity, much research has demonstrated the heterogeneity amongst the deaf population (in Germany, i.a., Haug, 2012; Haug & Mann, 2007; Langer, 2012, 2018; Mann et al., 2013). There are multiple reasons for this, so this challenge is not special to this dissertation. However, diverse backgrounds can become relevant when developing a standardized tool that, on top, relies on shared memories, thus, a collective experience of the past. This collective memory has been shaped in two separate German states until the fall of the Berlin Wall. During my fieldwork in 2022 and 2023 for Study 1, I encountered deaf people from the former DDR who sadly reported how the sense of community had changed, even within the small Deaf community, and

that it had been challenging for them to grow together as one German Deaf community after 1990. Separate collective memories of political and sports events made the foundation of one joint Deaf collective memory harder. Differentiating carefully between collective and individual experience demonstrated as a key point during this dissertation.

5.3.2 Being hearing or deaf

It should not be ignored that this research was conducted by a hearing researcher, who is a fluent signer of DGS though. During the fieldwork, when I met with the 99 study participants of Study 1, the deaf person often instantly switched to spoken language with me, once informed about my hearing status. For readers without prior knowledge and experience of interacting with deaf sign language users, it is important to understand this as the deaf individual's choice to communicate in a language (spoken German) that they could not perceive themselves in. This is due to the internalized communication patterns rooted in oral education and forced practice of articulation when communicating with hearing people, which older deaf adults experienced in their early life.

When I continued signing with them during our meeting, most of them uttered a relief to "save their voice" (as they signed in DGS 'STIMME SPAREN'[10]) and said that it was unusual for a hearing person to sign with them. It was crucial to make sure that the study participant used the preferred language to answer to the KoDGS tasks. A hearing researcher may impact the chosen language of expression without consciously thinking about the consequences. A change in language and language modality may heavily influence their fluency and elaborateness of linguistic expression and, therefore, their cognitive performance. These behavioral observations support findings in bilingualism research on cognitive costs in bilingual processing (Emmorey et al., 2016; Emmorey et al., 2020).

5.3.3 Cross-language and cross-cultural processes

A study conducted in a sign language requires a written language for many subsequent research steps, e.g., annotation, transcription, analysis and publication. The empirical studies (Study 1 and 2) of this dissertation (just as all studies in the field) involved cross-language and cross-cultural processes (see Orfanidou et al., 2015; Temple & Young, 2004). Young et al. (2014) reflected on this issue for BSL and English in their study on interviews with deaf people living

[10] Words in capitalized letters are used to write glosses that signify the uttered signs

with dementia. “Data were collected in BSL, analyzed in BSL and are being presented in English to a largely non-culturally Deaf readership” (ibid, p. 64). The same holds for the empirical studies of this dissertation in which BSL, English, DGS and German were the present languages. Different from an interview study, however, is that the research results are publicly available in DGS and German as ‘products’ of the studies: the KoDGS test videos and test manual (Study 1) and the stimuli signs and the connected sign iconicity and sign frequency rating data (Study 2). However, presenting the deaf individuals who participated, in particular, in the norming study of the KoDGS (Study 1) in a more “explicit and visible” (ibid., p. 64) manner remained a challenge due to the high need of anonymity and protection of the personal data that was shared. Nevertheless, chapter 5.4. will make an attempt to describe the explicitly expressed needs within the current healthcare situation that deaf people are exposed to.

5.3.4 In-person or online

This piece of interdisciplinary research encompasses different research methods. Both empirical studies (Study 1 and 2) used a cross-sectional study design, Study 1 an in-person and Study 2 an online setting. While Study 2 originally aimed at an in-person data collection, as reflected upon in detail in the full publication of the study (see Appendix), the study design had to be adjusted to online. Online data collection within the field of sign language psycholinguistics is common (Caselli et al., 2017; Ortega et al., 2025; Sehyr et al., 2021), however, little open discourse has taken place around the topic of reliability in online study results. Measures to reveal a participant’s identity as a deaf signer in an anonymous online setting were proposed and applied (e.g., Caselli et al., 2017), and post-data collection cleaning of the data respectively were used (Ortega et al., 2025). Study 2 contributed to the field by adding a two-level cross-data comparison, which indicated a direct association with objective measures. What remains unclear is whether the mode of data collection had the most impact on this, probably not. Future research may elaborate on this issue to clarify the effects of online vs in-person data collection in experimental studies. Study 1, however, is a behavioral study that assessed the cognitive functions of the study participants in the vulnerable realm of dementia diagnostics. The in-person participation allowed for interaction between study administrator and participant, enabling attunement and reacting in case of fatigue or irritation. Fortunately, research is also exploring online assessment of cognitive functioning (Timperlake, 2024). This dissertation argues that the face-to-face encounters with all study participants should not be underestimated. Every single person who participated in the study came with some form of question about dementia, cognition, behavioral changes, aging, or need of support. The limited

availablity of information on dementia for deaf people (Young et al., 2016) became evident, which is generally not unusual for minoritized populations (Duran-Kiraç et al., 2022; LaFontaine et al., 2007; Parial et al., 2023). The in-person design opened the floor for a more informative, reciprocal, interactional and intercorporeal experience. The research setting initiated and formalized the meeting. In the 20 to 60 minutes long pre-testing interviews and during experimental testing, the study participants then shared personal information. Personal life experiences that included trauma and periods of mental health issues over the entire lifespan were shared. The openness and trust of the persons were invaluable and not taken for granted. In those in-person interviews, I attuned with the person (study participant), and the vulnerability of the topic at hand revealed itself. The willingness to participate in the study, despite the possible and fearful stigmatization from other deaf people within the community, revealed the high need for information and improved services in healthcare around dementia for deaf people.

5.4 Call for action – a phenomenological perspective

During the detailed interviews prior to the KoDGS testing, the participants gave deep insights into their personal life stories. Since it was not the main research objective of the study to document life stories and medical history, the interviews were not recorded, but notes were taken by the interviewer (the author) with any identifying details removed to protect participants' anonymity. This camera-free and safe space with full presence might well be the reason why so many of the participants shared their stories generously. The reviewed evidence of the underserved healthcare situation of deaf people (chapter 3) became visible during data collection for Study 1. The total lack of appropriate services for most deaf people is their daily reality. In order to strengthen the arguments regarding the lack of support services, the higher risk of dementia due the lack of mental health services and information to stay educated, and the lack of culturally sensitive dignified care, three scenes are presented. All three scenes took place as they are described from my perspective and are therefore phenomenological descriptions. They convey the increased vulnerability, the heterogeneity, the experienced ostracism and discrimination, and the needs of the deaf population. These issues require to be understood in the context provided in this dissertation.

The uncared for carer

She smiled as she welcomed me to her cozy home and made sure that I felt completely comfortable. Since it was lunch time, she prepared a warm delicious meal that she had decided

on after inquiring my food preferences. I sat with her mother in the kitchen and enjoyed my lunch. But she, herself, barely ate, and was taking care of her mother and myself. The restlessness in her whole body, her eyes focusing just for a short moment before continuing to spot the next thing to serve, a person to take care of, or a need to satisfy. We eventually sat down, just the two of us, in her living room. Her restlessness followed her into this moment, her eyes had a searching quality about them, constantly moving and not holding eye contact for long. Her signing was quick and short, and her shoulders tight. I asked her if she wanted to start with the study, and she agreed. Her eyes appeared tired, and she mentioned other tasks related to her mother, her body tense and restless despite the exhaustion. She told me that she was the primary caregiver of her mother-in-law, who lived with dementia and was bedridden. Her eyebrows furrowed and her forehead tense, she signed about the shouting and dismissive behavior of her mother-in-law, who shouted at her and expected her to understand her spoken words. But she didn't, because she was deaf. Her hearing aids transported the shouting, but did not intelligibly convey everything that was said. Her arms moved with noticeable heaviness. Then she told me that she was still working on a daily basis while caring for her mum, her mother-in-law with dementia, and for her home. When we reached the point in the conversation about her health, her facial expressions conveyed apprehension. Her eyes were moving, seeking for something. She admitted that she was forgetful and had difficulties memorizing all her daily tasks, and that she felt regularly sad and depressed simply from the exhaustion of her day. I asked her what she did for herself. In that moment, her eyes welled up, searching, while her shoulders slumped. I offered her the glass of water that she had provided for me, and I thought of the warm welcome and the carefully and thoughtfully prepared lunch she had taken only few bites of and did so mostly standing or running around. She continued to sign that there was no support for her as a deaf caregiver: where can I find information in DGS on caring for someone with dementia? The support groups for family caregivers in the region were all for hearing people and ran in spoken German. She had gone once, but couldn't keep up, and felt uncomfortable, and couldn't connect with the hearing people, on top of her limited access to the shared information. She mentioned that gossiping within the Deaf community built a barrier for her to reach out and look for other deaf persons to feel understood and comforted. She conveyed a never-ending circle of more and more tasks and closed doors of support every day. As I approached the front door to leave, we hugged. My chest and shoulders felt heavy. Standing by the door, she waved goodbye with melancholic eyes, and I asked myself: Who is caring for her as she cares for everyone around her?

It's not (always) how it seems

When he entered the Deaf club, he greeted me using speech. He smiled broadly and enthusiastically at me. I signed back to him which he answered may not be necessary. I was irritated. We sat down and started the interview and he told me that he was hard-of-hearing because he could hear voices and understand language through the supporting hearing aids. He smiled proudly and emphasized that he spoke much better than many of the deaf people around him and that he supported many of them with his good speech. His friendly voice, his warm and open smile made the impression on me that he was well. I wondered if he needed a sign language-based assessment, given that he indicated that he can manage in spoken language interactions. But when I stopped signing and spoke to him, his eyes got focused on my mouth, his facial expression showed strain, while his mouth tried to keep the smile. I started signing again and told him that I was more than happy to sign and that he could sign with me as well. He told me that he had learnt to speak well as a child and "enjoyed talking to them", with 'them' referring to hearing people. Over time, the intensity of his smile softened, and a soft melancholy and tiredness began to show in his eyes. He opened up to me and described the exhaustion he experiences in spoken language interactions and how challenging they are for him. I proposed that he use the language in which he felt totally comfortable to answer the KoDGS. And he mostly signed them. After the test session, he revealed that he couldn't have been tested like this in a spoken language. And he used DGS and some spoken words to tell me about how supported he feels within the Deaf community. And that he lived through a phase of depression at some point in his life, without deeper explanation of the cause. He continued that he felt at ease with the effortless visual communication while getting informed during social Deaf events. When he left, his face had changed. He smiled warmly and softly, and we hugged.

A life (not) worth living

We met at his home. He invited me in and straight away indicated the way to the living room where he asked if we could start soon. His small eyes were deeply set and were focused. He rarely used facial expressions, and it was difficult for me to read his emotions. His focused eyes had an earnestness about them. His signing was large, fast, and soft. He didn't use any sound and hardly any mouthings when he signed. I had the impression that he was very concentrated on the task and so I hurried to set up for the interview. Almost immediately after starting the interview, he told me about his experience as a child when he was in a boarding school and

exposed to oral education. When he told me about those years at school, his neutral facial expression changed as his eyebrows and eyes narrowed, and his signing lost its gentle, fluid movements and became harder and more distinct. He shared that he had witnessed dementia in his family as an adult and that he was afraid of having or getting dementia himself, knowing that therapies and appropriate dementia care for deaf people did not exist in Germany. I could see that he was very well informed, and based on his rational argumentation, his job and educational background, he was a well-educated person. He made it very clear and repeated it more than once that he would rather take his own life than be kept in a nursing home surrounded only by hearing people who couldn't sign, and have to relive his traumatic years from his childhood in the oral school environment at the boarding school. His signing was large, clear and emphatic when he emphasized that being locked away and totally isolated from a signing environment, would not be a life worth living. After the interview, he drove me to the train station. When we said goodbye, his facial expression had changed, there was a slight smile, warm and gentle, next to the heaviness around his eyes. He hugged me tightly, I got out of his car, he waved at me and drove off.

6 CONCLUSION

"Dementia is hard, but it needn't be this hard"
Basting, 2009, p. 1

The currently profoundly underserved deaf population requires significantly improved, appropriate high-quality services that are at least equivalent to those available to the hearing majority, in order to reduce existing disparities. This dissertation demonstrated the importance of adapting tests rigorously, taking linguistic, psycholinguistic and memory processes into account. The frequency or the iconic value of a sign has significant impact on the ability to retrieve an information in a diagnostic test setting or a therapeutic care practice. Research, therefore, benefits from acknowledging the multidisciplinary aspects of certain constructs such as memory or dementia to develop, transfer or adapt applications with validity and reliability.
Cognitive assessments for deaf individuals to detect acquired cognitive impairment and dementia require sign language-based screening tools, even for individuals who may use spoken language with the medical staff. While the KoDGS as a new screening tool which is the first to appropriately screen deaf signers for acquired cognitive impairment and dementia in DGS, may improve the protocol of dementia diagnostics for deaf people and facilitate more accurate diagnoses, it is the first step of many to what is needed to improve the situation of the tremendously underserved group of deaf people.
Caring for deaf people with dementia through an embodied perspective enables more dignified care. As dementia affects explicit memory while implicit memory is retained much longer into the (neurodegenerative) process, it is the body memory through which the person senses their continuity and, therefore, their selfhood. More embodied dementia-related practices in clinics and care homes, the use of appropriate affordances and awareness trainings that convey the needs and background information of diverse populations, may function as bridges between (hearing) staff and (deaf) persons with dementia to promote well-being and better quality of life. Shifting the perspective from considering dementia only from the brain to acknowledging the role of the body shaping the mind, will foster an environment, which supports people with dementia and their caregivers, and sees the life with dementia and not just the painful road towards the end.

7 REFERENCES

2024 Alzheimer's disease facts and figures. (2024). *Alzheimer's & Dementia*, *20*(5), 3708–3821. https://doi.org/10.1002/alz.13809

Adelman, S., Blanchard, M., & Livingston, G. (2009). A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain. *International Journal of Geriatric Psychiatry, 24*(6), 657–665. https://doi.org/10.1002/gps.2175

Alys, G. (Ed.). (1989). *Aktion T4 1939–1945: Die „Euthanasie"-Zentrale in der Tiergartenstraße 4*. Edition Hentrich.

Alzheimer's Disease International. (2024). World Alzheimer Report 2024: Global changes in attitudes to dementia. London, England: Alzheimer's Disease International.

Alzheimer's Research UK. (2023). Dementia attitudes monitor. Wave 3. https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf (accessed 05.09.2025).

American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders*. American Psychiatric Association.

Ammons, D., Engelman, A., & Kushalnagar, P. (2020). Quality of Life and Needs of Deaf Informal Caregivers of Loved Ones with Alzheimer's and Related Dementia. *Gerontology and Geriatric Medicine*, *6*, 233372142096651. https://doi.org/10.1177/2333721420966518

Armstrong-Mensah, E., Adjini, M., Pringle-Weston, B., Akosah, A., & Addo, R. (2024). Late Dementia Diagnosis Among Elderly Minority Populations in the United States: Causes, Effects, and Addressing Inequities. *International Journal of Translational Medical Research and Public Health*, *8*, e010. https://doi.org/10.25259/IJTMRPH_38_2024

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.

Atkinson, R. C., & Juola, J. F. (1973). Factors influencing the speed and accuracy of word recognition. In S. Kornblum (Ed.), *Attention and performance IV* (pp. 583–612). Academic Press.

Audrain, S., Gilmore, A. W., Wilson, J. M., Schacter, D. L., & Martin, A. (2022). A Role for the Anterior Hippocampus in Autobiographical Memory Construction Regardless of Temporal Distance. *The Journal of Neuroscience*, *42*(33), 6445–6452. https://doi.org/10.1523/JNEUROSCI.0832-22.2022

Baddeley, A., Eysenck, M. W., & Anderson, M. C. (2015). *Memory* (2nd ed.). Psychology Press.

Ballasch, I., De Kruif, A., Hendel, M. K., Rohr, C., Brünecke, I., Kalbe, E., Völter, C., & Kessler, J. (2023). O-DEM: Ein neues kognitives Screening bei Schwerhörigkeit. *HNO*, *71*(9), 599–606. https://doi.org/10.1007/s00106-023-01293-y

Bartolomei, F., Lagarde, S., Médina Villalon, S., McGonigal, A., & Benar, C. G. (2017). The "Proust phenomenon": Odor-evoked autobiographical memories triggered by direct amygdala stimulation in human. *Cortex*, *90*, 173–175. https://doi.org/10.1016/j.cortex.2016.12.005

Basting, A. D. (2009). *Forget memory: Creating better lives for people with dementia*. JHU Press.

Bauman, H.-D. L. (Ed.). (2008). *Open Your Eyes: Deaf Studies Talking.* University of Minnesota Press.

Bauman, H. (2010). *DeafSpace Design Guidelines.* Gallaudet University.

Behuniak, S. (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society 31*(1), 70–92.

Bell, M. D., Hauser, A. J., & Weinstein, A. J. (2023). The Automated Test of Embodied Cognition: Concept, development, and preliminary findings. *Brain Sciences, 13*(6), 856. https://doi.org/10.3390/brainsci13060856

Bell, M. D., Weinstein, A. J., Pittman, B., Gorman, R. M., & Abujelala, M. (2021). The Activate Test of Embodied Cognition (ATEC): Reliability, concurrent validity, and discriminant validity in a community sample of children using cognitively demanding physical tasks related to executive functioning. *Child Neuropsychology, 27*(7), 973–983.

Bellini-Leite, S. C. (2022). Dual Process Theory: Embodied and Predictive; Symbolic and Classical. *Frontiers in Psychology*, *13*, 805386. https://doi.org/10.3389/fpsyg.2022.805386

Bierbrauer, A., Fellner, M.-C., Heinen, R., Wolf, O. T., & Axmacher, N. (2021). The memory trace of a stressful episode. *Current Biology, 31*(22), 5204–5213.e8. https://doi.org/10.1016/j.cub.2021.09.013

Biesold, H. (1988). *Klagende Hände: Betroffenheit und Spätfolgen in Bezug auf das Gesetz zur Verhütung erbkranken Nachwuchses, dargestellt am Beispiel der "Taubstummen"*. Jarick Oberbiel.

Blotenberg, I., Hoffmann, W., & Thyrian, J. R. (2023). Dementia in Germany: Epidemiology and prevention potential. *Deutsches Ärzteblatt international*. https://doi.org/10.3238/arztebl.m2023.0100

Boller, F., & Forbes, M. M. (1998). History of dementia and dementia in history: An overview. *Journal of the Neurological Sciences*, *158*(2), 125–133. https://doi.org/10.1016/S0022-510X(98)00128-2

Bosworth, R. G., & Emmorey, K. (2010). Effects of iconicity and semantic relatedness on lexical access in american sign language. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *36*(6), 1573–1581. https://doi.org/10.1037/a0020934

Bourdieu, P. (1990). *The logic of practice* (R. Nice, Trans.). Stanford University Press.

Braak, H., Thal, D. R., Ghebremedhin, E., & Del Tredici, K. (2011). Stages of the pathologic process in Alzheimer disease: Age categories from 1 to 100 years. *Journal of Neuropathology & Experimental Neurology, 70*(11), 960–969. https://doi.org/10.1097/NEN.0b013e318232a379

Brandt, M., Ehrlich, U., Geyer, J., Haan, P., & Kelle, N. (2025). Größter Pflegedienst in Deutschland: Millionen Menschen pflegen Angehörige inner- und außerhalb ihres Haushalts. *DIW Wochenbericht*. https://doi.org/10.18723/DIW_WB:2025-37-1

Briceño, E. M., Mehdipanah, R., Gonzales, X. F., Heeringa, S. G., Levine, D. A., Langa, K. M., Zahs, D., & Garcia, N. (2021). Bilingualism, assessment language, and the Montreal Cognitive Assessment in Mexican Americans. *Journal of the American Geriatrics Society, 69*(7), 1971–1981. https://doi.org/10.1111/jgs.17209

Brijnath, B., Croy, S., Sabates, J., Thodis, A., Ellis, S., De Crespigny, F., Moxey, A., Day, R., Dobson, A., Elliott, C., Etherington, C., Geronimo, M. A., Hlis, D., Lampit, A., Low, L., Straiton, N., & Temple, J. (2022). Including ethnic minorities in dementia research: Recommendations from a scoping review. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *8*(1), e12222. https://doi.org/10.1002/trc2.12222

Brockmann, E., & Kozelka, E. (2020). Forced sterilization of deaf people during German National Socialism – A trauma and its compensations after 1945. In R. Pfau, A. Göksel, & J. Hosemann (Eds.), *Elderly deaf signers: Cultural, linguistic, and sociolinguistic perspectives* (pp. 197-216). De Gruyter Mouton.

Brünecke, I., Hölsken, S. & Kessler, J. (2018). Der DemTect Eye+Ear - Neues kognitives Screeningverfahren bei schwerhörigen Menschen mit Demenzverdacht. *Zeitschrift für Audiologie*, *57*(3), 121.

Buchanan, B., Tsiakas, K., & Bell, M. (2019). Towards an automated assessment for embodied cognition in children: The sailor step task. *Proceedings of the 12th ACM International Conference on PErvasive Technologies Related to Assistive Environments*, 331–332. https://doi.org/10.1145/3316782.3322744

Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) & Bundesministerium für Gesundheit (BMG) (2020). *Nationale Demenzstrategie*. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/2020-07-01_Nationale_Demenzsstrategie.pdf (accessed 25.08.2025)

Buñuel, L. (1987). *My last breath* (Mon dernier soupir). Fontana. (Original work published 1985).

Büttner, M. (2005). *Nicht minderwertig, sondern mindersinnig... Der Bann G für Gehörgeschädigte in der Hitler-Jugend*. Peter Lang.

Camp, C. J., Foss, J. W., O'Hanlon, A. M., & Stevens, A. B. (1996). Memory Interventions for Persons with Dementia. *Applied Cognitive Psychology*, *10*(3), 193–210. https://doi.org/10.1002/(SICI)1099-0720(199606)10:3<193::AID-ACP374>3.0.CO;2-4

Caruso, G., Perri, R., Fadda, L., Caltagirone, C. & Carlesimo, G.A. (2020). Recall and Recognition in Alzheimer's Disease and Frontotemporal Dementia. *Journal of Alzheimer's Disease, 77*(2), 655-666. doi:10.3233/JAD-200126

Caselli, N., Sevcikova Sehyr, Z., Cohen-Goldberg, A. M., & Emmorey, K. 2017. ASL-LEX: A lexical database of American Sign Language. *Behavior Research Methods 49*(2): 784-801. doi:10.3758/s13428-016-0742-0

Chen, M.-S., Chen, W.-R., & Lee, H.-M. (2019). Memory performance of people with different dementia severity for different semantic hierarchies. *Experimental Aging Research, 45*(3), 266–281. https://doi.org/10.1080/0361073X.2019.1609157

Claparède, E. (1911). Reconnaissance et moitié. *Archives de Psychologie, 11*, 79–90.

Clark, D.M., & Teasdale, J.D. (1982). Diurnal variation in clinical depression and accessibility of memories of positive and negative experiences. *Journal of Abnormal Psychology, 91*(2), 87-95.

Co, M., Couch, E., Gao, Q., Mac-Ginty, S., Das-Munshi, J., & Prina, M. (2021). Access to Health Services in Older Minority Ethnic Groups with Dementia: A Systematic Review. *Journal of the American Geriatrics Society*, *69*(3), 822–834. https://doi.org/10.1111/jgs.16929

Cüre, E. (2020). *Erfahrungen gehörloser Patienten im ambulanten Gesundheitssystem: Eine qualitative Befragung von Gehörlosen und Gebärdensprachdolmetschern* [Experiences of deaf patients in the outpatient healthcare system: A qualitative survey of deaf individuals and sign language interpreters]. (Doctoral dissertation). Friedrich-Schiller-University Jena.

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

Dean, P. M., Feldman, D. M., Morere, D., & Morton, D. (2009). Clinical Evaluation of the Mini-Mental State Exam with Culturally Deaf Senior Citizens. *Archives of Clinical Neuropsychology*, *24*(8), 753–760. https://doi.org/10.1093/arclin/acp077

De Biran, M. (1929). *The influence of habit on the faculty of thinking.* Williams & Wilkins.

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

Descartes, R. (1894). *Discours de la méthode pour bien conduire sa raison et chercher la vérité dans les sciences* [Discourse on the method to conduct one's reason and search for truth in the sciences]. Librairie de la Bibliothèque Nationale.

DGN e. V. & DGPPN e. V. (2025). S3-Leitlinie Demenzen, Version 5.2, 17.07.2025, available via: *https://register.awmf.org/de/leitlinien/detail/038-013*, accessed 21.08.2025

Dittrich, L. (2016). *Patient H.M. A story of memory, madness and family secrets*. Vintage.

Dunn, R. (1845). Case of suspension of the mental faculties. *The Lancet, 2*, 588–590.

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., Van Hout, H., & Broese Van Groenou, M. I. (2022). Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: A scoping review of European literature. *Dementia*, *21*(2), 677–700. https://doi.org/10.1177/14713012211055307

Dzwiza-Ohlsen, E. N. (2021). Dementia as Social Disorder – A Lifeworld Account. *Phenomenology & Mind*, 74. https://doi.org/10.17454/pam-2106

Dzwiza-Ohlsen, E. N., & Kempermann, G. (2023). The embodied mind in motion: A neuroscientific and philosophical perspective on prevention and therapy of dementia. *Frontiers in Psychology*, *14*, 1174424. https://doi.org/10.3389/fpsyg.2023.1174424

Eich, J.E. (1980). The cue-dependent nature of state-dependent retrieval. *Memory and Cognition, 8*(2), 157-173.

Eich, E., Macaulay, D., & Ryan, L. (1994). Mood dependent memory for events of the personal past. *Journal of Experimental Psychology: General, 123*(2), 201-215.

Emmorey, K., Giezen, M. R., & Gollan, T. H. (2016). Psycholinguistic, cognitive, and neural implications of bimodal bilingualism. *Bilingualism: Language and Cognition*, *19*(2), 223–242. https://doi.org/10.1017/S1366728915000085

Emmorey, K., Li, C., Petrich, J., & Gollan, T. H. (2020). Turning languages on and off: Switching into and out of code-blends reveals the nature of bilingual language control. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *46*(3), 443–454. https://doi.org/10.1037/xlm0000734

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

Fanon, F. (2004). *The wretched of the earth* (1963). Grove Press. https://dn790007.ca.archive.org/0/items/the-wretched-of-the-earth/The%20Wretched%20Of%20The%20Earth.pdf

Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet, 379*(9820), 1037–1044. https://doi.org/10.1016/S0140-6736(11)61143-4

Ferguson-Coleman, E. L. (2016). *Deaf with dementia: A narrative*. (Doctoral dissertation). University of Manchester.

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

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

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). « Mini-mental state »: a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research*, *12*(3), 189–198.

Fried, L. P., Tangen, C. M., Walston, J., Newman, A.B., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W.J., Burke, G. & McBurnie, M.A. (2001). Frailty in older adults: Evidence for a phenotype. *Journal of Gerontology*, 56A(3), 146–156.

Fuchs, T. (2008). Leibgedächtnis und Lebensgeschichte [Body memory and life history]. In F. A. Friedrich, T. Fuchs, J. Koll, B. Krondorfer, & G. M. Martin (Eds.), *Der Text im Körper. Leibgedächtnis, Inkarnation und Bibliodrama* [The text in the body. Body-memory, incarnation, and bibliodrama] (pp. 10–40). EB-Verlag.

Fuchs, T. (2012). The phenomenology of body memory. In S. C. Koch, T. Fuchs, M. Summa, & C. Müller (Eds.), *Body memory, metaphor and movement* (pp. 9–22). John Benjamins Publishing Company.

Fuchs, T. (2017). Self across time: The diachronic unity of bodily existence. *Phenomenology and the Cognitive Sciences, 16*(3), 291–315. https://doi.org/10.1007/s11098-017-0864-2

Fuchs, T. (2020). Embodiment and personal identity in dementia. *Medicine, Health Care and Philosophy*, *23*(4), 665–676. https://doi.org/10.1007/s11019-020-09973-0

Gallagher, S. (2005). *How the Body Shapes the Mind* (1st ed.). Oxford University Press. https://doi.org/10.1093/0199271941.001.0001

Gallagher, S. (2023). *Embodied and Enactive Approaches to Cognition*. Cambridge University Press. https://doi.org/10.1017/9781009209793

Gates, N. J., Sachdev, P. S., Fiatarone Singh, M. A., & Valenzuela, M. (2011). Cognitive and memory training in adults at risk of dementia: A Systematic Review. *BMC Geriatrics*, *11*(1), 55. https://doi.org/10.1186/1471-2318-11-55

G-BA (Gemeinsamer Bundesausschuss). (2024). Richtlinie des Gemeinsamen Bundesausschusses über die Durchführung der Psychotherapie (Psychotherapie-Richtlinie) Stand: 01.11.2024. https://www.g-ba.de/downloads/62-492-3647/PT-RL_2024-08-15_iK-2024-11-01.pdf (accessed 20.09.2025)

Gentsch, A., & Kuehn, E. (2022). Clinical Manifestations of Body Memories: The Impact of Past Bodily Experiences on Mental Health. *Brain Sciences*, *12*(5), 594. https://doi.org/10.3390/brainsci12050594

Gibson, J. J. (1979). *The theory of affordances*. In *The ecological approach to visual perception.* Houghton Mifflin.

Glenberg, A. M. (1997). What memory is for. *Behavioral and Brain Sciences*, *20*(1), 1–19. https://doi.org/10.1017/S0140525X97000010

Glickman, N. S., & Gulati, S. (Eds.). (2003). *Mental health care of deaf people: A culturally affirmative approach*. Routledge. https://doi.org/10.4324/9781410607577

Godden, D.R. & Baddeley, A. (1975). Context-dependent memory in two natural environments: on land and underwater. *British Journal of Psychology, 66*(3), 325-331.

Goodwin, D.W., Powell, B., Bremer, D., Hoine, H., & Stern, J. (1969). Alcohol and recall: State-dependent effects in man. *Science, 163*(3873), 1358-1360.

Graf, P., & Schacter, D. L. (1985). Implicit and explicit memory for new associations in normal and amnesic subjects. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 11*(3), 501–518. https://doi.org/10.1037/0278-7393.11.3.501

Grote, K., & Linz, E. (2003). The influence of sign language iconicity on semantic conceptualization. In W. G. Müller & O. Fischer (Eds.), *From sign to signing: Iconicity in language and literature* (pp. 23–40). John Benjamins.

Gulati, S. (2019). Language deprivation syndrome. In N. S. Glickman & W. C. Hall (Eds.), *Language deprivation and deaf mental health*. Routledge. https://doi.org/10.4324/9781315166728

Gupta, A. D. (2021). On the Bodily Basis of Human Cognition: A Philosophical Perspective on Embodiment. *Frontiers in Human Neuroscience*, *15*, 745095. https://doi.org/10.3389/fnhum.2021.745095

Hackett, R. A., Davies-Kershaw, H., Cadar, D., Orrell, M., & Steptoe, A. (2018). Walking Speed, Cognitive Function, and Dementia Risk in the English Longitudinal Study of Ageing. *Journal of the American Geriatrics Society*, *66*(9), 1670–1675. https://doi.org/10.1111/jgs.15312

Hall, M. L., Eigsti, I. M., Bortfeld, H., & Lillo-Martin, D. (2017). Auditory deprivation does not impair executive function, but language deprivation might: Evidence from a parent-report

measure in deaf native signing children. *The Journal of Deaf Studies and Deaf Education, 22*(2), 122–131.

Hallet, W. (2012). Conceptual transfer: A cognitive approach to the construction, re-interpretation, and re-contextualisation of academic concepts. In B. Neumann & A. Nünning (Eds.), *Travelling concepts for the study of culture* (pp. 389–410). De Gruyter. https://doi.org/10.1515/9783110227628.389

Harmer, L. M. (1999). Health Care Delivery and Deaf People: Practice, Problems, and Recommendations for Change. *Journal of Deaf Studies and Deaf Education*, *4*(2), 73-110.

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

Harrison, B. E., Son, G.-R., Kim, J., & Whall, A. L. (2007). Preserved Implicit Memory in Dementia: A Potential Model for Care. *American Journal of Alzheimer's Disease & Other Dementias®*, *22*(4), 286–293. https://doi.org/10.1177/1533317507303761

Haug, T. (2012). Methodological and theoretical issues in the adaptation of sign language tests: An example from the adaptation of a test to German Sign Language. *Language Testing*, *29*(2), 181–201. https://doi.org/10.1177/0265532211421509

Haug, T., & Mann, W. (2007). Adapting Tests of Sign Language Assessment for Other Sign Languages—A Review of Linguistic, Cultural, and Psychometric Problems. *Journal of Deaf Studies and Deaf Education, 13(*1), 138–147. https://doi.org/10.1093/deafed/enm027

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioral and Brain Sciences*, *33*(2–3), 61–83. https://doi.org/10.1017/S0140525X0999152X

Higgins, P. C. (1979). Outsiders in a Hearing World: The Deaf Community. *Urban Life, 8*(1), 3-22. https://doi.org/10.1177/089124167900800101

Hill-Briggs, F., Dial, J., Morere, D., & Joyce, A. (2007). Neuropsychological assessment of persons with physical disability, visual impairment or blindness, and hearing impairment or deafness. *Archives of Clinical Neuropsychology*, *22*(3), 389–404. https://doi.org/10.1016/j.acn.2007.01.013

Hoffstadt, A. (2018). *Gehörlosigkeit als „Behinderung“: Menschen in den Gehörlosenschulen des Landschaftsverbandes Rheinland nach 1945*. Metropol Verlag. https://doi.org/10.5771/9783748961604

Höcker, J.T. (2010). *Sozialmedizinische Aspekte der medizinischen Versorgung gehörloser Menschen in Deutschland. Entwicklung und Durchführung einer internetbasierten Umfrage mit Gebärdensprachvideos*. (Doctoral dissertation). Johannes Gutenberg-Universität Mainz.

Hulme, C. (2003). High- and low-frequency words are recalled equally well in alternating lists: Evidence for associative effects in serial recall. *Journal of Memory and Language*, *49*(4), 500–518. https://doi.org/10.1016/S0749-596X(03)00096-2

Hydén, L.-C., & Örulv, L. (2009). Narrative and identity in Alzheimer’s disease: A case study. *Journal of Aging Studies*, *23*(4), 205–214. https://doi.org/10.1016/j.jaging.2008.01.001

Jack, C. R., Knopman, D. S., Jagust, W. J., Petersen, R. C., Weiner, M. W., Aisen, P. S., Shaw, L. M., Vemuri, P., Wiste, H. J., Weigand, S. D., Lesnick, T. G., Pankratz, V. S., Donohue, M. C., & Trojanowski, J. Q. (2013). Tracking pathophysiological processes in Alzheimer’s disease: An updated hypothetical model of dynamic biomarkers. *The Lancet Neurology*, *12*(2), 207–216. https://doi.org/10.1016/S1474-4422(12)70291-0

Jellinger, K. A. (2010). Should the word ‘dementia’ be forgotten? *Journal of Cellular and Molecular Medicine*, *14*(10), 2415–2416. https://doi.org/10.1111/j.1582-4934.2010.01159.x

Jessen, F., Amariglio, R. E., Van Boxtel, M., Breteler, M., Ceccaldi, M., Chételat, G., Dubois, B., Dufouil, C., Ellis, K. A., Van Der Flier, W. M., Glodzik, L., Van Harten, A. C., De Leon, M. J., McHugh, P., Mielke, M. M., Molinuevo, J. L., Mosconi, L., Osorio, R. S., Perrotin, A., … Subjective Cognitive Decline Initiative (SCD-I) Working Group. (2014). A conceptual

framework for research on subjective cognitive decline in preclinical Alzheimer's disease. *Alzheimer's & Dementia*, *10*(6), 844–852. https://doi.org/10.1016/j.jalz.2014.01.001

Kaul, T., Gelhardt, A., Klinner, S. & Menzel, F. (2009). *Zur Situation gehörloser Menschen im Alter (SIGMA). Abschlussbericht der wissenschaftlichen Untersuchung*. Universität zu Köln.

Kaul, T., Gelhardt, A., Klinner, S. & Menzel, F. (2010). „Bleibe ich da, wo meine Wurzeln sind oder gehe ich dorthin, wo ich verstanden werde?" (2). *Das ZEICHEN*, 84, 54 - 66.

Kaul, T., Büchler, N., Gelhardt, A. & Menzel, F. (2018). *Handlungsperspektiven zur Verbesserung der Versorgungssituation gehörloser Menschen im Alter*. Universität zu Köln.

Kessler, J., Calabrese, P., Kalbe, E. & Berger, F. (2000). DemTect: Ein neues Screening Verfahren zur Unterstützung der Demenzdiagnostik. *Psycho*, 26, 243-347.

Kessler, J. & Sener, S. & Kalbe, E. & Brand, M. (2005). TRAKULA: Transkulturelles Assessment mentaler Leistungen bei türkischen Mitbürgern. *Aktuelle Neurologie*, 32 - P309 https://doi.org/10.1055/s-2005-919343

Kessler, E.-M. & Tegeler, C. (2018). Psychotherapeutisches Arbeiten mit alten und sehr alten Menschen. *Psychotherapeut*, 63(6), 501–518.

Kietzmann, D., Wiehn, S., Kehl, D., Knuth, D., & Schmidt, S. (2016). Migration background and overall satisfaction with pre-hospital emergency care. *Applied Nursing Research, 29*, 96–100. https://doi.org/10.1016/j.apnr.2015.05.009

Klee, E. (2010). *"Euthanasie" im Dritten Reich: Die "Vernichtung lebensunwerten Lebens"*. Fischer.

Klima, E. S., & Bellugi, U. (1979). *The signs of language*. Harvard University Press.

Kolovou, M. (2022). In Search of Assessment Shifts in Embodied Learning Science Research: A Review. *Journal of Science Education and Technology*, *31*(2), 246–257. https://doi.org/10.1007/s10956-021-09952-x

Konrad, R., Hanke, T., Langer, G., Blanck, D., Bleicken, J., Hofmann, I., Jeziorski, O., König, L., König, S., Nishio, R., Regen, A., Salden, U., Wagner, S., Worseck, S., Böse, O., Jahn, E., Schulder, M. (2020). *MEINE DGS – annotiert. Öffentliches Korpus der Deutschen Gebärdensprache, 3. Release / MY DGS – annotated. Public Corpus of German Sign Language, 3rd release* [Dataset]. Universität Hamburg. https://doi.org/10.25592/dgs.corpus-3.0

Kontos, P. C. (2003). "The painterly hand": Embodied consciousness and Alzheimer's disease. *Journal of Aging Studies*, *17*(2), 151–170. https://doi.org/10.1016/S0890-4065(03)00006-9

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, *24*(6), 829–849. https://doi.org/10.1017/S0144686X04002375

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia*, *4*(4), 553–570. https://doi.org/10.1177/1471301205058311

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

Kontos, P., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*, *12*(3), 288–302. https://doi.org/10.1177/1471301213479787

Kontos, P., Miller, K.-L., Mitchell, G. J., & Stirling-Twist, J. (2017). Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia. *Dementia*, *16*(1), 46–66. https://doi.org/10.1177/1471301215580895

Kontos, P. C., & Naglie, G. (2009). Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness*, *31*(5), 688–704. https://doi.org/10.1111/j.1467-9566.2009.01158.x

Kuenburg, A., Fellinger, P., & Fellinger, J. (2016). Health care access among deaf people. *The Journal of Deaf Studies and Deaf Education, 21*(1), 1–10. https://doi.org/10.1093/deafed/env042

Kruse, A. (2017). *Lebensphase hohes Alter: Verletzlichkeit und Reife*. Springer.

Ladd, P. 2003. *Understanding Deaf Culture: In Search of Deafhood*. Multilingual Matters.

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

LaFontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyebode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of advanced nursing*, *60*(6), 605–614. https://doi.org/10.1111/j.1365-2648.2007.04444.x

Langer, G. (2012). A colorful first glance at data on regional variation extracted from the DGS-Corpus: With a focus on procedures. In O. Crasborn, E. Efthimiou, S.-E. Fotinea, T. Hanke, J. Kristoffersen, & J. Mesch (Eds.), *Proceedings of the LREC2012 5th Workshop on the Representation and Processing of Sign Languages: Interactions between Corpus and Lexicon* (pp. 101–108). European Language Resources Association (ELRA). https://www.sign-lang.uni-hamburg.de/lrec/pub/12017.pdf

Langer, G. (2018). Regional variation in DGS: Monthly signs in the corpus and DGS feedback [Poster presentation]. *6th German Deaf Cultural Days*, Potsdam, Germany. https://www.sign-lang.uni-hamburg.de/dgs-korpus/infomaterial.html

Lee, H.-S., & Park, S.-W. (2017). Assessment of Gait as a Diagnostic Tool for Patients with Dementia. *Journal of The Korean Society of Physical Medicine*, *12*(2), 129–136. https://doi.org/10.13066/kspm.2017.12.2.129

Liddle, J., Smith-Conway, E. R., Baker, R., Angwin, A. J., Gallois, C., Copland, D. A., Pachana, N. A., Humphreys, M. S., Byrne, G. J., & Chenery, H. J. (2012). Memory and communication support strategies in dementia: Effect of a training program for informal caregivers. *International Psychogeriatrics*, *24*(12), 1927–1942. https://doi.org/10.1017/S1041610212001366

Lin, P., Daly, A., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., Fillit, H. M., & Freund, K. M. (2020). Dementia diagnosis disparities by race and ethnicity: Health services research: Cost of care and implications for intervention. *Alzheimer's & Dementia*, *16*(S10), e043183. https://doi.org/10.1002/alz.043183

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

Löwe, A. (1983). Deaf education. In S. Solarova (Ed.), *History of special education* (pp. 12–48). Kohlhammer. https://doi.org/10.25656/01:7018

Malmberg, K. & Murnane, K. (2002). List Composition and the Word-Frequency Effect for Recognition Memory. *Journal of Experimental Psychology: Learning Memory and Cognition.* 28. 616-630. https://doi.org/10.1037/0278-7393.28.4.616

Malmberg, K. J., & Nelson, T. O. (2003). The word frequency effect for recognition memory and the elevated-attention hypothesis. *Memory & Cognition*, *31*(1), 35–43. https://doi.org/10.3758/BF03196080

Mandler, G. (1980). Recognizing: The judgment of previous occurrence. *Psychological Review,* 87, 252–271.

Mann, W., Roy, P., & Marshall, C. (2013). A Look at the Other 90 Per Cent: Investigating British Sign Language Vocabulary Knowledge in Deaf Children from Different Language Learning Backgrounds. *Deafness & Education International, 15*(2), 91–116. https://doi.org/10.1179/1557069X12Y.0000000017

Marchant, N. L., Hossain, E., Chen, S., Kabra, G., Ahmad, L., Fraser, I., Cezair-Phillip, L., Fotoupoulou, A., Sihre, H., Mukadam, N., & Cox, A. L. (2025). A multiperspective investigation of the underrepresentation of minoritized ethnic participants in dementia research and proposed strategies to improve inclusive recruitment practices. *Alzheimer's & Dementia*, *21*(4), e70129. https://doi.org/10.1002/alz.70129

Marian, V. & Fausey, C.M. (2006). Language-dependent memory in bilingual learning. *Applied Cognitive Psychology, 20*(8), 1025-1047.

Marian, V., & Neisser, U., (2000). Language-dependent recall of autobiographical memories, *Journal of Experimental Psychology: General, 129*(3), 361-368.

McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., Csipke, E., & Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging & mental health*, *23*(4), 393–403. https://doi.org/10.1080/13607863.2017.1423031

McGeoch, J. A., & Irion, A. L. (1952). *The psychology of human learning*. Longmans.

McKee, M. M., Paasche-Orlow, M. K., Winters, P. C., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. (2015). Assessing health literacy in deaf American Sign Language users. *Journal of Health Communication, 20(*sup2), 92-100. https://doi.org/10.1080/10810730.2015.1066468

McKinnon, M. C., Nica, E. I., Sengdy, P., Kovacevic, N., Moscovitch, M., Freedman, M., Miller, B. L., Black, S. E., & Levine, B. (2008). Autobiographical memory and patterns of brain atrophy in fronto-temporal lobar degeneration. *Journal of cognitive neuroscience*, *20*(10), 1839-1853.

McRae, R., Zorbas, C., O'Shea, A., Adam, R., & Backholer, K. (2025). The association between early life access to communication and perceived mental health in a cross-sectional study of deaf Australian adults. *Critical Public Health*, *35*(1), 2497352. https://doi.org/10.1080/09581596.2025.2497352

Meek, D. R. (2020). Dinner table syndrome: A phenomenological study of Deaf individuals' experiences with inaccessible communication. *The Qualitative Report, 25*(6), 1676-1694.

Meier, R. (2002). Why different, why the same? Explaining effects and non-effects of modality upon linguistic structure in sign and speech. In R. P. Meier, K. Cormier, & D. Quinto-Pozos

(Eds.), *Modality and structure in signed and spoken languages* (pp. 1–25). Cambridge University Press.

Melchinger, H. (2011). Psychotherapie im Alter: Anspruch und Wirklichkeit. *NeuroTransmitter*, 10, 16–22.

Menary, R. (2010). Introduction to the special issue on 4E cognition. *Phenomenology and the Cognitive Sciences, 9*(4), 459–463.

Mercieca, A., Scott, I., Ward Thompson, C., & Wilkinson, H. (2025). Proposing a multi-method phenomenological approach in exploring the perceived daily life experiences of people with dementia in their dementia care environments and immediate outdoor settings. *Frontiers in Dementia, 4*, 1502911. https://doi.org/10.3389/frdem.2025.1502911

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). Routledge & Kegan Paul.

Mesulam, M. M. (2007). Primary progressive aphasia: a 25-year retrospective. *Alzheimer Disease & Associated Disorders*, *21*(4), S8-S11.

Miles, C. & Hardman, E. (1998). State-dependent memory produced by aerobic exercise. *Ergonomics, 41*(1), 20-28.

Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, *21*(11), 1078-1085. https://doi.org/10.1002/gps.1610

Mirza, N., Panagioti, M., Waheed, M. W., & Waheed, W. (2017). Reporting of the translation and cultural adaptation procedures of the Addenbrooke's Cognitive Examination version III (ACE-III) and its predecessors: A systematic review. *BMC Medical Research Methodology*, *17*(1), 141. https://doi.org/10.1186/s12874-017-0413-6

Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the Mythical Ten Percent: Parental Hearing Status of Deaf and Hard of Hearing Students in the United States. *Sign Language Studies*, *4*(2), 138–163. https://doi.org/10.1353/sls.2004.0005

Mittelstädt, A., & Hosemann, J. (2020). Impairment vs. disability – The paradoxical situation of deaf people during the German Nazi regime. In R. Pfau, A. Göksel, & J. Hosemann (Eds.), *Elderly deaf signers: Cultural, linguistic, and sociolinguistic perspectives* (pp. 171-196). De Gruyter Mouton.

Moore, S., Sandman, C. A., McGrady, K., & Patrick Kesslak, J. (2001). Memory training improves cognitive ability in patients with dementia. *Neuropsychological Rehabilitation*, *11*(3–4), 245–261. https://doi.org/10.1080/09602010042000222

Muhs, J. (2002). Deaf people as eyewitnesses of National Socialism (R. Harmon, Trans.). In D. F. Ryan & J. S. Schuchman (Eds.), *Deaf people in Hitler's Europe* (pp. 78–97). Gallaudet University Press.

Musselman, C., & Szanto, G. (1998). The Written Language of Deaf Adolescents: Patterns of Performance. *Journal of Deaf Studies and Deaf Education, 3*(3), 245–257. https://doi.org/10.1093/oxfordjournals.deafed.a014354

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCa: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society, 53*, 695-699. https://doi.org/10.1111/j.1532-5415.2005.53221.x

O'Brien, D. (2021). Theorising the Deaf body: Using Lefebvre and Bourdieu to understand Deaf spatial experience. *Cultural Geographies, 28*(4), 645-660. https://doi.org/10.1177/14744740211003632

Orfanidou, E., Woll, B., & Morgan, G. (2015). *Research methods in sign language studies*. Wiley Blackwell.

Ormel, E., Hermans, D., Knoors, H., & Verhoeven, L. (2009). The Role of Sign Phonology and Iconicity During Sign Processing: The Case of Deaf Children. *Journal of Deaf Studies and Deaf Education*, *14*(4), 436–448. https://doi.org/10.1093/deafed/enp021

Ortega, G., Schiefner, A., Lazarus, N., & Perniss, P. 2025. A lexical database of British Sign Language (BSL) and German Sign Language (DGS): Iconicity ratings, iconic strategies, and concreteness norms. *Behavior Research Methods*, *57*(5), 139. https://doi.org/10.3758/s13428-025-02660-z

Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a Culture*. Harvard University Press. https://doi.org/10.4159/9780674041752

Parahoo, K., Whall, A. L., Colling, K., & Nusbaum, D. (2006). Expert nurses' use of implicit memory in the care of patients with Alzheimer's disease. *Journal of Advanced Nursing*, *54*(5), 563–571. https://doi.org/10.1111/j.1365-2648.2006.03864.x

Parial, L. L., Amoah, P. A., Chan, K. C. H., Lai, D. W. L., & Leung, A. Y. M. (2023). Dementia literacy of racially minoritized people in a Chinese society: A qualitative study among South Asian migrants in Hong Kong. *Ethnicity & Health*, *28*(5), 757–780. https://doi.org/10.1080/13557858.2022.2139818

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

Parma, C., Doria, F., Zulueta, A., Boscarino, M., Giani, L., Lunetta, C., Parati, E. A., Picozzi, M., & Sattin, D. (2024). Does Body Memory Exist? A Review of Models, Approaches and Recent Findings Useful for Neurorehabilitation. *Brain Sciences*, *14*(6), 542. https://doi.org/10.3390/brainsci14060542

Paulini, A. (2008). *Hörgeschädigte Patienten: Ärztliche Behandlungszufriedenheit gehörloser, schwerhöriger und ertaubter Patienten* (Doctoral dissertation). Universität Hamburg.

Perniss, P., Thompson, R. L., & Vigliocco, G. (2010). Iconicity as a general property of language: Evidence from spoken and signed languages. *Frontiers in Psychology, 1*, 227. https://doi.org/10.3389/fpsyg.2010.00227

Poskowsky, J., Heißenberg, S., Zaussinger, S., & Brenner, J. (2018). *Beeinträchtigt studieren–best2. Datenerhebung zur Situation Studierender mit Behinderung und chronischer Krankheit 2016/17* [Studying with impairments–best2. Data collection on the situation of students with disabilities and chronic illnesses 2016/17].

Prillwitz, S., Leven, R., Meyenn, A. v., Zienert, H., & Schmidt, W. (1985). *Skizzen zu einer Grammatik der Deutschen Gebärdensprache*. Forschungsstelle Dt. Gebärdensprache.

Proust, M. (1992). *In search of lost time (À la recherche du temps perdu)* (Vol. 1, Swann's way / Du côté de chez Swann). The Modern Library. https://uberty.org/wp-content/uploads/2015/12/Proust-1.pdf

Rainò, P. (2010). *Cerad – Kognitiviinen tehtäväsarja suomalaiselle viittomakielelle. Ohjekirja* [CERAD – Cognitive task series for Finnish sign language. Instruction manual]. Kuurojen Palvelusäätiö.

Rannefeld, J. (2025). *Akutmedizinische Versorgung gehörloser und gehörgeschädigter Personen: Eine Bedarfsanalyse des Status quo.* (Doctoral dissertation). Freie Universität Berlin.

Rannefeld, J., O'Sullivan, J. L., Kuhlmey, A., & Zoellick, J. C. (2023). Deaf and hard-of-hearing patients are unsatisfied with and avoid German health care: Results from an online survey in German Sign Language. *BMC Public Health*, *23*(1), 2026. https://doi.org/10.1186/s12889-023-16924-w

Rantapää, M. (2024). *Supportive strategies used by family members and formal caregivers in social interaction with deaf people with dementia*. (PhD thesis). University of Helsinki.

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

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

Ratcliff, R., Sheu, C. F., & Gronlund, S. D. (1992). Testing global memory models using ROC curves. *Psychological Review*, 99, 518 –535.

Reeves, D., Kokoruwe, B., Dobbins, J., & Newton, V. (2003). *Access to primary care and accident and emergency departments for deaf people: GPs and PCTs*. National Primary Care Research and Development Centre, University of Manchester.

Reilly, J., Rodriguez, A. D., Lamy, M., & Neils-Strunjas, J. (2010). Cognition, language, and clinical pathological features of non-Alzheimer's dementias: an overview. *Journal of communication disorders*, *43*(5), 438-452.

Ricke, A., Klusmann, H., Heinrich, M., Haering, S., Blecker, M. K., Knaevelsrud, C., & Schumacher, S. (2024). Taube Menschen in Deutschland: Mental Health Literacy und Einschätzung der Angebote des psychiatrisch-psychotherapeutischen Versorgungssystems – eine Online-Studie. *Verhaltenstherapie*, *34*(1), 11–21. https://doi.org/10.1159/000535009

Riva, G. (2018). The neuroscience of body memory: From the self through the space to the others. *Cortex*, *104*, 241–260. https://doi.org/10.1016/j.cortex.2017.07.013

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

Rohrer, J.D., Knight, W.D., Warren, J.E., Fox, N.C., Rossor, M.N., & Warren, J.D. (2008) Word-finding difficulty: a clinical analysis of the progressive aphasias. *Brain*, *131*(1), 8–38.

Rotello, C. M., Macmillan, N. A., & Reeder, J. A. (2004). Sum-difference theory of remembering and knowing: A two-dimensional signal detection model. *Psychological Review, 111*(3*)*, 588 – 616.

Roy, D. S., Kitamura, T., Okuyama, T., Ogawa, S. K., Sun, C., Obata, Y., Yoshiki, A., & Tonegawa, S. (2017). Distinct Neural Circuits for the Formation and Retrieval of Episodic Memories. *Cell*, *170*(5), 1000-1012.e19. https://doi.org/10.1016/j.cell.2017.07.013

Ryan, C., & Kushalnagar, P. (2018). Towards health equity: Deaf adults' engagement in social ehealth activities and e-communication with health care providers. *Journal of Health Communication, 23*(9), 836–841. https://doi.org/10.1080/10810730.2018.1527875

Sachdev, P. (2000). Is It Time to Retire the Term "Dementia"? *J Neuropsychiatry Clin Neurosci*, 12(2), 276-279.

Saragih, I. D., Susanto, H., Saragih, I. S., Chen, P. J., Lee, B. O., & Lopez, R. P. (2025). A systematic review and meta-analysis of randomised controlled trials on the effect of cognitive behavioural therapy for people with dementia. *Journal of Clinical Nursing*. Advance online publication. https://doi.org/10.1111/jocn.70005

Schacter, D. (1987). Implicit memory: History and current status. *Journal of Experimental Psychology, 13*(3), 501–518.

Schaeffer, D., Kuhlmey, A. & Kleina, T. (2017). Pflegerische Langzeitversorgung: Pflege- und Altenheime, ambulante pflegerische Versorgung. In Pfaff, H., Neugebauer, E. A. M., Glaeske, G. & Schrappe, M. (Eds.), *Lehrbuch Versorgungsforschung* (pp. 265-270). Schattauer.

Scharf, L. (2006). *Taubstumme in der Hitlerjugend? Fridolin W. erzählt - Biografie und Dokumentation zu „Gehörlose im 3. Reic*h". Selbstverlag.

Schröder, L., & Vereenooghe, L. (2021). „Mixed-methods"-Studie zu Barrieren in der ambulanten Psychotherapie von Gehörlosen: Rahmenbedingungen der Psychotherapie und Umgang mit Therapieanfragen aus Sicht der Psychotherapeut*innen. *Psychotherapeut*, *66*(1), 62–69. https://doi.org/10.1007/s00278-020-00476-0

Scoville, W. B., & Milner, B. (1957). *The medial temporal lobe and the human memory*. *Journal of Neurology, Neurosurgery & Psychiatry, 20*, 11–21. https://doi.org/10.1136/jnnp.20.1.11

Seidl, U., Völker, L., Lueken, U., Rez, S., Becker, S., Kruse, A. & Schröder, J. (2007). Nicht-kognitive Störungen und psychopharmakologische Behandlung bei demenzkranken Altenheimbewohnern. *Fortschritte der Neurologie Psychiatrie*, 75, 720–727.

Sevcikova Sehyr, Z., Caselli, N., Cohen-Goldberg, A. M., & Emmorey, K. (2021). The ASL-LEX 2.0 project: A database of lexical and phonological properties for 2,723 signs in American Shapiro, L. (2007). The embodied cognition research programme. Philosophy Compass, 2(2), 338–346.

Sidhu, D. M., Vigliocco, G., & Pexman, P. M. (2020). Effects of iconicity in lexical decision. *Language and Cognition*, *12*(1), 164–181. https://doi.org/10.1017/langcog.2019.36

Sign Language. *Journal of Deaf Studies and Deaf Education*. https://doi.org/10.1093/deafed/enaa038

Signhealth (2014). *Sick of it report.* SignHealth. http://www.signhealth.org.uk/healthinformation/sick-of-it-report/ (accessed 24.08.2025)

Signoret, J. L., & Hauw, J. J. (1991). *Maladie d'Alzheimer et autres démences*.

Smith, E. E. (2015). Cognitive psychology: History. In J. D. Wright (Ed.), *International encyclopedia of the social & behavioral sciences* (2nd ed., pp. 103–109). Elsevier. https://doi.org/10.1016/B978-0-08-097086-8.03028-2

Smith, S.M., & Vela, E. (2001). Environmental context-dependent memory: A review and meta-analysis. *Psychonomic Bulletin and Review, 8*(2), 203-220.

Spaan, P. E. J., Raaijmakers, J. G. W., & Jonker, C. (2005). Early Assessment of Dementia: The Contribution of Different Memory Components. *Neuropsychology*, *19*(5), 629–640. https://doi.org/10.1037/0894-4105.19.5.629

Spinoza, B. (1941). *Ethics*. Dents. https://archive.org/details/in.ernet.dli.2015.263056/page/n1/mode/2up

Squire, L. R. (2009). The Legacy of Patient H.M. for Neuroscience. *Neuron*, *61*(1), 6–9. https://doi.org/10.1016/j.neuron.2008.12.023

Steeman, E., De Casterlé, B.D., Godderis, J. & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing,* 54, 722-738. https://doi.org/10.1111/j.1365-2648.2006.03874.x

Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A. & Zazove, P. (2006). Health care system accessibility. Experiences and perceptions of deaf people. *Journal of General Internal Medicine, 21*(3), 260-266.

Stevens, J. S., Reddy, R., Kim, Y. J., Van Rooij, S. J. H., Ely, T. D., Hamann, S., Ressler, K. J., & Jovanovic, T. (2018). Episodic memory after trauma exposure: Medial temporal lobe function is positively related to re-experiencing and inversely related to negative affect symptoms. *NeuroImage: Clinical*, *17*, 650–658. https://doi.org/10.1016/j.nicl.2017.11.016

Stokoe, W. C. (1960). *Sign language structure: An outline of the visual communication systems of the American deaf*. Studies in linguistics: Occasional Papers, 8.

Stokoe, W. C. (2005). Sign Language Structure: An Outline of the Visual Communication Systems of the American Deaf. *Journal of Deaf Studies and Deaf Education*, *10*(1), 3–37. https://doi.org/10.1093/deafed/eni001

Sukhawathanakul, P., Crizzle, A., Tuokko, H., Naglie, G., & Rapoport, M. J. (2021). Psychotherapeutic Interventions for Dementia: A Systematic Review. *Canadian Geriatrics Journal*, *24*(3), 222–236. https://doi.org/10.5770/cgj.24.447

Sullivan, P., Brookhauser, P., & Scanlan, J. (2000). Maltreatment of Deaf and Hard of Hearing children. In P. Hindley & N. Kitson (Eds.), *Mental Health and Deafness* (pp. 149-184). Whurr Publishers.

Swallow, J., & Hillman, A. (2019). Fear and anxiety: Affects, emotions and care practices in the memory clinic. *Social Studies of Science*, *49*(2), 227–244. https://doi.org/10.1177/0306312718820965

Taylor, J. (2017). *Translating the Mini-Mental State Exam into American Sign Language* (PhD dissertation). Western University.

Teasdale, J.D., & Fogarty, S.J. (1979). Differential effects of induced mood on retrieval of pleasant and unpleasant events from episodic memory. *Journal of Abnormal Psychology, 88*(3), 248-257.

Temple, B., & Young, A. (2004). Qualitative Research and Translation Dilemmas. *Qualitative Research*, *4*(2), 161–178. https://doi.org/10.1177/1468794104044430

Thompson, R. L., Vinson, D. P., & Vigliocco, G. (2009). The link between form and meaning in American Sign Language: Lexical processing effects. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *35*(2), 550–557. https://doi.org/10.1037/a0014547

Timperlake, E. C. (2024). *Development of an American Sign Language cognitive screening tool* (Doctoral dissertation). Gallaudet University.

Traxler, C. B. (2000). The Stanford Achievement Test, 9th edition: National norming and performance standards for deaf and hard-of-hearing students. *Journal of Deaf Studies and Deaf Education, 5*(4), 337–348.

Trettenbrein, P. C., Pendzich, N.-K., Cramer, J.-M., Steinbach, M., & Zaccarella, E. (2021). Psycholinguistic norms for more than 300 lexical signs in German Sign Language (DGS). *Behavior Research Methods*. https://doi.org/10.3758/s13428-020-01524-y

Tulving, E. (1983). *Elements of episodic memory.* The Clarendon Press.

Ubido, J. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health & Social Care in the Community*, 10, 247-253.

Veditz, G. (1912). *Ninth Convention of the National Association of the Deaf and Third World's Congress of the Deaf*. Philosophicus Press.

Villarejo-Galende, A., García-Arcelay, E., Piñol-Ripoll, G., Del Olmo-Rodríguez, A., Viñuela, F., Boada, M., Franco-Macías, E., De La Peña, A. I., Riverol, M., Puig-Pijoan, A., Abizanda-Soler, P., Arroyo, R., Baquero-Toledo, M., Feria-Vilar, I., Balasa, M., Berbel, Á., Rodríguez-Rodríguez, E., Vieira-Campos, A., García-Ribas, G., … Maurino, J. (2022). Awareness of Diagnosis in Persons with Early-Stage Alzheimer's Disease: An Observational Study in Spain. *Neurology and Therapy*, *11*(3), 1183–1192. https://doi.org/10.1007/s40120-022-00367-3

Vinson, D. P., Cormier, K., Denmark, T., Schembri, A., & Vigliocco, G. (2008). The British Sign Language (BSL) norms for age of acquisition, familiarity, and iconicity. *Behavior Research Methods*, *40*(4), 1079–1087. https://doi.org/10.3758/BRM.40.4.1079

Völter, C., Fricke, H., Faour, S., Lueg, G., Nasreddine, Z. S., Götze, L., & Dawes, P. (2023). Validation of the German Montreal-Cognitive-Assessment-H for hearing-impaired. *Frontiers in Aging Neuroscience*, *15*, 1209385. https://doi.org/10.3389/fnagi.2023.1209385

Vogel, H. (2015). *Gehörlose Opfer der Zwangssterilisation und der "Euthanasie" in der NS-Zeit* [Documentary film in German Sign Language (DGS) and spoken German, with subtitles]. https://www.euthanasiegeschaedigte-zwangssterilisierte.de/dokfilme/film-gehoerlose-opfer-zwangssterilisationen-und-euthanasie-ns-zeit/

Warren, A. (2023). An integrative approach to dementia care. *Frontiers in Aging*, 4, 1143408. https://doi.org/10.3389/fragi.2023.1143408

Watkins, M. J., & Gardiner, J. M. (1979). An appreciation of generate-recognize theory of recall. *Journal of Verbal Learning and Verbal Behavior, 18*(6), 687–704. https://doi.org/10.1016/S0022-5371(79)90207-4

Werner, A. (2024). *"Deaf History" as the history of science: The participation of deaf people in academic discourses on deafness in divided Germany* (Vol. 7). transcript Verlag.

Williams, C. R., & Abeles, N. (2004). Issues and implications of deaf culture in therapy. *Professional Psychology: Research and Practice, 35*(6), 643. https://psycnet.apa.org/doi/10.1037/0735-7028.35.6.643

Wilson, M. (2002). Six views of embodied cognition. *Psychonomic Bulletin & Review, 9(*4), 625–636.

Winniewski, R. (2022). Disrupted Intercorporeality and Embodiedness in Dementia Care during the COVID-19 Crisis. *Puncta*, *5*(1), 79–96. https://doi.org/10.5399/pjcp.v5i1.5

Wixted, J. T. (2007). Dual-process theory and signal-detection theory of recognition memory. *Psychological Review*, *114*(1), 152–176. https://doi.org/10.1037/0033-295X.114.1.152

Wixted, J. T., & Stretch, V. (2004). In defense of the signal detection interpretation of remember/know judgments. *Psychonomic Bulletin & Review,* 11, 616 – 641.

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. World Health Organization. https://iris.who.int/handle/10665/259615

World Health Organization (WHO). (2021). Global status report on the public health response to dementia.

Xie, W., Bainbridge, W. A., Inati, S. K., Baker, C. I., & Zaghloul, K. A. (2020). Memorability of words in arbitrary verbal associations modulates memory retrieval in the anterior temporal lobe. *Nature Human Behaviour*, *4*(9), 937–948. https://doi.org/10.1038/s41562-020-0901-2

Yet, A. X. J., Hapuhinne, V., Eu, W., Chong, E. Y. C., & Palanisamy, U. D. (2022). Communication methods between physicians and deaf patients: A scoping review. *Patient Education and Counseling.* https://doi.org/10.1016/j.pec.2022.05.001

Yonelinas, A. P. (1994). Receiver-operating characteristics in recognition memory: Evidence for a dual-process model. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 20*, 1341–1354.

Young, A., Ferguson-Coleman, E., & Keady, J. (2014). Understanding the personhood of Deaf people with dementia: Methodological issues. *Journal of Aging Studies*, 8, 62-69.

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

Zanetti, O., Binetti, G., Magni, E., Rozzini, L., Bianchetti, A., & Trabucchi, M. (1997). Procedural memory stimulation in Alzheimer's disease: Impact of a training programme. *Acta Neurologica Scandinavica*, *95*(3), 152–157. https://doi.org/10.1111/j.1600-0404.1997.tb00087.x

Zaurov, M. (2003). *Gehörlose Juden: Eine doppelte kulturelle Minderheit [Deaf Jews: A double cultural minority]*. Peter Lang.

- APPENDIX -

Overview of the publications and statement of contributions

Study 1:

Stockleben, L., Woll, B. & J. Atkinson. (2026). Screening for acquired cognitive impairment and dementia in deaf users of German Sign Language: the Cognition Test German Sign Language. *Archives of Clinical Neuropsychology, 41*(2), acaf094. https://doi.org/10.1093/arclin/acaf094

Lisa Stockleben designed the study, developed the methodology, and coordinated the project. Lisa Stockleben collected and analyzed the data. Lisa Stockleben drafted the manuscript and revised it in collaboration with Bencie Woll and Joanna Atkinson. All authors revised the manuscript and gave their approval for publication.

Study 2:

Stockleben, L., Straub, A. & L. Klinner. (in revision). How reliable are subjective ratings? The issue of reliability in psycholinguistic measures of sign frequency and iconicity in German Sign Language (DGS).

Lisa Stockleben initiated the project. Lisa Stockleben, Alexander Straub and Leonid Klinner designed the study and developed the methodology. All authors collected and analyzed the data. Lisa Stockleben drafted the manuscript and revised it in collaboration with Alexander Straub and Leonid Klinner. All authors read and revised the manuscript and gave their approval for submission.

Study 3:

Stockleben, L. & Gelhardt, A. (in revision). Deaf (collective) body memory and intercorporeality: an embodied perspective on deaf persons living with dementia.

Lisa Stockleben and Anne Gelhardt designed the study and developed the methodology. Lisa Stockleben and Anne Gelhardt drafted and revised the manuscript. All authors read and revised the manuscript and gave their approval for submission.

Study 1: Screening for acquired cognitive impairment and dementia in deaf users of German Sign Language: the Cognition Test German Sign Language

Lisa Stockleben, Bencie Woll, Joanna Atkinson

Open access publication:

Stockleben, L., Woll, B. & J. Atkinson. (2026). Screening for acquired cognitive impairment and dementia in deaf users of German Sign Language: the Cognition Test German Sign Language. *Archives of Clinical Neuropsychology, 41*(2), acaf094. https://doi.org/10.1093/arclin/acaf094

Study 2: How reliable are subjective ratings? The issue of reliability in psycholinguistic measures of sign frequency and iconicity in German Sign Language (DGS)

Lisa Stockleben, Alexander Straub, Leonid Klinner

(in revision)

How reliable are subjective ratings? The issue of reliability in psycholinguistic measures of sign frequency and iconicity in German Sign Language (DGS)

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This manuscript contains included tables and appended tables as supplementary material, six figures. The supplementary material will be published open access at the time of publication.

Tables:

Figures:

Supplementary Material - open access data sharing with publication:

ABSTRACT

Psycholinguistic norms of iconicity and frequency are resources in language studies to inform other empirical work, such as test material for language and cognitive assessments. The reliability and validity of those norms are therefore essential to their further use. This study explores the reliability of subjective rating norms in sign language studies in order to improve our understanding of the use of psycholinguistic norms from different sources. It also discusses, specifically, a research collaboration approach between deaf and hearing researchers. This paper provides a transparent report of collaborative work exploring subjective iconicity and frequency ratings for 351 German Sign Language (DGS) signs, rated by deaf signers, compared with previously existing data sets of subjective iconicity measures and subjective and objective measures of sign frequency. Strategies to evaluate reliability within and across data sets are highlighted. Small stimuli differences in the use of mouthing and other non-manual elements that may impact sign iconicity perception are also discussed. The benefits and challenges of a collaborative approach are reported, as it contributes to the broader discourse about collaboration between deaf and hearing researchers in the field of empirical sign language studies. The paper argues that the triangulation of data sets and measures deepens our understanding of the concepts iconicity and frequency and the data at hand and strengthens reliability and validity when data in the field of sign language research is shared.

INTRODUCTION

This paper documents a collaborative research endeavor and reports both psycholinguistic data of DGS (German Sign Language) for 351 lexical signs and detailed insight into a collaborative research approach. The focus of this study is the subjective judgments involved in subjective rating studies, which are a common method for collecting features of language such as iconicity, frequency, age of acquisition, etc. While it is a great advantage for the field of sign language studies to pool the knowledge in shared data bases, it is difficult to control for the reliability of single subjective rating studies. Different rating studies use different stimuli, i.e., signed variants, which may affect the outcome and the reliability of the data. Controlling for reliability has the potential to help us better understand the study results and ultimately improve data quality. The paper at hand, gives a detailed report of investigating reliability in subjective ratings from a collaborative research project. Besides this, the paper also discusses *how* our research itself was approached, as presented in the sections "notes from the collaboration". A number of challenges were encountered, which are addressed in the forthcoming report in more depth to promote and encourage transparent study publication.

The "*How*": Collaboration and/or participation

Researching in the field of sign languages has fortunately evolved to a discipline emphasizing inclusive research teams, acknowledging that a perspective from deaf researchers and appropriate research ethics in sign language studies are invaluable (Orfanidou, Woll & Morgan, 2015). The inclusion of deaf researchers is essential to avoid linguistic and cultural misunderstandings and to ensure the quality and ethics of the research. Singleton, Jones and Hanumantha (2014) demonstrated that many studies with deaf participants are conducted by researchers who lack sufficient sign language and cultural competence – which can lead to misinterpretation of the actual data and mistrust in the findings.

One example is the analysis of nonmanual markers which can occur in lexical signs and which have a significant impact on the prosodic interpretation and evaluation of the data. As Sandler (2012) points out, the prosodic structure of sign languages is complex, multi-layered and highly context-dependent. Subtle differences in those multi-modal and multi-layered

articulations (Mohr, 2014; Pfau & Quer, 2010) can easily be misinterpreted without in-depth linguistic and cultural knowledge. Hearing researchers in the field often acquire a sign language as L2 as adults, which makes recognizing and differentiating subtle phonological contrasts between signs – including path movements, handshape transitions and nonmanual features - more challenging (Beal & Faniel, 2018). Therefore, the involvement of native signers - ideally also as co-researchers - is not only ethically required, but methodologically essential. Deaf researchers not only contribute their language and cultural expertise, but also bring new perspectives to the scientific discourse, such as Deaf epistemologies. Their active participation ensures that research is not done on the Deaf community, but with the Deaf community - on equal terms and in a spirit of true participation.

We decided to include a detailed report of our collaborative process into this paper to encourage hearing-deaf research teams to share stakes equally in sign language research and to promote deaf access in science. (Ensuring deaf access in science, 2023) and in research in general. In the German scientific discourse around sign language studies and Deaf studies, the term 'participatory research' has become prominent over recent years (Staudt et al., 2024). Participatory research is defined as a collaborative endeavor with individuals who are in some way connected to the subject of the research (Cornwall & Jewkes, 1995). As most hearing researchers in the field are no stakeholders of Deaf culture and sign languages, collaborating and sharing intellectual ownership among hearing and deaf researchers will enhance scientific practice and challenge current normalized biases.

Such a collaboration model was proposed by Arnstein (1969) within the context of citizen research involvement and has been referenced in discussions around participatory research with vulnerable populations. For sign language research, the eight stages of participation proposed by Arnstein are not quite adequate as a framework, but they do provide an orientation to the collaborative research environment, especially in mixed teams of deaf and hearing researchers. This is because the term collaboration can still cover a working environment where real participation by all team members is lacking. Collaboration for the authors of this study does not mean that deaf researchers only take the role of stimulus developers and have no say in the analysis and interpretation of the results (what Arnstein calls stages 1-3). Neither is it a mere consultation with deaf signers about the research topic (corresponding to stage 4), but a sharing of power (stages 6-8). The three authors have, therefore, deliberately chosen to collaborate with each other at every stage, with the full

participation of everyone, all having a stake in the process and the outcome for the purpose of transparency and empowerment.

The "*What*": The gap - initiating the project

Looking now at the "what" of this investigation, it all started with the need to control for frequency and iconicity in DGS signs. Iconicity is found across languages (Perniss et al., 2010), regulates language production and comprehension (Perlman et al., 2018; Pretato et al., 2018; Vinson et al., 2015, and it modulates language acquisition (Caselli & Pyers, 2017; Ortega, 2017). It also affects language processing (McGarry et al., 2023), like lexical frequency (Caselli et al., 2021; Caselli et al., 2022). High levels of iconicity and frequency show advantages in lexical processing (Caselli et al., 2021; Caselli et al., 2022; Vinson et al., 2015), which highlights the importance of controlling for these variables in various applied experimental and clinical settings (Atkinson et al., 2015; Denmark et al., 2016). Large databases bundling psycholinguistic knowledge about signs are available in the data bases "ASL-LEX" for American Sign Language (ASL; Caselli et al., 2017; Sehyr et al, 2021), "LSE-Sign" for Spanish Sign Language (LSE; Gutiérrez-Sigut et al., 2016) and "ISL-LEX" for Israeli Sign Language (ISL; Morgan et al., 2022). Psycholinguistic norming data have been collected through the method of subjective ratings in which signers judged the sign iconicity and sign frequency of a presented body of signs. Following in the footsteps of Vinson et al., 2008 for BSL and Mayberry et al., 2014 for ASL, we started our project in early 2019 with the aim to collect iconicity and frequency subjective ratings for DGS which were not available at that time. By the end of 2019, Trettenbrein et al. (2021) presented their data on psycholinguistic norms of frequency and iconicity in DGS. We were unaware of their data when we started our study.

Apart from subjective ratings, objective measures of lexical sign frequency have demonstrated great value (Fenlon et al., 2014; Johnston, 2012; McKee and Kennedy, 2006; Morford and MacFarlane, 2003) for sign language research. Objective measures of sign frequency can be derived from natural language corpora and large data sources in which the frequency of a certain sign is measured and not subjectively rated. The combination and relation of subjective and objective measures of sign frequency have been the subject of debate (Fenlon et al., 2014; Johnston, 2012), with Fenlon et al., advocating for the triangulation of measures of both subjective and objective ratings when available, which we planned to do.

The first turning point - adjustments needed

We originally designed an in-person experiment which we agreed on would yield good and ethical data. The deaf researchers of our team suggested that inviting several participants together at testing days would strengthen the study experience and lower the barrier to participate in research. The authors of this study considered such a format ideal in two ways: a) for the (deaf) study participants to meet and create shared experience and b) for us as researchers to evaluate the study by the study participants. The DGS study by Trettenbrein and colleagues involving an in-person subjective rating with 32 deaf signers and 30 hearing non-signers who rated more than 300 DGS signs on frequency, iconicity, and age of acquisition (AoA), meaning the age at which the deaf signers acquired the signs. After reviewing the stimuli list and comparing it with ours, we identified a 50% overlap in stimuli signs. To promote replication in science, we kept a stimuli overlap of over 131 DGS signs and modified the rest to enlarge the norming data for DGS lexical signs. At that first step, we decided to focus on deaf adults over the age of 60 who are rarely the primary interest of basic linguistic research and who were not represented in the existing psycholinguistic norming studies (Caselli et al., 2017; Trettenbrein et al., 2021; Vinson et al., 2008). To approach this age gap and to inform future studies targeting deaf signers over the age of 60, two adjustments were applied. Signs from a list of care-related words were added, such as CARE and DEMENTIA[11]. The second modification concerned the frequency task. Instead of asking how often a sign was encountered in the environment, the task was adapted to ask how often a sign was produced by the study participant. This adjustment was chosen due to the expected discrepancy between what deaf older adults sign themselves and what people in their environment sign to them. By asking deaf older signers how often they encounter a specific lexical sign, social factors such as a signing living environment, come into place which possibly bias the results.

The second turning point - the corona pandemic changed it all

In early 2020, however, we had to make changes to our research design and target population since the group of people over 60 were at higher risk of the coronavirus. Thus, we switched to an online format and opened our study to all age groups.

[11] DGS signs are written in capital letters and are hyperlinked to the DGS video throughout this article.

The issue of task instruction and validity

The method of subjective ratings is a useful tool to collect psycholinguistic sign features and build a deeper understanding of a sign language inventory. This study contributes to the discussion about databases and shared data sets, and how important it is to have a clear understanding of what is shared exactly. In previous studies, familiarity ratings as proxy measures for frequency were suggested (Occhino et al., 2017; Vinson et al., 2008) and were regarded as the subjective counterpart to objective frequency measures. During the planning stage of our study, we discussed the question of how comprehensible the task would be when a deaf signer is asked about the "familiarity" of a sign. Even with appropriate wording, the task instruction alone may be misleading in an experimental set-up with limited possibilities for clarification. In fact, even Vinson et al. (2008) reported "familiarity ratings" while actually the task instruction asked for sign frequency. Rating lexical frequency, whether it is about how often the signer signs the sign or versus how often they see it, tries to access highly subconscious processing. We are aware of the limited validity of a study that asks about unconscious processes. Mayberry et al. (2014), however, showed how robust subjective frequency ratings are in the context of chronological age, age of language exposure and native, early or late learner effects.

Asking a signer about sign iconicity is another matter. Studies of iconicity ratings need to decide how to present a concept as abstract as iconicity to a lay audience. In DGS, as for other sign languages, the imagery of a sign, is often taken for explaining iconicity (Ortega et al., 2025; Trettenbrein et al., 2021). Another, more theoretical way to explain iconicity is the relation between form and meaning (Caselli et al., 2017; Occhino et al., 2017). This option may be challenging without metalinguistic awareness of one's signing.

Ethics

Our study got ethical approval through the ethical committee of the Faculty of Human Sciences at the University of Cologne, in accordance with the guidelines set forth in the Declaration of Helsinki. All participants provided informed consent in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

METHODS

The rating study was conducted using the online survey platform SoSci Survey (Leiner, 2024). We asked deaf signers to rate lexical DGS signs for iconicity and frequency. The instructions, task, and stimuli were presented in DGS by deaf signers through videos integrated into the platform. The online format of the study made it possible to have standardized instructions for all participants. Where needed, additional German written translations were provided. For example, informed consent form, task, and questions and answer options on a Likert-scale were available in DGS and written German.

The videos were recorded by the authors of this paper. For the task instructions, the authors chose formulations carefully and avoided scientific register wherever possible. The DGS instructions were presented to different DGS signers (age 18 - 70) before a final version was decided on.

Notes from the collaboration - a sensitive approach to instructing

The team cautiously chose formulations to explain the study goal, study design, the data protection and consent form. The deaf approach in our team was to elaborate the condensed information on the written version of the material to make the study information more accessible even for people who were unfamiliar with the wording of written study material.

Participants

The study was accessible for people who know DGS/German Sign Language. Eligible for participation were culturally deaf and hard of hearing people over the age of eighteen with DGS as their preferred language of communication and 99 individuals participated in the online rating of frequency and iconicity.

We asked the participants to provide us with demographic information concerning their age group (18-30; 31-45; 46-60; 61+), their status (deaf, hard of hearing, hearing), their federal state of birth and childhood as well as federal state of current home, splitting the federal states of Germany up into four categories: North (Schleswig-Holstein, Hamburg, Bremen, Lower Saxony, Mecklenburg-Western Pomerania), South (Baden-Wuerttemberg und Bavaria), East (Thuringia, Saxony, Saxony-Anhalt, Brandenburg und Berlin) and West (Saarland, Rhineland-Palatinate, Hesse und North Rhine-Westphalia). We further asked whether the

participant had deaf and signing parents and siblings, which language was used at home, and in which context DGS is used mostly by the person. We added a self-assessment, asking about DGS competence in production and reception as well as in one-handed DGS finger spelling. Stating their gender was optional to answer with female, male, identifying neither as female, nor as male, and not answering as answer options. The participants were informed about the data's anonymity and gave their informed consent.

Due to the online study design, we decided to keep the time of study participation to a reasonable timeframe to avoid fatigue or even dropouts. This meant that each participant rated either frequency or iconicity and not both tasks. In addition, for each task, all stimuli (for frequency, 347 signs, and for iconicity, 351 signs) were separated into three stimuli lists of different items, resulting in one participant rating one task and one list. The data set encompasses the ratings of all 98 participants for the lexical items in all three lists of the two tasks. The participants were split into sub-groups for each task: for sign frequency (*n*=50), 38% of the participants were in the age group 46-60 and 36% between the age of 31 and 45. 80% of the participants in the sign frequency task described themselves as congenitally-prelingually deaf, 14% became deaf before the age of 4. Around 76% of the participants in this task acquired DGS before the age of 6, 40% of them from birth. 92% stated to be deaf and 8% to be hard of hearing.

In the sign iconicity task group (*n*=48), around 48% were between 46 and 60 years of age, and 42% between 31 and 45. 81% stated to be congenitally-prelingually deaf and 10% became deaf under the age of 4. Around 21% of this sub-group acquired DGS from birth, 62.5% before 6 years of age. Finally, 92% identified as deaf and 8% as hard of hearing.

The demographic variables of all participants are displayed in Table 1.

Table 1: Demographic variables of all participants

	Frequency	Iconicity
n	50	48
status (deaf/HoH/hearing)	46 / 5/ 0	44 / 4 / 0
AoD (congenital-prelingual/<4 yrs/later)	40 / 7 / 4	39 / 5 / 4
AoA DGS (from birth/ <4 / <6 / <14 / >14)	20 / 9 / 9 / 7 / 6	10 / 6 / 14 / 11 / 7
language as child (DGS / German / DGS and German / other)	14 / 19 / 17 / 4	10 / 17 / 18 / 9
age group (18-30 / 31-45 / 46-60 / 60+)	8 / 18 / 19 / 6	7 / 20 / 13 / 8
region (North / East / South / West)	10 / 4 / 12 / 24	7 / 4 / 10 / 27
born in Germany (yes/no)	44 / 6	40 / 8
gender (female / male / diverse / not specified)	28 / 20 / 0 / 3	23 / 24 / 0 / 1

Material

Lexical signs were chosen from different studies. First, we based parts of our list, 242 lemmas, on the BSL sign list from the BSL norm(ing) study (Vinson et al., 2008) and added 29 lemmas from a DGS-ASL comparative rating study (Occhino et al., 2017) for future possible comparison between data sets. Moreover, 8 lemmas used in the cognitive screening tool for Deaf BSL signers (Atkinson et al., 2015) were added for a subsequent research project on a test adaptation into DGS (Stockleben et al., in press). As a last addition, 46 lemmas for age-related topics were added or specifically retained such as OLD, DEMENTIA, SICK, NURSING/CARE, REHAB, PAIN, VERTIGO, TO LIMP which reflect common themes in the daily lives and health-related conversations of older signers. Second, inclusion criteria and the removal of items were discussed, and idiomatic signs, polysemy, signs for which there is no equivalent in DGS, such as VERY-BAD as well as culturally unusual signs like SANDWICH were removed. Third, the remaining list was cross-checked with the DGS sign list from Trettenbrein and colleagues (2021). To keep a reasonable overlap for data comparison but to also enlarge the norming data for DGS lexical signs, we kept an overlap of 131 lemmas and selected different DGS variants for our study whenever this was possible. For example, we chose the variant preferred by older adults or 'old' DGS signs after consulting deaf older adults themselves. Two examples are the signs for 'alcohol' and 'to work'. For ALCOHOL, we deliberately chose the variant often used by older deaf signers – i.e., the sign that is more associated with "drinking", but in this context clearly understood as "drinking alcohol". For 'to work' we deliberately included two signs, one of them TO WORK_var2 — is hardly used in the signing of younger DGS signers. An analysis using DGS corpus data (DGS-Annis; Isard & Konrad, 2022) confirmed this observation: the variant TO-WORK3 occurs only four times, while TO-WORK1 is signed significantly more frequently, with 534 tokens. Notably, TO-WORK3 is exclusively found among signers aged between 46 and 61 years (see DGS Corpus: https://www.sign-lang.uni-hamburg.de/meinedgs_r4/types/type14994_de.html#type6695) Both variants were included to enrich the data. The next step was comparing our sign list to the open access online DGS-Corpus (see https://www.sign-lang.uni-hamburg.de/dgs-korpus) for number of types and tokens. By accessing the DGS-Corpus for type and token search, we checked for variation and chose widely spread variants and types.

The final list of 351 lexical DGS signs was recorded collectively by the entire research team while the two deaf researchers signed each half of the stimuli list. Each recording lasted 3

seconds per sign, with a resolution of 1080 and 25 frames per second. The 351 signs were assigned to three lists with 117 signs each. For the iconicity task, the number of signs was higher because each list included nine additional signs. This way, every study participant was asked the same nine signs which we could use as reliability items for the study. By doing this, we could check for reliability between the lists. The reliability items were selected on the basis of a small-scale pre-study that our team conducted in which eight deaf signers who worked as DGS lecturers in different parts of Germany and were familiar with scientific concepts like iconicity were asked to rate 29 DGS lexical signs. The signs BALL, BANANA, KEY, BUTTERFLY, PEN and CRY were selected for high iconicity with a rating value of > 5, and BIRTHDAY, TO LIE, GUILTY were selected for low in iconicity with a rating value around 2. This resulted in nine reliability items in total. Figure 1 depicts two signs for each category: low-iconic and high iconic signs.

Figure 1: Reliability items

Reliability items: a) upper left and upper right = high-iconic sign, b) lower left and lower right = low-iconic sign

Notes from the collaboration - the issue of stimuli articulation

The selection of the item list was a team effort every step of the way. The team of hearing and deaf signers did the stimuli video recording together. We were determined to choose

carefully DGS variants familiar to most regions in Germany. We discussed the importance of nonmanual markers for rating sign iconicity. From a perspective of the deaf authors, the question was raised what counts towards iconicity in a rating? Is it mostly the manual sign that influences the perception of iconicity or is it the manual and the nonmanual features in combination? If it is the latter, how much of an effort should we put on the precise and neutral articulation of signs for experimental purposes then? We decided to add this exploratory layer to the analysis of the study.

Procedure

The study participants were virtually welcomed on the online survey platform SoSci Survey (Leiner, 2024) and informed about the study before they provided their consent to participate. After consent was given, one task (rating the DGS signs for iconicity or frequency) was randomly selected by the platform. The video instructions for the task were presented and examples were given. In the following step, the participants were presented with single videos from one of the three lists of signs which were randomly selected and the order of each list rotated for each participant by the program. Their task was to rate each single video accordingly on a Likert-scale (1-7) for about 25 minutes. The set-up was self-paced. Each stimuli list was programmed to rotate the order in which the videos were presented among participants to counterbalance the effect of possible fatigue during the study.

After completing the rating, participants were asked about their demographics as well as their social and linguistic background. They self-reported on a Likert-scale (1-7) their level of DGS proficiency in expressing themselves, in understanding DGS, and their level of proficiency in signing one-handed DGS fingerspelling and understanding it. Participants with a self-reported level of 3 and lower were cross-checked with the other answers about their background. Having high competence in DGS in production and comprehension was an essential criterion, so we added another task to control for this. It was checked by asking the participant to type the numerals “7 4“ into a blank field, which was a proficiency check task. In the proficiency screening video, the participants viewed the instruction exclusively in DGS, with no German translation. The number comprehension task was inspired by previous work by Caselli (2017), who asked their participants to sign numeral five, verifying comprehension of the task instruction. 66.3% of the participants gave the correct answer “7 4“ and another 20.4% answered “4 7“ which can still be regarded as correct due to the order of signing numerals in

DGS. Other answers were given by 13.3% and encompassed mostly feedback to the study in general or particular signs that were regarded as regional variants or not known to the individual. Two participants (one in each task) gave incorrect or irrelevant responses, one typed “6“ and another one wrote that the “gestures” were interesting „to guess“. Cross-checking with the self-reported DGS language-proficiency of both participants, the individual who answered “6” showed no profile of a non-signer (self-reported DGS level of 6) whereas the other person self-reported very low DGS competence and was therefore excluded from the sample.

Task

To investigate sign frequency, the participants were asked: ‘Do you use this sign very often? Or do you only use a sign very rarely or even never? We would like to know from you. How often do you use this sign?’ The task instruction explained the seven answer options ranging from “never“ to “very often/daily“. There was an eighth answer option for signaling that the sign was unknown to the person.

For sign iconicity the participants were asked: ‘Does the form of a sign look like what it means? Your task is to evaluate how iconic each sign in the video is. In the text, you are to rate each sign on a scale from 1 to 7 based on its visual connection to what it represents.’ The task instruction explained the scale: 1 meant “The sign has no visual connection to what it represents”, 7 meant “The sign has a direct visual connection to what it represents”. There was an eighth answer option for cases where the sign was unknown.

Notes from the collaboration: considerations of the task constructs

The deaf researchers in our team raised concerns that a video-based task instruction may increase misunderstandings and the error rate in comparison to live in-person instruction. This concern stemmed from different task instructions in different studies on iconicity and frequency. (Examples: frequency as how often you see/hear a sign/word versus how often you use the sign/word yourself; iconicity as transparency, as imageability etc.)

We decided that the task instruction for the iconicity task would be elaborated through examples with actual photographs of the depicted concept of the sign, i.e., 1) a cake with lit candles for one DGS variant of ‘birthday’, 2) drinking out of a cup for ‘to drink’ and 3) bicycle leaning against the wall for ‘bicycle’ (https://uni-koeln.sciebo.de/s/MWHHKxrvUpNF1PH).

Research questions

To analyze the data, the following research questions led the investigation:

Frequency

1F) How often are certain DGS signs used – sign frequency?

2F) How reliable are our data compared to other subjective frequency ratings?

3F) How reliable are subjective frequency ratings compared to objective measures?

Iconicity

1I) How iconic do deaf signers rate DGS signs – sign iconicity?

2I) How reliable are our data compared to other subjective iconicity ratings?

3I) How to check for reliability across the different study ratings?

Data Analysis

Frequency

To address research question 1F) the mean per sign as well as the grand mean for sign frequency across all signs were calculated.

The subjective rating (SR) data of this study, subjective ratings A (= SR-A), were compared to Trettenbrein et al. (2021), subjective ratings B (= SR-B). We asked, whether these two subjective rating studies for DGS show similar patterns of frequency. Since the two rating studies did not use identical stimuli or have the same raters, a t-test comparison between groups could not be used. A more careful and exploratory approach was chosen.

Thus, research question 2F) was addressed by calculating the effect size measure *Hedges' g* for inter-study comparison on rater-level. Reporting and comparing the rating data by only comparing the means would limit the analysis. We decided for effect size over mean difference comparison because *Hedges' g* uses a weighted pooled standard deviation to compare different samples as it merges the spread of separate samples into one to describe variability (Hedges, 1981). It is preferred over the often-used *Cohen's d* when two sample groups are significantly different in size, as it is the case for this study. The estimated effect size *Hedges' g* is interpreted in the same way as *Cohen's d* with a low effect of 0.2, > 0.5 identifying a medium effect and > 0.8 a large effect.

Our research team qualitatively examined all signs for phonological and morphological differences between SR-A and SR-B, such as different handshape, movement, orientation, location, mouthing or mouth gesture, and nonmanual marking. The signs were marked accordingly ('same' or 'different') and calculated as a group factor for comparison with 72 'same' signs and 59 'different' signs of the same lemma. We included both same and different sign variants from the same lemma due to exploratory nature of this analytic step.

Inspired by Fenlon et al. (2014), we were interested in looking beyond the subjective rating and compared subjective ratings and objective measures of sign frequency to answer question 3F). As the objective measure, we used the frequency ratings from the DGS-Corpus project data. The DGS-corpus data was searched for the types and tokens that were included as stimuli in SR-A and SR-B, using the search software DGS-ANNIS[12] (Isard & Konrad, 2022) and the annotated open access DGS corpus data, MY DGS-annotated, Release 3 (Konrad et al., 2020). A ratio was calculated for each SR-A and SR-B token based on the number of tokens belonging to a type within the DGS-corpus. For instance, SR-A type EVENING2, with 205 tokens, was divided by the overall 262 tokens for EVENING in the DGS corpus, and SR-B type EVENING1, with 53 tokens, was divided by the overall 262 tokens in the DGS corpus. This way we calculated a measure of relative frequency, ranging from 0 to 1, which displayed that the closer the ratio was to 1 the more frequently used was the token in the natural language data resource, the DGS-Corpus project data.

Pearson's and Spearman's correlations were performed between SR-A and SR-B, and between subjective and objective measures.

Iconicity

The data analysis for sign iconicity addressed the research questions 1I), how iconic do deaf signers rate DGS signs?, 2I) how reliable are our data compared to other subjective iconicity ratings?, and 3I) how to check for reliability among the different participant groups?

To address 1I), we calculated the mean iconicity rating per sign (based on a 7-point Likert scale) as well as the grand mean across all signs.

2I) was assessed the same way as the frequency rating data, using *Hedges*' *g* on rater-level between SR-A and SR-B. For 3I) we looked for agreement between the small-scale pre-study

[12] "ANNIS is an open source, browser-based search and visualization architecture for multi-layer corpora": https://dock.fdm.uni-hamburg.de/meinedgs/ (accessed 22.09.2025)

data (*n* = 8) and the SR-A study data (*n* = 48). We compared the ratings from the eight pre-raters for each of the nine reliability signs to the ratings from our study participants for those same nine signs. We assessed the items through the mean difference for each of the nine items across subjects between groups.

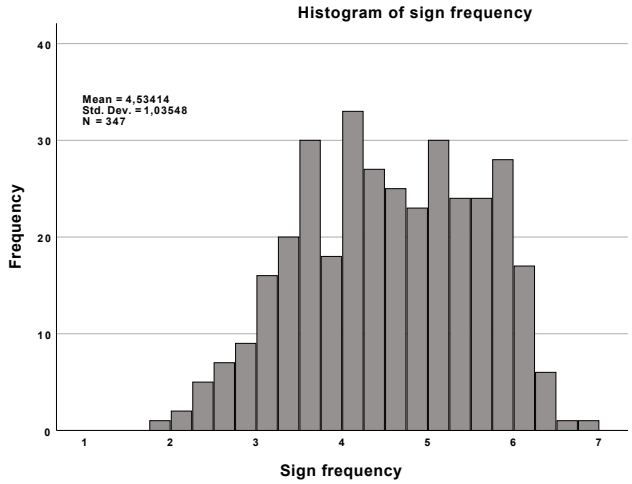
For all data analysis, SPSS version 29 (IBM Corp, 2023) was used for calculations and R (R Core Team, 2020), package ggplot (Wickham, 2016), for data visualization.

RESULTS

Frequency

For 1F), mean sign frequency data are displayed in Figure 2. The full data is shared in the supplementary material in Table Y. The results are plotted from low (1 = "never") to high (7 = "very often/daily"). The 347 signs had a grand frequency mean of 4.5 (SD = 1) and were normally distributed. The signs PILLOW and METAPHOR were the lowest rated signs, meaning the least frequently used signs from our data set, with a mean of 1.9 (SD = 1.2, range 1-4) for PILLOW and *M* = 2 (SD = 1.5, range 1-6) for METAPHOR. The signs TO EAT and WHAT were rated as the most frequently used signs from our data set, with a mean of 6.6 (SD = 0.6, range 5-7) for TO EAT and *M* = 6.8 (SD = 0.4, range 6-7) for WHAT.

Figure 2: Histogram of sign frequency from SR-A all participants and all signs



About 2F), the 131 overlapping lemmas of the SR-A, our original data collected within this study, and SR-B, Trettenbrein et al. (2021)' study were included to investigate reliability in the

frequency ratings. The ratings for the overlapping items were normally distributed with a SR-A mean = 4.8 (SD = 1) and a SR-B mean = 4.9 (SD = 1).

The qualitative phonological and morphological similarity analysis revealed that 45% (n = 59) of the overlapping lemmas corresponded to different signs in each study while 55% (n = 72) corresponded to the same sign.

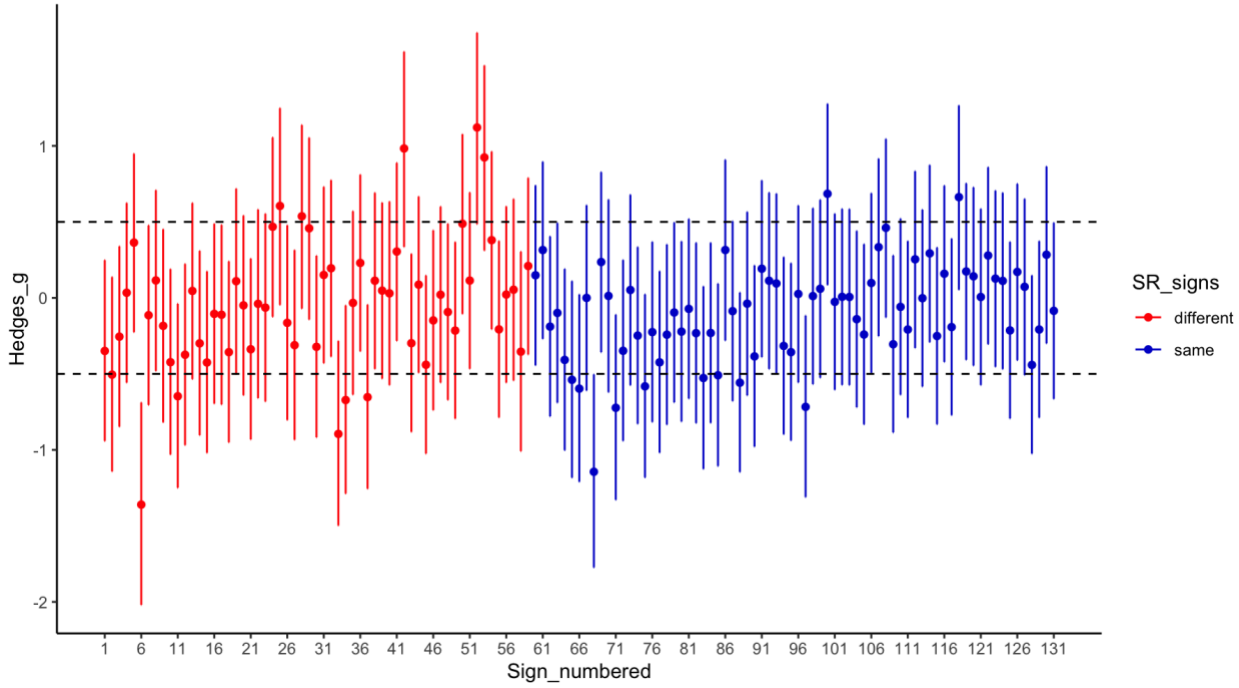
For the inter-study comparison between SR-A and SR-B, we report corrected effect size *Hedges' g*. The full table is available in the supplementary material, Table X, including mean difference and corrected effect size. Figure 3 shows all lemmas grouped into different or same sign with *Hedges' g*. The dotted black line shows the 0.5 threshold of a medium effect (Cohen, 1977) and the bars display the confidence intervals, facilitating a more precise effect size interpretation. A negative Hedges' *g* reveals a higher frequency rating value on the SR-B data by Trettenbrein et al. (2021) and a positive Hedges' *g* reveals a higher frequency rating value of the SR-A data, that was collected by our team.

The data show quantitively larger effects for the group of lemmas with different signs across the two studies and wider deviation of the data points, which was to be expected. This indicates that participants rate the actual sign variant and not the lemma. As for the threshold of 0.5 for a medium discrepancy between the two SR studies, an equal number of signs (whether the signs were the same or different) showed medium and large effects. The largest rating discrepancies, indicated by the Hedges' *g,* of different and same signs of the same signified word of $g > 0.6/-0.6$ are presented in Table 2. Considering the confidence intervals, a significant difference between the two subjective rating data can be assumed for these signs.

Table 2: Hedges' g for indicating discrepancies between SR-A and SR-B frequency ratings

Different sign*	Hedges' *g*	95% CI [LL, UL]	Same sign*	Hedges' *g*	95% CI [LL, UL]
bed	-1.36	[-2.02, -0.69]	simple	-1.14	[-1.77, -0.5]
watch	1.12	[0.49, 1.74]	to decide	-0.72	[-1.33, -0.11]
horrible	0.98	[0.34, 1.62]	gossip	-0.72	[-1.31, -0.12]
mother	-0.9	[-1.5, -0.28]	mouse	0.69	[0.09, 1.28]
new	-0.67	[-1.29, -0.05]	to dive	0.66	[0.05, 1.27]
to check	-0.65	[-1.26, -0.05]			
interpreter	-0.65	[-1.25, -0.04]			
*Lemmas of same or different sign variants					

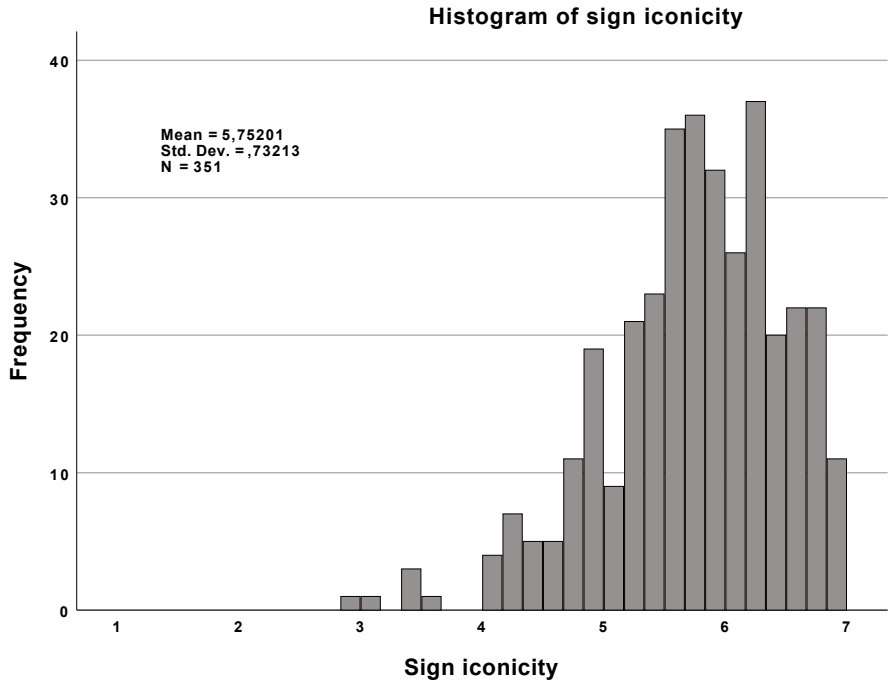
Figure 3: Hedges' g of sign frequency between SR-A and SR-B



About 3F), the analysis of the relative frequency values from the two subjective measures, SR-A and SR-B were compared with the objective measure extracted from the DGS-Corpus to provide additional insights into the data. A full display of the relative frequency values is seen in the supplementary material, Table X.

A significant Pearson correlation of $r(130) = .79$, $p < .001$, 95% CI [0.71, 0.84] showed a medium strong agreement between the two subjective rating data sets. To compare the objective measures and the subjective ratings, the earlier introduced relative frequency value (the calculation of the number of tokens of the used variant divided by the total number tokens of that lemma) was interpreted. For both SR-A and SR-B, the relative frequency value was not normally distributed and the assumption of linearity was not violated. For SR-B and the DGS corpus data, no significant correlation was found with Spearman correlation coefficients for SR-B $r = .13$, $p = .16$. But the SR-A data showed a significant yet small correlation $r = .25$, $p = .005$ between the subjective rating data from both studies and the objective measure. This means that the higher a sign was rated, the more frequent the sign was used in the DGS-Corpus.

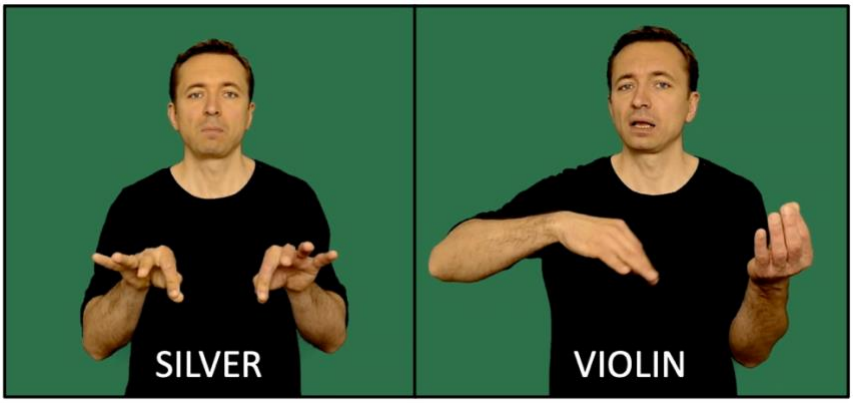
Figure 4: Histogram of sign iconicity from SR-A all participants and all signs



Iconicity

For 1l), mean sign iconicity data are displayed in Figure 3. The full data is shared in the supplementary material in Table Z. The results are plotted from low to high sign iconicity. The 351 signs had a grand iconicity rating mean of 5.8 (SD = 0.7) and the ratings were normally distributed. The signs FACETIME and SILVER were the lowest rated signs, meaning the least iconic signs from our data set, with a mean of 2.9 (SD = 2.1) for FACETIME and *M* = 3 (SD = 1.6) for SILVER. With a mean value of 3.5, FEBRUARY (SD = 2.6), PILLOW (SD = 2) and METAPHOR (SD = 1.8) were rated the lowest in iconicity. The large standard deviation among the signs showed however the wide range of the data and possible incongruence between raters. The signs TO COOK, HOUSE and VIOLIN were rated by all raters with a 7, the highest value, followed by BALL (mean = 6.9, SD = 0.2), and TO EAT and ICE-CREAM, both rated with a mean of 6.9 (SD = 0.3) with smaller deviation within the data. In Figure 5, screenshots of one of the lowest rated signs, SILVER, and VIOLIN, as one of the highest rated signs in iconicity are presented.

Figure 5: Highest and lowest rated DGS signs in sign iconicity



Concerning 2I), the overlap between SR-A and SR-B on sign iconicity consisted of 136 lemmas. Both overlapping data sets were normally distributed with a SR-A mean = 5.9 (SD = 0.7) and a SR-B mean = 5.4 (SD = 1).

The same groupings into same or different sign as for the frequency analysis were applied. The corrected effect size is reported in Figure 7 below and Table X (supplementary material), showing that the SR-B study iconicity ratings were higher. The data deviates more strongly in the group of different signs, which would be expected in the context of the form-meaning relation of sign iconicity. This points to participants rating the iconicity of the actual sign variant and not of the lemma. The large difference between the ratings for the signs for BOY with a Hedges'*g* of 1.03 95% CI [1.67, 0.37] is still an interesting example for future follow-up investigations. Less expected were the medium and large effects ($g > 0.5$) in the group of same sign. A medium to large positive Hedges' *g,* higher than 0.6, with higher rating values for iconicity in SR-B, were found for TO SUMMARIZE[13] ($g = 0.75$, 95% CI [1.36, 0.11], YESTERDAY ($g = 0.74$, 95% CI [1.36, 0.12], TO COOK ($g = 0.69$, 95% CI [1.31, 0.07] and TO TEACH ($g = 0.62$, 95% CI [1.21, 0.01]. A medium to large negative Hedges' *g*, higher than -0.6, with higher rating values for iconicity in SR-A, were found for AIRPLANE ($g = -0.71$, 95% CI [-0.1, -1.31], TO SLEEP ($g = -0.64$, 95% CI [-0.02, -1.25] and DUCK ($g = -0.62$, 95% CI [-0.01, -1.22].

In a post-hoc qualitative analysis of the signs that we categorized a priori as being 'same', we looked for the slightest differences in articulation to explain the statistical differences.

For DUCK, the only difference between the two study data sets was that the mouthing was well visible in SR-B while the mouthing was covered by the signing hand in SR-A. Since lexical

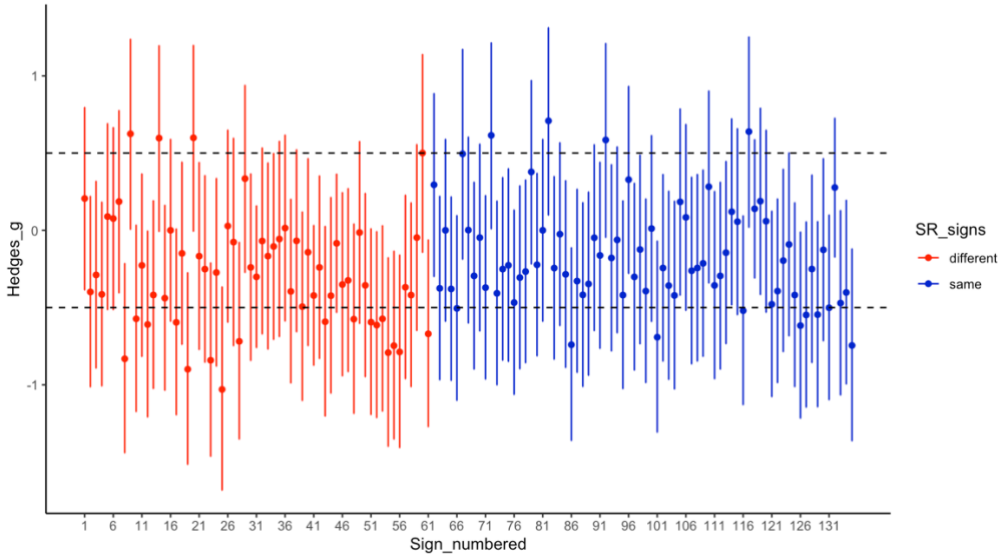
[13] The hyperlinks present the SR-A sign variant of this comparison.

sign information is provided through mouth actions (Mohr, 2014; Pfau & Quer, 2010) and meaning is facilitated (Perniss et al., 2020), the impact of covered mouthings for subjective judgments (showing lower iconicity ratings), opens a new path for investigation which is beyond the scope of this study. Interestingly, AIRPLANE and TO SLEEP were both more visually and gesturally motivated in the sign variant in SR-B. One could argue that the more gestural-based use of a two-handed sign and closed eyes for TO SLEEP may raise the perception of sign iconicity. The same goes for AIRPLANE, where the SR-B sign depicts a steeply departing airplane, while the SR-A sign was less depicting in this way. For the two signs, the frequency ratings were similar, with higher and more distributed data in Trettenbrein et al. (2021)'s study: SR-A: *mean* = 4.6, SD = 1.1; SR-B: *mean* = 5, SD = 1.7. All details are displayed in Table X in the supplementary material. The SR-A sign AIRPLANE, of our data, is displayed in Figure 6.

Figure 6: Stimuli item AIRPLANE

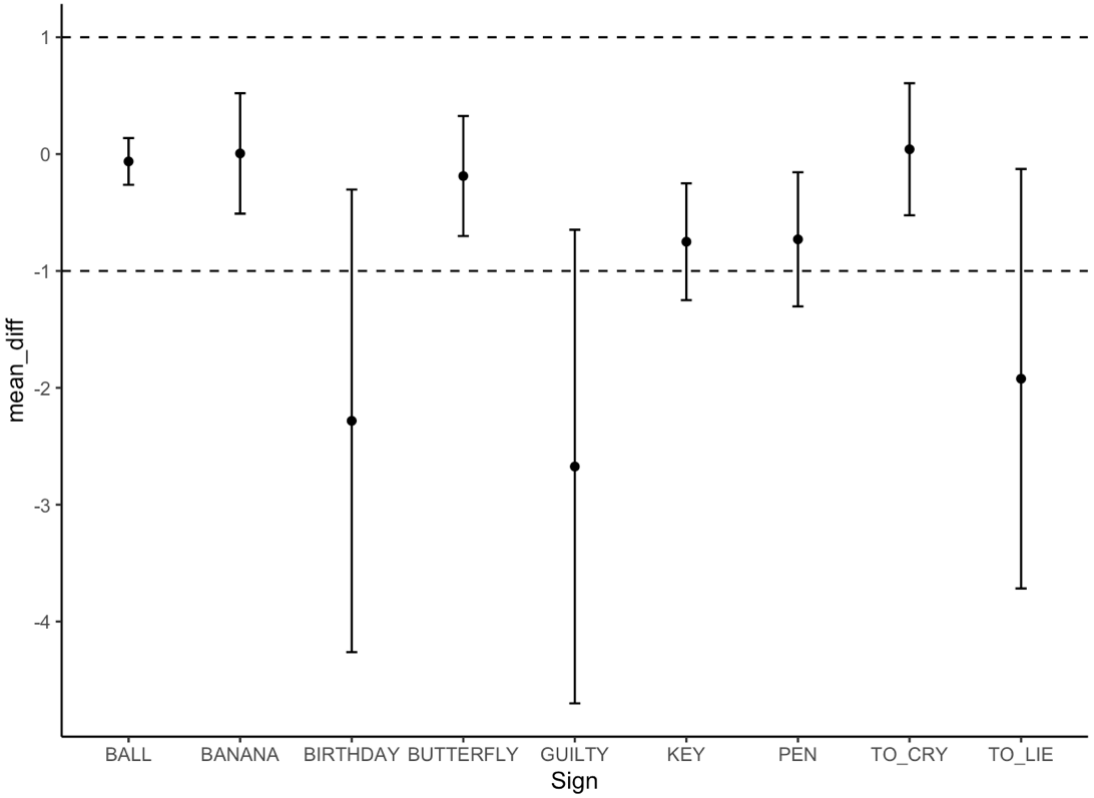
Lastly, the difference in data mean and deviation found in the compared ratings for the two different signs for BOY suggests an association with sign frequency. The SR-A sign had a relative frequency value of .69 with a mean frequency of 5.1 compared to the SR-B sign for BOY with a mean of 3.9 and no corresponding sign in the DGS-corpus (meaning a relative frequency value of 0). This study's original data (SR-A) showed a small yet significant Pearson correlation of $r(345) = .21$, $p < .001$, 95% CI [0.11, 0.31] between sign frequency and sign iconicity data.

Figure 7: Hedge' g of sign iconicity between SR-A and SR-B



About 3I), the comparison between the pre-study and the ratings from our participants assessed the reliability of the individual ratings, answering 2I). The items which were classified as high in iconicity based on the pre-study data from 8 raters were also rated as highly iconic by the study rating participants (*n* = 48) with means higher than six; BUTTERFLY (*mean* = 6.7, SD = 0.7), KEY (*mean* = 6.8, SD = 0.6), PEN (*mean* = 6.6, SD = 0.7), TO CRY (*mean* = 6.7, SD = 0.8), BALL (*mean* = 6.9, SD = 0.3) and BANANA (*mean* = 6.7, SD = 0.7). The results for mean difference remained within a band between -1 and 1, meaning not more than one rating unit difference, as displayed in Figure 8. We therefore saw no difference between groups.

Figure 8: Mean difference of sign iconicity ratings from the pre-study and the study participants for the reliability items



The group comparison showed negative effect size Hedges' *g* across almost all items, which translates as lower rating values in the pre-study ratings across seven of the nine items. This effect was also found for the items that were low in iconicity, for which the study participants showed a medium mean; TO LIE (*mean* = 4.1, SD = 2.3), GUILTY (*mean* = 4.7, SD = 2.4) and BIRTHDAY (*mean* = 4.4, SD = 2.5). The low rating value from the pre-study could not be confirmed by the study participants' ratings. A full display of the corrected effect size is presented in Figure 9.

Figure 9: Hedge' g of sign iconicity of the reliability items from the pre-study and study participants' ratings

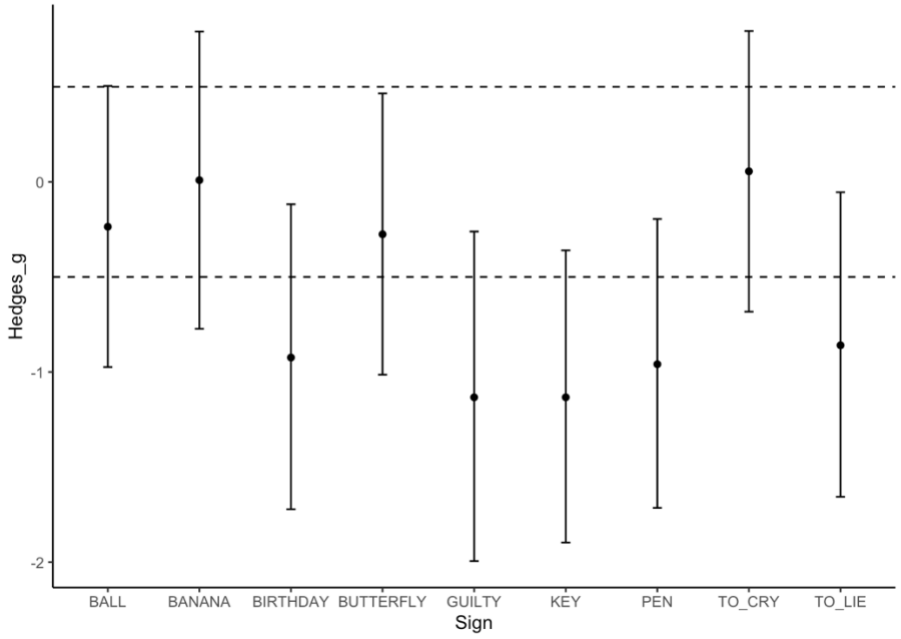


Table 3: Pre-study and study participants' iconicity ratings of reliability items

Sign	pre-study_N	rating_N	pre-study_mean	pre-study_sd	rating_mean	rating_sd	Hedges g_RI	95% CI Lower Limit	95% CI Upper Limit	Mean difference_RI	95% CI Lower Limit	95% CI Upper Limit
TO_LIE	7	46	2.14	1.345	4.07	2.294	-0.859	-1.656	-0.055	-1.922	-3.717	-0.128
KEY	8	48	6.00	0.926	6.75	0.601	-1.133	-1.897	-0.36	-0.75	-1.25	-0.25
BUTTERFLY	8	48	6.50	0.535	6.69	0.689	-0.276	-1.014	0.466	-0.188	-0.701	0.326
GUILTY	6	46	2.00	1.549	4.67	2.395	-1.133	-1.994	-0.261	-2.674	-4.7	-0.648
PEN	8	48	5.88	0.835	6.60	0.736	-0.959	-1.715	-0.195	-0.729	-1.303	-0.155
TO_CRY	8	48	6.75	0.463	6.71	0.771	0.056	-0.683	0.794	0.042	-0.523	0.607
BIRTHDAY	7	47	2.14	1.952	4.43	2.491	-0.924	-1.722	-0.117	-2.283	-4.262	-0.303
BALL	8	48	6.88	0.354	6.94	0.245	-0.236	-0.974	0.505	-0.063	-0.263	0.138
BANANA	7	48	6.71	0.488	6.71	0.651	0.009	-0.772	0.791	0.006	-0.509	0.521

DISCUSSION

The present study enriches the sign iconicity and sign frequency psycholinguistic norms data base for DGS. We present new empirical data which we triangulated with existing DGS rating data and DGS-Corpus data. We addressed the issue of the reliability of subjective rating norms in order to better understand the use of psycholinguistic norms from different sources and to discuss issues of validity in online studies.

Main results

Our data was collected with an online survey and recruited a diverse participant sample. Our data set was compared to the psycholinguistic DGS norms from Trettenbrein et al. (2021). This comparison revealed both consistencies and differences, prompting further exploration of the data sets and studies.

The two compared study samples exhibit differences in participants demographics, which highlights the potential for supplementing studies to build larger, more comprehensive databases (ASL-LEX 2.0: Sehyr et al., 2021; DGS-LEX: Trettenbrein et al., 2024). Our study's original main aim was to recruit individuals over 50 years of age, because they are less represented in psycholinguistic research. Yet the importance of collecting linguistic as well as psycholinguistic norms for this population in ageing societies increases. While we reached only a few people above 60 years of age (14% in total), 69% of the sample for the frequency task and 72,5% for the iconicity task were between 31 and 60 years. A slightly younger sample with approximately 68% between 28 and 53 years of age was reported in Trettenbrein et al. (2021), and an even younger sample was recruited for the initial ASL-LEX study (Caselli et al., 2017). A similar age distribution is found in a more recent study, which included DGS iconicity ratings (Ortega et al., 2025) from a group with an age range of 19-60 years. The ASL-LEX 2.0 project (Sehyr et al., 2021) did include a wider participant age distribution. Interestingly, deaf signers over the age of 70 were not recruited in any of the cited studies. In our study, we faced the same challenges and would still argue that experimental sign language research in general would benefit from more age-inclusive recruitment to inform studies relating to age-sensitive topics.

When we compared the two studies in terms of regional distribution, an interesting pattern showed up. In our study, most participants stated their location to be in the western (52%) and southern (22%) regions of Germany, with only a quarter from the northern (17%) and eastern (8%) regions. In the study by Trettenbrein et al. (2021), the participants were concentrated in the northern (40%), eastern (40%), and southern region (20%). We regard this supplementary pattern in demographics as a strengthening factor of combining subjective ratings to establish norms of all regions.

With regard to the actual rating results, the comparison between our study and Trettenbrein et al.'s, revealed a fair amount of overlap in rating results, meaning that the ratings of both DGS studies dmeonstrated similar answers. Both sign frequency and sign iconicity ratings had very similar means and standard deviations and produced a skew towards higher iconicity ratings. These findings support the pattern of higher iconicity ratings for DGS, even in comparison to other sign languages (Fuks, 2023; Occhino et al., 2017, Ortega et al., 2025; Trettenbrein et al., 2021), even though data on American Sign Language is inconclusive with a study reporting lower iconicity ratings for ASL compared to DGS (Sehyr & Villwock, 2022).

Intrigued by the rating differences between studies, our post-hoc qualitative analysis of the phonological properties of the investigated signs raised new questions around the importance of mouthing and phonological features in DGS sign iconicity evaluation. The fact that mouthing is a reliable cue for meaning (Perniss et al., 2020) underlines the importance of the use of mouthing in creating stimuli and the influence that mouthing has on the comprehension and the perception of the sign. Perniss et al. (2020) found that mouthings did create incongruence costs when an image and the presented sign had the incorrect mouthing. A mismatch in the manual features produced significantly higher costs though. We therefore examined those signs for which we found a difference in the ratings between studies, such as the instance in which the sign for DUCK where the mouthing was covered produced lower iconicity ratings than when the mouthing was visible. The observed differences in gestural degree in the signs TO SLEEP and AIRPLANE across both studies warrant further investigation within the frame chosen by Ortega et al. (2025). Their data clearly demonstrated an effect of the strategy used to express iconicity. This could explain some of the reported cross-study rating differences in our study but would need further investigation.

To get a clearer picture of our data, objective measures from corpus-based data deepened the analyses and showed a significant correlation with our data set in terms of sign frequency.

The strong correlation between the two studies SR-A and SR-B for sign frequency rating congruence of .79 ($p < .001$) strengthens both compared data sets of psycholinguistic subjective ratings. After discussing the results and focusing on the matter of "what" was investigated, we now shift to the "how", discussing the study approach and issues of reliability and validity in rating studies.

The matter of reliability in subjective rating studies

Subjective rating data, particularly if collected online, presented challenges in our study. At different stages throughout the study, we added reliability items to strengthen the study with very different outcomes: i) assessing signed task comprehension in DGS for general background check of the sample, ii) "reliability items" added for the iconicity task and iii) a "relative frequency value" for the frequency task. i) The inclusion or exclusion of participants through the correct or incorrect response to screening question "type 7 4", strengthened our understanding of the participants'sample. However, the proportion of 13.3% alternative responses (i.e., general feedback, "6" and the removed participant who indicated that the "gestures" where interesting "to guess") to that question showed a susceptibility to errors. Therefore, future studies may benefit from looking into options of checking inclusion of signers into sign language studies if those are anonymous online studies.

ii) To check reliability across all iconicity raters, nine reliability items were added to control the iconicity task. The ratings from the pre-study and the study ratings produced congruency for the highly iconic signs but not for the low iconic signs. With a grand mean iconicity rating of 5.8 across all signs, it would seem that, overall, the study participants' rating results revealed a tendency for high iconicity ratings throughout the stimuli lists. An examination of the ratings for the reliability items hint at a possible explanation for this finding and a take-away for future studies. The eight raters of the pre-study were a well-informed group of DGS educators who have had professional meta-linguistic training and awareness of the concept which they had to rate. Thus, they used the full range 1-7 for their ratings of sign iconicity. The study participants revealed a different rating behavior, which supports the impact of language experience (Occhino et al., 2017) and linguistic knowledge (Ortega et a., 2025) on evaluating a concept like sign iconicity.

The reliability control measure may be misleading in the analysis. However, due to the anonymous online study design, we interpret the results from the items, decided on as

'reliability items' based on the pre-study ratings, carefully and would not recommend to exclude someone from the study based on a diverting rating response. It may well be that the task itself was perceived differently and may have elicited different or incorrect answers.

A third layer of reliability check was applied to the frequency analysis iii). The significant correlation between the subjective measure from our study, and the objective measure through the proposed 'relative frequency value', strengthens the reliability of our data. This correlation was not found for the Trettenbrein et al. (2021) data. Regional variation might explain this difference, since our data was collected online, accessible from across Germany and showed a bias mostly for western regions where many deaf signers have gone to school, while Trettenbrein et al. (2021) recruited participants mostly from eastern and northern regions of Germany. Since the relative frequency value is a novel measure and highly dependent on the objective measure, the DGS-corpus data in this case, a cautious interpretation is recommended. One might raise the question of data quality of the measures, and one might criticize the computation of the measuring variable itself. The proposal of triangulating subjective rating data with objective measures has been proven to be a reliable source of psycholinguistic knowledge about sign frequency (Johnston, 2012; Fenlon et al., 2014). We therefore align with Fenlon et al. (2014) and encourage future studies on sign frequency in language studies to consider measure triangulation to strengthen the reliability of norming data.

Limitations

Despite meticulous considerations, limitations are unpreventable. The small sample size reduces the representability of the data. The online design may have limited participant recruitment. Also, we saw the risk of study participants not fully understanding the task by themselves if no live clarification was available. Direct live interaction in sign language would maximize understanding of the task at hand and strengthens validity. Consequently, we expected more errors and misunderstandings than the data indicated. The resulting correlations of our data with SR-B data and the corpus data ('relative frequency value') pointing otherwise.

Our initial intention was to include deaf signers over the age of 50. However, only very few individuals of higher age participated in the study. We assume that an online study may pose a higher barrier for older age groups, which would be different in a face-to-face study design.

Specific for online studies like ours is that one first needs to know about the study, which was advertised online due to the circumstances during the COVID pandemic, then one needs a technical set up to participate online. This requires a certain amount of technological affinity that is certainly given for most younger people in our digital world but less so for older cohorts (Lee et al., 2019).

Reflections on the collaborative process - which language first and other take aways

Lastly, we offer our reflections on the collaboration in the team and the challenges that we faced. Over the course of this project, we worked collaboratively on every step of the study. This meant a lot of communication and messaging. We found ways of video messaging for short direct communication feasible, especially when we discussed our signed data. However, since most research relies on written documents, the concern about which language leads the project arose. In a deaf and hearing research team in which hardly any language barrier is perceived by the team members, the common language for co-working is the common sign language. Written communication however is a must for documentation and messaging via email. However, if the study is about a sign language and the language of instruction to the participants is a sign language, will the study be designed sign language first? Meaning, is the first language in which the study is conducted a sign language or not? In research studies in Germany, this may differ in other countries, all information needs to be available in written form for different purposes: a) to search ethical approval by the responsible ethical committee, b) to give out information about the study to the participants and c) to give informed consent. For a) even the task instructions need to be in written form. How does this obligatory written form impact the formulation of the equivalent text in sign language? We tried to translate the task instructions from DGS to written German and not the other way around. This came with challenges. To give an example, the ethical committee required the informed consent form to follow standardized wording, which was evaluated by the deaf researchers as quite abstract for those of our deaf participants who are seldom in contact with research studies. We wondered how other research teams have approached this issue for their projects. The detailed task instructions can be found in the supplementary material in DGS and written German.

Over the course of the collaboration, we valued full transparency to ensure that we all had the same information and state of knowledge about the project. At the end of the project, we took the time to evaluate the collaborative process and to practice open and constructive communication.

Future research

The exploratory analysis of comparing the signs at the phonological and morphological level across studies may be encouraging for future research endeavors. Study replications and enlarging data bases are essential in the field of sign language research, where so many scientific questions remain to be answered. The question of the impact of nonmanual articulators and mouthings for iconic ratings requires further research. The relative frequency value can be seen as a variable of exploration to triangulate different measures of frequency and may encourage others in the field to elaborate on the idea. In general, this study raised the question how we define rating differences across rating studies which could be explored in future studies and would enrich the discussion.

Conclusion

Comparisons between data sets both challenge the individual study data and enhance replicability in sciences.

This study contributes to the existing psycholinguistic norming data on DGS and revealed both differences between data sets as well as reliable overlap. Regional variation may be one factor influencing the outcome of the ratings. Nonmanual information in the video stimuli seems to be another. A future resource for further investigation will be the project DGS-LEX (Trettenbrein et al., 2024) in which different DGS data sets are linked (comparable to the ASL-LEX 2.0: Sehyr et al., 2021), facilitating comparison across and use of the data sets. We encourage a conscious approach to linking different data sets to establish a valid data base for future applications.

The study documents transparently the research process in detail and may provide orientation to future researchers and students in their research. However, the documented process shall not be understood as an ideal way of collaboration between deaf and hearing researchers,

more shall it encourage a process of reflection about how we, deaf and hearing researchers, actually work together in the field and what participation actually means in the investigation of sign languages.

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Conflict of Interest

None to declare.

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REFERENCES

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

Arnstein, S. 1969. A Ladder of Citizen Participation. *Journal of the American Institute of Planners* No. 4: 216-224.

Beal, J. S., & Faniel, K. 2018. Hearing L2 Sign Language Learners: How Do They Perform on ASL Phonological Fluency? *Sign Language Studies 19*(2): 204–224. https://doi.org/10.1353/sls.2018.0032

Bosworth R.G & Dobkins K.R. 2002. The effect of spatial attention on motion processing in deaf signers, hearing signers, and hearing nonsigners. *Brain and Cognition* 4: 152–169.

Caselli, N., Occhino, C., Artacho, B., Savakis, A., & Dye, M. 2022. Perceptual optimization of language: Evidence from American Sign Language. *Cognition* 224: 105040. https://doi.org/10.1016/j.cognition.2022.105040

Caselli, N. K., Emmorey, K., & Cohen-Goldberg, A. M. 2021. The signed mental lexicon: Effects of phonological neighborhood density, iconicity, and childhood language experience. *Journal of Memory and Language 121*: 104282. https://doi.org/10.1016/j.jml.2021.104282

Caselli, N. K., & Pyers, J. E. 2017. The road to language learning is not entirely iconic: Iconicity, neighborhood density, and frequency facilitate acquisition of sign language. *Psychological Science* 28: 979–987.

Caselli, N., Sevcikova Sehyr, Z., Cohen-Goldberg, A. M., & Emmorey, K. 2017. ASL-LEX: A lexical database of American Sign Language. *Behavior Research Methods* 49(2): 784-801. doi:10.3758/s13428-016-0742-0

Cohen, J. 1977. *Statistical power analysis for the behavioral sciences.* Routledge.

Cornwall, A., & Jewkes, R. 1995. What is participatory research? *Social Science & Medicine 41*(12): 1667–1676. https://doi.org/10.1016/0277-9536(95)00127-s

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

Ensuring deaf access in science. 2023. *Nat Rev Mater* 8, 635. https://doi.org/10.1038/s41578-023-00604-7

Fenlon, J., Schembri, A., Rentelis, R., Vinson, D., & Cormier, K. 2014. Using conversational data to determine lexical frequency in British Sign Language: The influence of text type. *Lingua 143*: 187–202. https://doi.org/10.1016/j.lingua.2014.02.003

Fuks, O. 2023. Iconicity perception under the lens of iconicity rating and transparency tasks in Israeli Sign Language (ISL). *Sign Language Studies, 24*(1), 46–92. https://doi.org/10.1353/sls.2023.a912330

Gutiérrez-Sigut, E., Costello, B., Baus, C., & Carreiras, M. 2016. LSE-Sign: A lexical database for Spanish Sign Language. *Behavior Research Methods 48(1): 123–137. https://doi.org/10.3758/s13428-014-0560-1*

Hedges, L.V. 1981, Distribution Theory for Glass's Estimator of Effect Size and Related Estimators", *Journal of Educational Statistics*, 6(2): 107-128.

IBM Corp. 2023. IBM SPSS Statistics for Windows, Version 29.0.2.0 Armonk, NY: IBM Corp

Isard, A., & Konrad, R. 2022. *MY DGS – ANNIS: ANNIS and the Public DGS Corpus*. Proceedings of the 10th Workshop on the Representation and Processing of Sign Languages (sign-lang@LREC 2022): 73–79.

Johnston, T. (2012). Lexical Frequency in Sign Languages. *Journal of Deaf Studies and Deaf Education 17*(2): 163–193. https://doi.org/10.1093/deafed/enr036

Konrad, R., Hanke, T., Langer, G., Blanck, D., Bleicken, J., Hofmann, I., Jeziorski, O., König, L., König, S., Nishio, R., Regen, A., Salden, U., Wagner, S., Worseck, S., Böse, O., Jahn, E., Schulder, M. 2020. MEINE DGS – annotiert. Öffentliches Korpus der Deutschen Gebärdensprache, 3. Release / MY DGS – annotated. Public Corpus of German Sign Language, 3rd release [Dataset]. Universität Hamburg. https://doi.org/10.25592/dgs.corpus-3.0

Lee, C. C., Czaja, S. J., Moxley, J. H., Sharit, J., Boot, W. R., Charness, N., & Rogers, W. A. 2019. Attitudes Toward Computers Across Adulthood From 1994 to 2013. *The Gerontologist 59*(1): 22–33. https://doi.org/10.1093/geront/gny081

Leiner, D. J. 2024. SoSci Survey (Version 3.5.02) [Computer software]. Available at https://www.soscisurvey.de

Mayberry, R. I., Hall, M. L., & Zvaigzne, M. 2014. Subjective frequency ratings for 432 ASL signs*. Behavior Research Methods* 46(2): 526–539. *https://doi.org/10.3758/s13428-013-0370-x*

McKee, D., Kennedy, G., 2006. The distribution of signs in New Zealand Sign Language. *Sign Language Studies* 6, 372-390.

Mohr, S. 2014. *Mouth Actions in Sign Languages: An Empirical Study of Irish Sign Language*. Berlin, Boston: De Gruyter Mouton. https://doi.org/10.1515/9781614514978

Morford, J.P., MacFarlane, J., 2003. Frequency characteristics of American Sign Language*. Sign Language Studies* 3: 213-225.

McKee, D., Kennedy, G., 2006. The distribution of signs in New Zealand Sign Language. *Sign Language Studies* 6: 372-390.

Morgan, H. E., Sandler, W., Stamp, R., & Novogrodsky, R. 2022. ISL-LEX v.1: An Online Lexical Resource of Israeli Sign Language. In *Proceedings of the LREC2022 10th Workshop on the Representation and Processing of Sign Languages: Multilingual Sign Language Resources*, eds. E. Efthimiou, S.-E. Fotinea, T. Hanke, J. A. Hochgesang, J. Kristoffersen, J. Mesch, & M. Schulder, 148–153. European Language Resources Association (ELRA). *https://www.sign-lang.uni-hamburg.de/lrec/pub/22019.pdf*

Neville, H.J., Lawson, D.S. 1987. Attention to central and peripheral visual space in a movement detection task: an event related potential and behavioral study: II. Congenitally deaf adults. *Brain Research* 405: 268–283.

Occhino, C., Anible, B., Wilkinson, E., & Morford, J. P. 2017. Iconicity is in the eye of the beholder: How language experience affects perceived iconicity. *Gesture 16*(1): 100–126. https://doi.org/10.1075/gest.16.1.04occ

Orfanidou, E., Woll, B., and Morgan, G. 2015. *Research methods in sign language studies*. Malden, MA: Wiley Blackwell.

Ortega, G., Schiefner, A., Lazarus, N., & Perniss, P. 2025. A lexical database of British Sign Language (BSL) and German Sign Language (DGS): Iconicity ratings, iconic strategies, and concreteness norms. *Behavior Research Methods*, *57*(5), 139. https://doi.org/10.3758/s13428-025-02660-z

Ortega, G. 2017. Iconicity and Sign Lexical Acquisition: A Review. *Frontiers in Psychology 8*: 1280. https://doi.org/10.3389/fpsyg.2017.01280

Perlman, M., Little, H., Thompson, B., & Thompson, R. L. 2018. Iconicity in Signed and Spoken Vocabulary: A Comparison Between American Sign Language, British Sign Language, English, and Spanish. *Frontiers in Psychology*, *9*: 1433. https://doi.org/10.3389/fpsyg.2018.01433

Perniss, P., Vinson, D., & Vigliocco, G. 2020. Making Sense of the Hands and Mouth: The Role of "Secondary" Cues to Meaning in British Sign Language and English. *Cognitive Science*, *44*(7). https://doi.org/10.1111/cogs.12868

Perniss, P., Thompson, R. L., & Vigliocco, G. 2010. Iconicity as a general property of language: evidence from spoken and signed languages. *Front. Psychol* 1: 227. doi: 10.3389/fpsyg.2010.00227

Pfau, R. & Quer, J. 2010. Non-manuals: Their Prosodic and Grammatical Roles. In *Sign Languages*, ed. D. Brentari, 381-402. Cambridge: Cambridge University Press.

Pretato, E., Peressotti, F., Bertone, C., Navarrete, E., 2018. The iconicity advantage in sign production: the case of bimodal bilinguals. *Sec. Lang. Res*. 34 (4): 449–462. https://doi.org/10.1177/0267658317744009.

R Core Team 2020. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL. https://www.R-project.org/.

Sandler, W. 2012. The phonological organization of sign languages. *Language and Linguistics Compass, 6*(3), 162–182. https://doi.org/10.1002/lnc3.323

Sehyr, Z. & Villwock, A. 2022. *How does knowledge of a signed language influence perception of iconicity in another?* Talk at ILL13: Iconicity in Language and Literature, Lettres Sorbonne Université, Paris. 31.5.-2.6.2022.

Sevcikova Sehyr, Z., Caselli, N., Cohen-Goldberg, A. M., & Emmorey, K. 2021. The ASL-LEX 2.0 Project: A database of lexical and phonological properties for 2,723 signs in American Sign Language. *Journal of Deaf Studies and Deaf Education.* doi.org/10.1093/deafed/enaa038.

Singleton, J. L., Jones, G., & Hanumantha, S. 2014. Toward ethical research practice with Deaf participants. *Journal of Empirical Research on Human Research Ethics, 9*(3): 59–66. https://doi.org/10.1177/1556264614540589

Staudt, K., Benner, U., Fries, S. & Dannenbeck, C. 2024. Im Gespräch: Partizipative Forschung in Kontexten von Gebärdensprachen und marginalisierten Gruppen – Austausch von Perspektiven und Erfahrungen. *DAS ZEICHEN* 122: 8-26.

Stockleben, L., Woll, B. & J. Atkinson. (in press). Screening for neurodegeneration and dementia in deaf users of German Sign Language: the KoDGS. *Archives of Clinical Neuropsychology*. https://doi.org/10.1093/arclin/acaf094

Taub, S.F. 2001. *Language from the Body: Iconicity and Metaphor in American Sign Language*. Cambridge University Press.

Trettenbrein, P. C., Bümmerstede, J., Finkbeiner, T. A., Gehlbach, P., Meister, N.-K., Schiefner, A., Schumacher, P., Spruijt, D., Steinbach, M., & Perniss, P. 2024. Towards a “DGS-LEX”: A Roadmap for the Collaborative Creation of a Psycholinguistic Database for German Sign Language (DGS). Center for Open Science. https://doi.org/10.31234/osf.io/u8vgk

Trettenbrein, P. C., Pendzich, N.-K., Cramer, J.-M., Steinbach, M., & Zaccarella, E. 2021. Psycholinguistic norms for more than 300 lexical signs in German Sign Language (DGS). *Behavior Research Methods*. https://doi.org/10.3758/s13428-020-01524-y

Vinson, D., Thompson, R. L., Skinner, R., & Vigliocco, G. 2015. A faster path between meaning and form? Iconicity facilitates sign recognition and production in British Sign Language. *Journal of Memory and Language* 82: 56–85. https://doi.org/10.1016/j.jml.2015.03.002

Vinson, D. P., Cormier, K., Denmark, T., Schembri, A., & Vigliocco, G. 2008. The British Sign Language (BSL) norms for age of acquisition, familiarity, and iconicity. *Behavior Research Methods 40*(4): 1079–1087. https://doi.org/10.3758/BRM.40.4.1079

Wickham, H. 2016. ggplot2: Elegant Graphics for Data Analysis. Springer-Verlag, New York. ISBN 978-3-319-24277-4, https://ggplot2.tidyverse.org.

Study 3: Deaf (collective) body memory and intercorporeality: an embodied perspective on deaf persons living with dementia

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(in revision)

Deaf (Collective) Body Memory and Intercorporeality: An Embodied Perspective on Deaf Persons Living with Dementia

ABSTRACT

Reflecting on deaf persons living with dementia from an embodied perspective offers new insights to understand their needs in dementia therapy and care. In particular, the idea of the lived body's memory, which is shaped through continual interaction with others and the environment, gives valuable impulses. This paper explores how the concepts of *body memory* and *intercorporeality* are relevant to deaf persons. Different forms of *body memory* are discussed in relation to the psycho-social, legal and historical environments of today's deaf older adults. We deduce that *intercorporeality* and *body memory* play a central role in how deaf people with dementia interact, helping them to maintain their deaf being-in-the-world and promoting well-being in dementia care.

To support the interpretation of the lived experiences of deaf persons beyond their individual circumstances, we propose the concept of *Deaf (collective) body memory* as an embodied approach, offering an access point to what remains in deaf sign language users even when dementia clouds cognitive control.

Keywords: Dementia; Embodiment; Intercorporeality; Body memory; Deaf; Sign Language

INTRODUCTION

In a world where more people are getting very old, age-related conditions such as dementia increase in prevalence. Caring for persons living with dementia is a world-wide challenge. Although theory may seem distant from practical concerns and urgent needs of people, it plays an essential role in generating innovative concepts and influencing interventions. Small populations, in particular, require special consideration for their unique needs. Deaf persons in old age who live with dementia lack access to standard dementia care services. This paper presents a shift in perspective by applying the embodiment framework to promote more inclusive and ethical dementia care for deaf persons[14].

[14] Following Kusters et al. (2017), we use the term deaf with "small d" referring to the signing deaf population but we use capitalized "Deaf" for entities such as "Deaf community.

In this paper, we focus on deaf persons who are signing members of the Deaf Community, and identify with Deaf culture as outlined by Padden & Humphries (1988). Due to the sensory prerequisites of deaf persons, communication in sign language is the only language modality that they can fully access and, therefore, is the most reliable mode of communication. Deaf sign language users are visucentric (visually oriented), and use the immediate surroundings and space around them when signing. The pronounced use of the body by deaf signers aligns with the embodied paradigm.

According to the embodied paradigm, we accumulate experiences, feelings, and interactions over the course of our lives. These are not only stored in our cognitive memory, but also within the body. The body has its own memory, which plays an essential role for persons with dementia, as their conscious recollection of persons and events fades. Body memory, an implicit memory form, gains in importance as it remains accessible and a resource for interaction with the environment.

This paper is a conceptual transfer in the sense of re-interpretating existing concepts. Recognizing that "constructing and applying a concept in an 'environment' is interpretive and therefore, in a sense, experimental, anticipative and hypothetical" (Hallet, 2012, p. 403), we re-contextualize existing concepts for deaf persons. Over the last years, more research has approached dementia from an embodied perspective and proposed concepts that enhance the discourse on dementia. Re-interpreting *body memory* and *collective body memory* for the context of deaf persons living with dementia transforms the theoretical framework and stimulates the discourse on *embodied cognition*, deaf bodies, dementia, and ethical dementia care.

The paper introduces the group of deaf persons from an embodied perspective, followed by a description of the environment in which deaf persons (in old age) live, including the psycho-social, historical and physical contexts. After that, the concepts of *body memory* and *intercorporeality* are introduced into the discourse and re-contextualized for deaf persons. With due respect for individual experiences, we highlight collective aspects and introduce the term '*Deaf collective body memory*' as an extension of the concept *collective body memory*. We then proceed to select the distinctly narrow context of dementia within the group of deaf persons to be able to formulate theory- and concept-based implications as practical demonstrations of the transfer.

It is essential to point out that we approach the presented topic with a lived experience as hearing and signing researchers without dementia. In these roles, we are aware of our limitations in fully understanding the experience of being deaf or having dementia. Nevertheless, having experienced intercorporeal resonance with deaf persons at work and within private contexts, we respectfully offer our perspectives and reflections on this topic.

1. DEAF EMBODIED BEING-IN-THE-WORLD: SENSES AND PERCEPTION

The body is in ongoing interaction with others and the environment. Acknowledging this opens up a different approach to deaf persons in old age and those living with dementia. In this chapter, a brief introduction into the theoretical framework of embodiment precedes an outline of selected aspects in relation to deaf persons.

1.1. Embodiment as the theoretical framework

The theoretical framework of Embodied Cognition (Gallagher, 2005; Shapiro & Spaulding, 2024; Varela et al., 2017) is based on the assumption that cognitive processes, experiences, feelings, and memories are profoundly shaped and experienced through the entire body. These processes are created by the whole organism in interaction with the environment in which it is embedded. Emphasizing the importance of both the body and the environment in cognition, the embodied approach challenges the traditional view of cognitive science, which sees cognition as processed solely in the brain, and reduces the body to a mere vessel for the brain. Embodied cognition is influenced by various disciplines as the philosophy of mind including enactive (Varela et al., 2017) and phenomenological approaches, neuroscience (Gallese & Lakoff, 2005) and linguistics (Lakoff & Johnson, 1980/2003), among others. In this paper, we primarily refer to phenomenology, a philosophical tradition from the 20th century, established by Edmund Husserl, Jean-Paul Sartre, and Maurice Merleau-Ponty and others (Gallagher, 2024).

Husserl's distinction between the 'lived body', or body-as-subject (Leib), and the 'living body' as physical body (Körper), or body-as-object, offers a valuable new perspective for understanding deaf persons, particularly in the context of their interaction with others. By extending the concept of the 'lived body' to intersubjectivity, Merleau-Ponty introduced the idea of "intercorporeity – a kind of intertwining of two embodied subjects in perceptual and interactive contact" (Gallagher 2024, p.21). When the lived body interacts with other lived

bodies, “mutual incorporation, i.e., a process in which the lived bodies of both participants extend and form a common intercorporality” (Fuchs & De Jaegher, 2009, p. 465) occurs and comprises “bodily resonance, affect attunement, coordination of gestures, facial and vocal expressions and others” (Fuchs & De Jaegher, 2009, p. 466).

Aiming at a more comprehensive view of deaf persons living with dementia, the embodiment paradigm serves, therefore, as the lens through which individual experience and interbodily interaction can be described.

1.2. Visucentrism and sign language

When considering deaf persons, the common approach is to objectively narrow the focus to the physical aspects of deaf persons, especially the limited hearing sense. This perspective is in line with the medical view. Adding the phenomenological perspective of the lived body, sets the focus on the deaf persons’ subjective perception and experiences. In this frame “being deaf or deafblind doesn’t mean to have an incomplete form of experience but a different form of experience” (Gallagher, 2017, p. 55).
Deaf persons themselves narrate their ‘being-in-the-world’ (O’Brien, 2021) as significantly shaped by sensory perception and experiences within a predominantly hearing world. Perceiving the world primarily through visual means is characteristic to the deaf being-in-the-world, which is why deaf persons are referred to as “people of the eye” (Veditz, 1912). “[V]isucentrism is not only visual but embodied and tactile, made so through the embodiment of self and others in the visual-spatial modality of signed languages." (O’Brien, 2021, p. 650). Even neuroscientific findings stress the adaptation to visual processing of the environment in deaf persons (Bavelier & Neville, 2002).

For the majority of persons who have been deaf since early childhood, embodied deaf being-in-the world is characterized by interacting in sign language and using visual and spatial channels for communication. In sign language, a thought is expressed through the hands and body in motion in space and understood through the eyes of the recipient. The kinesthetic feedback of a deaf signer and the sensitivity of tactile and visual-spatial processing during language interaction is part of the embodied character of signed communication.

Sign languages are authentic languages that make use of the hands as articulators along with the whole upper body, including leaning of the torso, making distinct facial expressions, forming mouthings, directing gaze to convey meaning (Pfau et al., 2012), and facilitating

joint attention through eye contact (Lieberman et al., 2014). The shared eye gaze is according to Fuchs (2018, p. 214), "one of the most intense forms of social perception"[15], which raises the question of the elaborate meaning of eye gaze in visual-spatial communication. The visual-spatial nature of sign language embraces the entire body as "the embodied self is obvious and central throughout their whole lives because it is through the body that language is formed and identity is performed (the signing person, not the person who uses sign language)" (Young et al., 2014, p. 68).

2. ENVIRONMENT

In the paradigm of embodied cognition, cognition is shaped by the entire body interacting with the embedding environment. By this, the environment has a crucial impact, either promoting or hindering, as "physical, social, and cultural contexts may make specific forms of cognition possible. Certain environments may facilitate cognition and learning, while other environments don't." (Gallagher, 2023, p. 15).

2.1. Psycho-social context

2.1.1. Historical and psycho-social context factors for deaf older adults in Germany

Since the environment refers not only to physical surroundings but also to the historical and psycho-social context, we outline the relevant contextual factors that affect deaf older adults.

In addressing the group of deaf older adults, the cohorts of deaf persons discussed in this paper were born before 1965. This urges us to look at the historical context of deaf persons in the early 20th century up to the mid-sixties when these cohorts were growing up. As for the example of Germany, German Sign Language (DGS) was not approved by law as an official language of Germany until 2002 (*Gesetz zur Gleichstellung von Menschen mit Behinderungen/ Act on Equality for People with Disabilities*, § 6)[16]. The lives and experiences of deaf (older) adults are significantly shaped by discrimination, the devaluation of sign language, and both physical and psychological violence. This devaluation stems from the conviction "that one is superior

[15] Translated by the authors

[16] https://www.gesetze-im-internet.de/bgg/BJNR146800002.html (accessed 21.08.2025)

based on one's ability to hear or behave in the manner of one who hears", a form of ableism known as audism, a term originated by Humphries in 1975 (Bauman, 2008, p. 13).

In terms of school education, audism was carried out through the 'oral method', which meant that signing was forbidden in classrooms and students were punished if they were caught signing. Based on a decision in 1880 (the 'Milan resolution' (Gallaudet, 1881)) by hearing teachers of the '"deaf mute"' (Biesold, 1988), as deaf persons were discriminatorily called, this applied to many European countries, including Germany until the late 20th century.

Since deaf children rely on sign language for secure understanding, the school content was not communicated effectively, resulting in (their) limited understanding. Consequently, access to knowledge was very restricted. Since sign language was considered to be an inferior and primitive form of communication, and hearing and speech were considered superior attributes (Lane, 1992), hearing teachers adapted their teaching methods accordingly. Physical methods, including caning were used to teach how to roll the tongue, form vowels and consonants to the deaf students who in most cases could not even hear what they were articulating. From situations of punishment, deaf persons report:

> They [the teachers] would come striding towards you, walking right at us, forcing us to stumble backwards, mouthing out words, spitting as they did so - afterwards you could be full wet, but never know what they said! Poking you, twisting your ear, sometimes you didn't even know what you supposed to have done. (Ladd, 2003, p. 303)

The cohorts during the German Nazi regime in the 1930s and 1940s were severely affected. The Nazis were the force in power when half the cohorts of today's deaf older adults were born and in their early childhood. The ideological view of the Nazi regime dehumanized deaf persons, carrying out forced sterilizations and persecuting and assassinating them (Alys, 1989; Biesold, 1988; Brockmann & Kozelka, 2021; Vogel, 2015; Zaurov, 2003).

Societal norms and laws had a decisive impact as dominating environmental conditions and, more subtle, on people's thoughts and actions. For over a hundred years, the devaluation of signing and the increased value of oral language in Western societies has influenced how the general society as a majority (with its hearing and deaf members) regards deaf persons. Younger generations experienced a shift from hiding their signing to feeling proud to show

it and express themselves openly through it. But even today, audism is still present and continues to be a field of conflict between hearing and deaf persons.

2.1.2. Deaf among deaf: Deaf community

In this environment of tension with the hearing majority, networks between deaf persons have consistently provided support within the Deaf community (Woll & Ladd, 2011). Particularly for persons in old age, neighborly help is strongly limited due to language and intercultural barriers between deaf and hearing neighbors (Kaul et al., 2009).

In contrast, exchange with other deaf persons in the Deaf community remains the essential source of social exchange and belonging (Gerich & Fellinger, 2012). Deaf spouses, friends, and members of the local Deaf club, proverbially called 'home to the deaf', play a significant role in fostering social connection and mutual support (Kaul et al., 2009).

Being part of the Deaf community, being among deaf persons and sharing sign language is described as an experience of great relief. Suddenly, there is a peer group, a group of people who are alike and share experiences and memories. "I can't find the words to adequately describe what I felt when I was surrounded by a whole school full of deaf children for the first time. It felt like an awakening, a kind of rebirth, and all chains were shattered"[17] (Drolsbaugh, 1999, p. 46).

A feeling of a new home among deaf peers stands in contrast to feeling misunderstood and excluded during their childhood in hearing families.

> The bus ride home [...] was taking them from a place where they had full language access and communication with their teachers and peers to their homes, where they would have to simplify their language for non-fluent or non-signers to understand. [...] Home was frequently a place where they were bored and anxious to leave to return to their new "home," which included accessible communication. (Meek, 2020, p. 1682)

The so-called new home offered them a place where they could express themselves and experience agency.

[17] Translated by the authors

2.1.3. Impact on memory

Experiences form the foundation of a person's memory. This phenomenon is not limited to individual experience, but it extends to shared ones as well. The theory of collective memory was first introduced by Halbwachs (1950) and Warburg (2010) and interpreted by Assmann and Assmann (1988). Collective memory is thought in two forms: either having no fix point in time, which means that the here and now wanders with the present time., or having a fix point which creates 'memory figures' (Erinnerungsfiguren).

2.1.4. Deaf collective memory

Applying the theory, we can identify examples of collective memory among deaf persons. According to Supalla (2020) "[e]very generation contributes to our collective memory. […] collective memories span generations, […] they changed continuously" (p.2).

This can be understood as the outline of Deaf collective memory. Deaf people share the same psychosocial, historical and legal embedding environments, which impact collective memory. A project on deaf older signers' life stories in Europe broadcasted the strong link between the shared lived experiences as a deaf signer and the individual perspectives on collective memory (SIGN-HUB project: Pfau et al., 2021). An example of collective memory without a fix point is the shared collective experience of oralist education.

The collective memory of the oldest members of the Deaf community in Germany (as in many European countries) recollect the experience of signing secretly and not in public. The fact that signing was forbidden in educational settings, and deaf persons were forced to use speech, is a collective experience of many cohorts of deaf persons across the 20th century.

The decision to install the oral method in Deaf education in 1880 still serves as a 'memory figure' over time as it continues to draw attention for its lasting psychological, social and economic consequences for the community.

Beyond the onerous experiences that have shaped Deaf collective memory, positive and beneficial experiences are also preserved.

According to van Steenwyck (2008), the Deaf community positively reaffirms deaf identity through the constant and collectively shared exposure to the hearing environment. These positive attributes of Deaf identity are the

> "access to a unique and natural language, a culture, and a national and international community. This provides Deaf people with agency, allowing them to resist the control exercised over them and to enforce power over their own affairs. Certainly the sense of

> Deaf pride constitutes a collective memory and has become well recognised as a feature of the collective identity of Deaf people." (p. 5).

National and international Deaf communities with their gatherings are key collective memories and 'memory figures' based in the 19th century (Ladd, 2003). An example is the cultural formation in the form of Deaf clubs, where regular community meetings are held. Even the physical building of the Deaf club can be categorized as part of collective memory of a local Deaf community and essential to sustain identity, as they

> "have taken shape as socially meaningful and identifiable spaces to which a historical dimension is attributed. […] For Deaf people, Deaf Clubs represent feelings of safety. They counter the negative effects of the stigmatisation of Deaf people by providing a safe haven in which deafness, as well as their natural language – sign language – is valued and nurtured as part of a positive identity rather than discredited." (van Steenwyck 2008, p. 10).

The concept *collective memory* provides a tool to hypothesize/consider/reflect on how to approach members of a community based on their shared past experiences.

2.2. *DeafSpace* and *affordances*

The concept of *DeafSpace*[18] addresses how the deaf persons' experiences intersect with their environment, and characterizes a visually accessible space in which deaf persons are not limited in their sensory experience. It was introduced as an inclusive architectural and design concept that reflects and accommodates the 'deaf being-in-the world'. The concept seeks "the wisdom of deaf individuals to guide the design of a more humane environment not only for deaf people but for society at large" (Bauman, 2010, p. 14). Interaction in sign language requires certain aspects of spatial distance, orientation and visibility. Examples include having a clear visual field that enables eye contact and joint attention to initiate interaction. To make spaces visually accessible, auditory signals have to be replaced by visual or tactile signals. Taking the idea of '*affordances*' (Gibson, 1979), these signals foster interaction for those who rely on these senses. Gibson's concept of *affordances* suggests that objects are not perceived solely as objects as they are, but as 'affordances', meaning the possibilities they offer to a particular person. In this sense a chair affords sitting down for a person with the

[18] This term was proposed in the context of a project at Gallaudet University. https://infoguides.rit.edu/ld.php?content_id=59890829 (accessed 31.08.2025)

physical ability to do so, as bright lighting and open spaces afford deaf signers to communicate with ease. The concept of *affordances* is not limited to objects, but includes animals and other human beings. ”The richest and most elaborate affordances of the environment are provided by other animals and, for us, other people” (Gibson 1979, p. 135). Positive *affordances* are beneficial as they provide incentives that align with sensory abilities, such as a videophone. Others may be frustrating when they do not fulfill a person’s needs or can even evoke stress due to harmful prior experiences.

For deaf persons, the visually flashing doorbell affords opening the door to welcome visitors, possibly friends and people to communicate with. In home care or nursing homes the (flashing) doorbell is substituted by emergency buttons or equivalents to call for help to restore a sense of security. The following example by Young et al. (2014, p. 67) shows that the affordance - in this case a red cord to call for help - is strongly connected with the reaction that follows after ‘using’ the affordance. In the setting of a deaf person with dementia in a nursing care home with only hearing non-signing caregivers, the red cord may not afford pulling it.

> [t]he flashing doorbell that has been a part of her life always, still takes her to the door, but when she opens it there are now people who cannot sign, who cannot communicate with her and yet she still must open the door. [...] We sit down and I ask her about the red cord. It hangs in the corner of the room as it does for every resident of the sheltered housing complex. RED-CORD-THERE-WHAT-FOR? I ask, [...] But she does not look. [...] Without a shared eye gaze, our interaction ceases. She is telling me with her glance that this subject is closed. [...] To her it was not a source of security, something that could be pulled to attract the help she needed. No, it was just another way in which hearing people with whom she has nothing in common, with whom she cannot communicate, turn up on her doorstep. No reassurance there, only more frustration. In this non-verbal, fully linguistic response, Maggie is saying to me: “RED-CORD-THERE-WHAT-FOR?”

Deaf-sensitive *affordances* invite communication without misunderstandings or irritation. In the case of social *affordances*, the quality of interaction depends on the intercorporeality, the resonance between the bodies.

Looking beyond human interaction partners, it should be considered that animals do offer *affordances* that are not influenced by the intercorporeal memory associated with human

encounters (Brandt, 2004; Birke & Brandt, 2009; Verheggen et al., 2017). Given the possible experiences of disrupted intercorporeality, particularly between deaf and hearing persons, animals can serve as resourceful *affordances*, especially for deaf persons with dementia.

3. BODY MEMORY

The form of memory that is embodied, signifies the storage of all experiences of the lived body, or how Fuchs (2012) defines it, the "totality of bodily capacities, habits, and dispositions as they have developed in the course of one's life" (p. 10). In phenomenology, *body memory* is referred to as implicit memory that is mediated by the body, in contrast to the consciously retrievable explicit memory. Implicit memories are stored in *body memory* and re-enacted without the person necessarily consciously remembering them. Reflecting the different levels of *body memory* in the context of *collective memory* enriches the theoretical framework in relation to the proposed *Deaf collective body memory*.

3.1. Aspects of Deaf body memory

The concept of memory stored in the body has been elaborated in different disciplines, e.g., in philosophy/phenomenology (Merleau-Ponty, 1962, Fuchs, 2012), and in psychology/ psychiatry, often related to trauma (Gentsch & Kühn, 2022; Janet, 1925; Parma et al., 2024; Van der Kolk, 2014)

Regarding *Deaf body memory*, we apply Fuchs' (2012) typology of six forms of body memory: procedural, situational, intercorporeal, incorporative, pain, and traumatic memory. Due to their significance within the context of this paper, we highlight the situational, traumatic, and intercorporeal aspects, explore their potential implications for deaf persons, and extend it to dementia in the following chapter.

3.1.1. Situational memory

Situational memory emerges in certain situations in relation to the specific atmosphere, as "feeling of familiarity with some situations and the feeling of alienness with respect to others, thus allowing us to "get involved in" or to "be touched from" peculiar situations" (Summa et al., 2012, p.421).

For deaf persons, this may be related to the specific atmosphere of the Deaf club, referring to a space where deaf people gather and are familiar with the spatial conditions and the situation of the procedures of a Deaf club meeting. Situations with hearing persons, like sitting together at

the dinner table and hardly understanding what is talked about, may be sedimented in situational memory associated with an atmosphere of feeling excluded. This phenomenon has even been termed ‘dinner table syndrome’ to represent the common and (among deaf persons) shared experience in hearing environments (Meek, 2020). As forms of *body memory* are not distinct from one another, the dinner table syndrome has parts in, for example, the intercorporeal memory as well.

3.1.2. Traumatic memory

Traumatic experiences are embodied (Van der Kolk, 2014; Fuchs, 2012) and stored in *traumatic memory.* When activated by certain triggers, they become noticeable “in the form of bodily symptoms, without any explicit awareness of the connection between the past and the present experience“ (Summa et al., 2012, p. 421). For deaf persons in old age, many potential sources of trauma can be identified. Physical force and mental stress of the teaching methods and suppressed sign language are a source of trauma for many deaf persons (Hoffstadt, 2018; Sullivan et al., 2000). The lack of communication from early childhood, along with limited access to language and information, forms the basis for developmental trauma that persists throughout life (Anderson et al., 2016; Johnson et al., 2018; Schild & Dalenberg, 2012). For the very old deaf persons, the persecution and abuse of deaf persons in Nazi Germany remain sources of traumatic *body memory* (Brockmann & Kozelka, 2021; Vogel, 2015).

3.1.3. Intercorporeal memory

The concept of *intercorporeality*, as it was proposed by Merleau-Ponty (1962) and elaborated by Fuchs (2017b) among others, is a reciprocal form of bodily communication between bodies. “Intercorporeality means a pre-reflective intertwining of lived and living bodies, in which my own is affected by the other’s body as much as his by mine, leading to an embodied communication” (Fuchs, 2017b, p. 10). This intertwining engagement with other persons is sedimented as patterns of interaction in *intercorporeal memory* as “every past experience of being-in-relation and being-in-resonance shapes and forms the present and future individual potential to resonate” (Mühlhoff, 2014, p.1013).

As "[e]ven the earliest experiences of how infants are held, comforted, guided, and reacted to by their caregivers are imprinted in their implicit or body memory" (Fuchs 2017a, p. 338), we look at the family situation and early interactions of deaf children to approach possible aspects of their intercorporeal memory.

As one out of ten deaf children is born with deaf parents, only a minority grows up with the shared experience of sensory perception and a sign language. A diagnosis of deafness may sediment as a momentum of connection and belonging in the intercorporeal memory between deaf parents and deaf children. In contrast, a doctor's diagnosis of deafness in a child of hearing parents often evokes tremendous disappointment, grief, and concern for the child's future (Gilliver et al. 2013). These feelings, along with the uncertainty about how to communicate with their own child, may sediment in intercorporeal memory between the child and the parents as a momentum of disconnection and distance.

Early childhood communication among hearing persons typically focuses on auditory stimuli. As deaf babies may not respond as expected, uncertainty on both sides can be the consequence, and it can be assumed that the flow of mutual and reciprocal attunement (De Jaegher & Di Paolo, 2007) is significantly disrupted. Appropriate stimuli for deaf children rely on enhanced visual and tactile input, which is often unfamiliar to hearing parents. Strong feelings and mutually unfulfilled expectations may be sedimented in the *in-between* of parents and baby, the intercorporeality, which may be core pieces in the intercorporeal memories of deaf persons.

One example of an early memory of a deaf person who was dropped off by their parents without any prior information or communication about the context, shows the potential for disrupted interaction between deaf children and non-signing parents.

> My parents dropped me off at Deaf residential school when I was 3 years old. They didn't sign; I didn't speak. We had no shared communication, so I had no idea where I was. When they left, I was inconsolable. I was terrified that I would never see them again. (Anderson et al., 2016, p. 4).

The earlier mentioned 'dinner table syndrome' (Meek, 2020) describes impaired interaction that leads to restricted access to news and current family topics. This restricted access may even be the source of elevated trauma rates due to the experience of "sudden, unexpected death of someone close to you", which deaf persons reported as the second most frequent cause of trauma in a study by Anderson et al. (2016, p. 4). Through the embodied lens, the situation of being the only deaf person in a hearing family and the feeling of being excluded may be stored in the situational memory and reenacted in any social situation in which communication is key.

3.2. Deaf collective body memory

As the root of *collective body memory* Fuchs (2017b) positions that "Merleau-Ponty's notion of intercorporeality gains an additional aspect: It means not only the primary familiarity of our bodies with each other, or their pre-reflective communication, but also the entanglement of human bodies in a shared history that is preserved in their implicit collective memory." (p.16). In this sense, we interpret the shared corporeal experience of being deaf in the world as a manifestation of *Deaf collective body memory*. Fuchs (2017a) introduces the concept of *collective body memory*, positing that the explicitly remembered collective memories possess an embodied dimension, akin to the notions of 'embodied collective memory' (Narvaez, 2006). Based on a collection of shared experiences and Deaf culture across generations, deaf persons share what Fuchs (2017a) named an "ensemble of behavioral and interactive dispositions characterizing the members of a social group, which have developed in the course of earlier shared experiences and now prefigure similar interactions of the group" (p. 341). These dispositions may encompass the aforementioned coping strategies in classrooms, during early childhood interactions, and within the family environment. This strong bind is demonstrated in a quote by a hearing parent of a deaf child on the bodily mediated connectedness of deaf persons,

> I used to think that Deaf people just happened to support one another because it was 'the right thing to do' if you like. But something else is going on that doesn't really happen much in the hearing world. It's like you are inside that person, experiencing their pain, and their pain is actually *inside you as well*. (Ladd, 2003, p. 323)

Based on Fuchs (2017a), we apply two of the proposed phenomena of *collective body memory* - family memory and habitus - to the collective memory of the Deaf community.

The phenomenon of family memory can initially be referred to the family of origin with its specific roles, positions, specific rituals and interaction patterns, but we extend the term 'family' to places and gatherings with other deaf persons. Social and behavioral patterns rooted in experiences of one's 'family' have imprinted what may be incorporated in *Deaf collective body memory.*

As another significant phenomenon of *collective body memory*, Fuchs (2017a) names habitus as "formed by the continuous sedimentation of shared experiences into the body memory and embodied personality structure of the individual" (Fuchs 2017a, p. 346). The term 'habitus' was sociologically contextualized by Bourdieu (1990) and has been applied within the embodiment discourse (Kontos, 2004). The concept of an 'embodied deaf habitus' is discussed,

among others, by O'Brien (2021, p. 652) in relation to the shared bodily memory of deaf persons and the inscribed experiences of deaf signers through visual perception. Graham and Tobin (2019) define the term 'deaf bodily habitus' as norms and strategies, characterizing it as "Deaf cultural norms of eye gaze, attention elicitation strategies, joint attention, facial expressions, and body language" (p. 145).

If "environmental affordances and artifacts such as architecture" (Fuchs, 2017a, p. 346) are seen as expressions of the habitus, the concept of *DeafSpace* and *Deaf affordances*, i.e., *affordances* suitable for the perception of deaf persons, can be seen as part of Deaf habitus, thus, of *Deaf collective body memory*.

4. DEAF PERSONS AND DEMENTIA

Dementia has been discussed within the notion of "a fundamental disorder of higher-order consciousness" (Fuchs, 2020, p. 670). According to the World Health Organization, dementia is "an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behavior, and that interfere significantly with a person's ability to maintain the activities of daily living" (WHO, 2017, p. 2). While much research highlights the discontinuity of the self in dementia due to deficits in reflective thinking and autobiographical memory, Fuchs argues that the continuity of the self is maintained through the *body memory*.

In this paper, dementia is referred to as a condition, rather than a disease, that requires environmental adjustment to support the person with dementia to make the most of the available resources. In this chapter, the transferred concepts of this paper are finally re-contextualized for deaf persons with dementia.

4.1. Symptoms of dementia in deaf persons

Dementia in deaf people is very similar to hearing people. The symptoms encompass language-related changes, changes in behavior, cognitive changes, and general changes in managing daily life (American Psychiatric Association, 2013). Deaf persons show changes in signing words and sentences, and also linguistic non-verbal/non-manual features of sign languages, leading to changes in, mostly reduced, mouthing behavior, reduced facial expressions, gestural elements and signing space (the area in front of a signing person) (Falchook et al., 2013; Rantapää & Pekkala, 2016; Parker et al., 2010; Young et al., 2014).

> In one brief expression Harold had told me that he was referring to his language, his sign language, that was a fundamental part of his being, and that he knew this was slipping away from him and that this was a cause of deep sadness and despondency. Dementia has "got him" he was losing his battle to retain his language. (Young et al., 2014, pp.65f)

Since most deaf persons were raised in a spoken language setting, having hearing parents and siblings, their deeply stored memories may strongly be connected to spoken language. During the dementia-related going-back-in-time, deaf persons may switch languages even though they share a sign language with their children and caregivers (Ferguson-Coleman, 2016; Rantapää & Pekkala, 2016).

When linguistic expression decreases, more subtle cues to facilitate communication get emphasized such as the use of space, touch, proximity, and eye gaze. A common signing conversation would prefer face-to-face positioning for a clear visual field and eye contact. Yet some deaf persons with dementia prefer to sit next to the conversation partner rather than opposite (Ferguson-Coleman, 2016). Sitting closer to the conversation partner is interpreted as a coping strategy in the context of altered eye gaze and proximity behavior. The use of touch, such as tapping the shoulder or the knee, as typical communication behavior between signers, gained importance for raising awareness of a topic and helping to include the person with dementia who might otherwise be unable to follow or join a conversation. But when dementia progresses, even "subtle and conventionalized forms of conversation joining such as nodding one's head, making eye contact, eyebrow raising and raising one's hand subtly" (ibid, 161) become impossible.

In terms of cognitive and behavioral symptoms, common dementia-related difficulties were reported, such as feeling physically and temporally disoriented, sad, and frustrated or even depressed (Parker et al., 2010). Getting physically lost due to the deaf person with dementia 'running away' (which may actually be interpreted as a wandering to a non-obvious location), created a greater burden for the caregivers (Rantapää et al., 2023). That is evident because it is more difficult to find a deaf person when it is pointless to call their name. Besides, deaf persons with dementia are at higher risk of accidents when confused because they cannot hear environmental warnings the way hearing people can. Delusional states were interpreted in the context of the specific social and historical environment. Similarly, the anxiety of hearing people communicating beyond the control of deaf persons and potentially taking advantage of their deafness is also contextualized.

4.2. Detecting and caring for dementia in deaf persons

A shared language is key for the early detection of changes in a person's language and the general way they express themselves. If the daily care environment, such as the nursing home staff, does not provide a high level of sign language competence, early symptoms of dementia may go unnoticed. Due to language and culture barriers participating in group activities or receiving individual care in nursing homes without a specialized unit for deaf persons is challenging. Consequently, the risk of social isolation through the lack of language interaction is increased (Kaul et al., 2009). The observation that the deaf person does not sign, but speaks, can lead to serious misjudgments on the part of hearing persons. Assuming that) deaf persons with dementia do not need sign language (anymore) in their care, is simply wrong and leaves them becoming isolated. Networks of deaf persons and the Deaf clubs, on the other hand, are free from spoken language and culture barriers, but cannot provide the necessary extra care that a person with dementia needs. This can be understood as "double barriers that Deaf people living with dementia face in achieving full citizenship if by that we mean accessible, supportive services that enable participation in terms that make sense to the person with dementia" (Ferguson-Coleman, 2016, p. 157).

4.3. Embodied view on deaf persons living with dementia

When addressing the topic of dementia, *body memory* requires special consideration. *Body memory* retains lifelong experiences and consequently shapes present interactions with others and the environment across a diachronic dimension. While episodic memory of explicitly remembering memories of persons and circumstances decreases due to dementia, *body memory* remains preserved in dementia until advanced stages (Fuchs, 2020). *Body memory* "reenacts the past through the body's present performance; in other words, it may be regarded as our 'lived past'" (Fuchs, 2017b, p. 11). This 'lived past' is being reenacted by cues in the environment. Lifelong habits that were repeatedly executed, such as peeling potatoes or riding a bike, but also non-verbal interactional behavior, are preserved up until later dementia stages. In the context of dementia progression, "[t]he loss of verbal-cognitive powers means that non-verbal, emotional and bodily communication, as well as the knowing-how of everyday modes of behavior become even more meaningful." (Fuchs, 2020, p. 672). The lifelong experience of deaf persons interacting with non-signing hearing persons while using the visual-spatial modality for language (sign language) and orientation, skilled them in non-verbal communication. For deaf persons with dementia, Ferguson-Coleman (2016, p. 167) concludes that

> the life-long experience of visual language and visual orientation within the world potentially offer a source of strength and retained ability to communicate that may be different from the adjustments hearing people with dementia might need to make to accessing the non-verbal channel open to humans. Embodiment of the Deaf person's self has a positive life-long presence and is not altered through the development of dementia.

Since sedimented experiences which are stored in intercorporeal memory remain preserved in dementia (Fuchs, 2020), one might ask what impact these sediments have on a deaf person living with dementia. What consequences can be drawn about social interaction, for care and therapy, and for the general environment?

Medical treatment and institutional care can be aligned with *Deaf body memory*. For instance, the experience of teachers using instruments in the students' mouths to train oral articulation likely leaves sediments in *body memory*. Deaf older adults with advanced dementia could, therefore, be triggered through bodily sensations of instruments in the mouth during a dental treatment. This may lead to unrest and a decrease in well-being without obvious reasons to unskilled (deaf naive) caregivers and dentists. Being kept in nursing homes in a hearing environment may trigger memories of negative experiences in boarding schools, such as being 'locked away' or 'abused', and lead to distortions in intercorporeality with caregivers. Losing cognitive control about memories and orientation, about one's language and felt identity, may deepen this feeling of being lost.

As *body memory* becomes more important in dementia one must consider that "[c]rises and experiences of powerlessness can have long-term consequences for the entire experiential economy of a subject and inscribe themselves into 'body memory'" (Breyer, 2022, p. 388). Breyer's quote can be interpreted in two ways within the scope of this paper, namely a) dementia as a source of crises and powerlessness with all its consequences and b) the deaf being-in-the-world with its experience of powerlessness, neglect, and challenges in a hearing world as one aspect of *Deaf collective body memory.* Recognizing that one is showing symptoms of dementia, can be a source of personal crisis in itself. The combination of both interpretations emphasizes the doubly increased impact of dementia on a deaf person.

A deaf person's lifelong experience of rejection and discrimination by hearing persons, stored in the intercorporeal memory, may lead to increased anxiety and behaviors such as frustration or withdrawal when interacting with hearing caregivers, fellow residents and

others. This may be intensified by the loss of cognitive control, which makes it difficult to suppress previously learned adaptive behavior. Even the connection with the formerly highly important deaf peer group may be challenged for deaf persons with advanced stages of dementia. They may struggle to join deaf activities due to limited physical mobility and the advanced mental changes. This can lead to the threatening consequence of feeling excluded from their own Deaf community.

An additional field of reflection is how dementia changes the life of the immediate social environment, i.e., deaf spouse, deaf children, deaf friends, and members of the local Deaf community. A person with dementia carries part of the *Deaf collective body memory,* thus, of Deaf collective identity. When a deaf person with dementia switches from signing to speaking, it is irritating and has negative consequences for deaf interaction partners, disrupting intercorporeality. Because the person with dementia can sense this, but cannot explicitly name or discuss it, confusion and discomfort may grow on both sides, which increases the risk of spiraling.

5. IMPLICATIONS

At the end of this conceptual transfer, we outline concrete implications for dementia care for deaf persons to illustrate how the presented concepts can be applied in practice. Our aim is to take a resource-oriented approach and offer suggestions for an environment that strives to enhance the lived experience and quality of life for deaf persons with dementia by consciously addressing intercorporeality.

While one cannot change a person's *body memory* and intercorporeal memory, "positive emotions can be strengthened by interpersonal resonance, [...], then the interpersonal and affective levels are particularly important for the development of resilience." (Breyer, 2022, p. 387). Although past experiences cannot be changed, a safe environment is possible in the present with positive *affordances* and an awareness of the "affective and atmospheric dimensions of contact" (Fuchs, 2020, p. 672). The pre-reflective needs of deaf persons for 'fluent intercorporeality' can be met.

Caring for deaf persons living with dementia requires Deaf awareness, a basic understanding of Deaf habitus and of the visucentric nature, which calls for sign language and accessible spaces. This general attitude of acknowledging the person-to-person encounter, of truly seeing

the person with dementia, and the ability to see the individual needs, opens doors to an embodied sensitive care for deaf persons. Naturally, signed communication is required for appropriate care and activation. Beyond symbolically mediated interaction through sign language, intercorporeality connects one with others and may be severely impacted by the diverse sedimented layers of lived experience between hearing and deaf persons. Therefore, the goal should be to foster "[p]ositive affect, contentment, and resilience" in "elderly and severely disturbed clinical populations" (Summa et al., 2012, p. 436), and to highlight the ability to create something new, even in challenging conditions.

Based on the discussed theories and concepts, we see concrete implications regarding *Deaf (collective) body memory* awareness, *DeafSpace* and *Deaf affordances*:

5.1. Deaf (collective) body memory awareness

If intercorporeality gets disrupted, as can happen with recognition errors in persons with dementia, it is particularly impactful for caregivers to be aware of the *Deaf (collective) body memory*. Being able to classify a certain behavior and create space for new positive emotions and intercorporeal experiences is essential.

The sensory conditions ask for conscious use of tactile stimulation or touch for various purposes, such as informing or signaling, warning and calming an agitated deaf person with dementia.

Multisensory therapies may include olfactory stimulation through aromatherapy or visual stimulation with light therapy rather than therapies that require the hearing sense. It may be useful to make offers with a conscious use of music accessible through vibrations as dance therapy, for joyful activation and release of tension and agitation.

Relaxing the body through exercise and yoga helps to calm and deal with deeply rooted trauma in *collective body memory* for trauma sensitive care.

Getting awareness training that includes the 'dinner table syndrome' as an example of experienced discrimination and exclusion supports caregivers create positive intercorporeality with deaf persons.

Animal-assisted Services for deaf persons with dementia show positive effects by enabling interaction and a sense of closeness with another living being and lived body, distinct from the sedimented layers of intercorporeal memory layers with (hearing) humans.

5.2. DeafSpace

To promote signed communication, (Deaf) community and well-being, certain spatial guidelines are recommended:

> Leaving space around the arms to move for signing, circular positioning of persons for best visual accessibility, reduced neck turns and eye movement, and the sense of social connectedness in collective rooms and activities.
>
> Keeping pathways clear from obstacles to avoid tripping or falling as signed communication requires holding eye contact.
>
> Positioning deaf persons with dementia facing the door with a clear view of who is entering and leaving a room, is essential, since the acoustic knocking on a door or the noise of opening the door is not heard.
>
> Visual and tactile, vibratory cues stimulate peripheral vision and facilitate spatial orientation, but they must be used selectively to avoid confusion.
>
> Transparent materials enable better vision, for example glass walls, windows or doors instead of closed walls. Nevertheless, privacy and the feeling of comfort have to be maintained and must be respected. It is self-explanatory that devices and warning systems need to be visual or tactile as well to ensure the safety and well-being of deaf persons (e.g., visual doorbells, fire alarm with strobes, vibratory devices).
>
> To promote spatial orientation, visual cues - such as tracking movement, proximity, and orientation through light and color - are beneficial. These can be supported via colored rooms and distinctively shaped spaces, such as corners designed for specific activities or to guide the way.
>
> Lighting conditions are also key for the visucentric community. It is important to avoid backlighting to prevent glare, while dimmed lighting can negatively affect both visual orientation and communication.

A well-informed understanding and awareness of the collective interaction patterns of the Deaf community nonetheless requires attention to each individual's specific needs and preferences. These aspects can vary significantly from person to person and are perceived differently by each individual. While some deaf persons may find changes of color and dimmed lighting comforting, these adjustments may re-enact experiences from the past in others. The same holds true for proximity and eye gaze behavior.

5.3. Deaf affordances

To provide a safe and supportive environment for deaf persons with dementia, it is important to carefully consider and select beneficial *affordances*:

> It is essential to provide deaf persons with dementia with *affordances* that foster engagement, elicit reactions, and encourage emotions. These may be objects promoting sign language as a videoscreen, displaying signing persons, or a videophone.
>
> Supportive, signing and *Deaf (collective) body memory* sensitive persons can be of tremendous value, affording exchange and connectedness. Because of the shared experiences, contact with deaf persons is of special significance.
>
> Animals can afford physical closeness, which is becoming increasingly rare with other people, playful interactions, and the possibility to care for another living being, rather than always being the one cared for.

6. CONCLUSION

An embodied frame including phenomenological aspects of the lived body and intercorporeality sheds new light on the approach to deaf persons who live with dementia and leads to implications for care and therapy.

We consider sensitive awareness of *Deaf collective memory* as well as individual and *collective body memory* a core requirement to promote a life with dementia in dignity.

Our reflection does not encompass all factors of social contexts and the broad field of historical, social, and legal environment since they do interact with individual resources. Future work may continue to contribute by investigating *Deaf affordances* and the impact and extent of ‘memory figures’ on *Deaf collective body memory*.

For all the suggested applications, such as awareness training, implementing the concept of *DeafSpace* and *Deaf affordances*, a collaboration with deaf stakeholders is crucial.

Despite the scope of this paper being on deaf persons, this conceptual transfer can serve as an example for persons with other sensory prerequisites and other marginalized populations as well.

Reaching the end of life with dementia, it is impossible to explain exactly which sediments have been dominantly influential, but strengthening deaf being-in-the-world especially through a life of crises is what helps living a life with dementia.

REFERENCES

Aly, G. (Ed.). (1989). *Aktion T4 1939–1945: Die „Euthanasie"-Zentrale in der Tiergartenstraße 4*. Edition Hentrich.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Anderson, M. L., Craig, K. S. W., Hall, W. C., & Ziedonis, D. M. (2016). A pilot study of Deaf trauma survivors' experiences: Early traumas unique to being Deaf in a hearing world. *Journal of Child & Adolescent Trauma, 9*(4), 353–358. doi:10.1007/s40653-016-0111-2

Assmann, J., & Assmann, A. (1988). Kollektives Gedächtnis und kulturelle Identität. In J. Assmann & T. Hölscher (Eds.), *Kultur und Gedächtnis* (pp. 9–19). Suhrkamp. https://doi.org/10.11588/propylaeumdok.00001895

Bauman, H. (2010). *DeafSpace Design Guidelines*. Gallaudet University.

Bauman, H.-D. L. (Ed.). (2008). *Open Your Eyes: Deaf Studies Talking*. University of Minnesota Press.

Bavelier, D., & Neville, H. J. (2002). Cross-modal plasticity: Where and how? *Nature Reviews Neuroscience, 3*(6), 443-452. https://doi.org/10.1038/nrn848

Biesold, H. (1988). *Klagende Hände: Betroffenheit und Spätfolgen in Bezug auf das Gesetz zur Verhütung erbkranken Nachwuchses, dargestellt am Beispiel der "Taubstummen"*. Jarick Oberbiel.

Birke, L., & Brandt, K. (2009). Mutual corporeality: Gender and human/horse relationships. *Women's Studies International Forum, 32*(3), 189-197. https://doi.org/10.1016/j.wsif.2009.05.015

Bourdieu, P. (1990). *The logic of practice.* Translated by R. Nice. Stanford: Stanford University Press.

Brandt, K. (2004). A language of their own: An interactionist approach to human-horse communication. *Society & Animals, 12*(4), 299-316. https://doi.org/10.1163/1568530043068010

Breyer, T. (2022). Resilience – Its connections to vulnerability and crisis from analytic and phenomenological perspectives. *International Journal of Philosophy and Theology, 83*(5), 381-392. https://doi.org/10.1080/21692327.2022.2158907

Brockmann, E., & Kozelka, E. (2021). Forced sterilization of Deaf people during German National Socialism – A trauma and its compensations after 1945. In R. Pfau, A. Göksel, & J. Hosemann (Eds.), *Elderly Deaf Signers – Cultural, Linguistic, and Sociolinguistic Perspectives*. De Gruyter Mouton.

De Jaegher, H., & Di Paolo, E. (2007). Participatory sense-making. *Phenomenology and the Cognitive Sciences, 6*(4), 485-507. https://doi.org/10.1007/s11097-007-9076-9

Drolsbaugh, M. (1999). *Endlich Gehörlos!* Signum.

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

Ferguson-Coleman, E. (2016). *Deaf with dementia: A narrative* (PhD thesis). The University of Manchester.

Fuchs, T. (2012). Chapter 1. The phenomenology of body memory. In S. Koch, T. Fuchs, M. Summa, & C. Müller (Eds.), *Body Memory, Metaphor and Movement* (pp. 9-22). John Benjamins Publishing Company. https://doi.org/10.1075/aicr.84.03fuc

Fuchs, T. (2017a). Collective Body Memories. Embodiment, enaction, and culture: investigating the constitution of the shared world, 333-352.

Fuchs, T. (2017b). Intercorporeality and Interaffectivity. In C. Meyer, J. Streeck, & J. S. Jordan (Eds.), *Intercorporeality: Emerging Socialities in Interaction*. Oxford University Press. 3–23.

Fuchs, T. (2018). Zwischenleibliche Resonanz und Interaffektivität. PDP-Psychodynamische Psychotherapie, 17(4), 211-221. https://elibrary.klett-cotta.de/article/99.120110/pdp-17-4-211

Fuchs, T. (2020). Embodiment and personal identity in dementia. *Medicine, Health Care and Philosophy*, *23*(4), 665–676. https://doi.org/10.1007/s11019-020-09973-0

Fuchs, T., & De Jaegher, H. (2009). Enactive intersubjectivity: Participatory sense-making and mutual incorporation. *Phenomenology and the Cognitive Sciences, 8*(4), 465-486.

Gallagher, S. (2005). *How the Body Shapes the Mind* (1st ed.). Oxford University Press. https://doi.org/10.1093/0199271941.001.0001

Gallagher, S. (2017). Embodied intersubjective understanding and communication in congenital deafblindness. *Journal of Deafblind Studies on Communication, 3*(1), 46-58.

Gallagher, S. (2023). *Embodied and Enactive Approaches to Cognition*. Cambridge University Press. https://doi.org/10.1017/9781009209793

Gallagher, S. (2024). Phenomenology and embodied cognition. In L. A. Shapiro & S. Spaulding (Eds.), *The Routledge Handbook of Embodied Cognition* (2nd ed., pp. 13-22). Routledge.

Gallaudet, E. M. (1881). The Milan Convention. *American Annals of the Deaf*, *26*(1), 1–16.

Gallese, V., & Lakoff, G. (2005). The Brain's concepts: the role of the Sensory-motor system in conceptual knowledge. Cognitive Neuropsychology, 22(3–4), 455–479. https://doi.org/10.1080/02643290442000310

Gentsch, A., & Kuehn, E. (2022). Clinical manifestations of body memories: The impact of past bodily experiences on mental health. *Brain Sciences, 12*(5), 594. https://doi.org/10.3390/brainsci12050594

Gerich, J., & Fellinger, J. (2012). Effects of social networks on the quality of life in an elder and middle-aged Deaf community sample. *Journal of Deaf Studies and Deaf Education, 17*(1), 102-115. https://doi.org/10.1093/deafed/enr022

Gibson, J. J. (1979). *The ecological approach to visual perception*. Houghton Mifflin.

Gilliver, M., Ching, T. Y. C., & Sjahalam-King, J. (2013). When expectation meets experience: Parents' recollections of and experiences with a child diagnosed with hearing loss soon after

birth. *International Journal of Audiology, 52* Suppl. 2, S10-S16. https://doi.org/10.3109/14992027.2013.825051

Graham, P. J., & Tobin, J. J. (2019). The body as a canvas: Developing a Deaf bodily habitus in Deaf signing preschools. In I. W. Leigh & C. A. O'Brien (Eds.), *Deaf Identities: Exploring New Frontiers* (online ed., chapter 7). Oxford Academic. https://doi.org/10.1093/oso/9780190887599.003.0007

Halbwachs, M. (1950). *La mémoire collective*. Presses Universitaires de France

Hallet, W. (2012). Conceptual transfer: A cognitive approach to the construction, re-interpretation and re-contextualisation of academic concepts. In B. Neumann & A. Nünning (Eds.), *Travelling Concepts for the Study of Culture* (pp. 389-410). De Gruyter. https://doi.org/10.1515/9783110227628.389

Hoffstadt, A. (2018). *Gehörlosigkeit als „Behinderung": Menschen in den Gehörlosenschulen des Landschaftsverbandes Rheinland nach 1945*. Metropol Verlag. https://doi.org/10.5771/9783748961604

Janet, P. (1925). *Psychological healing: A historical and clinical study*. George Allen & Unwin.

Kaul, T., Gelhardt, A., Klinner, S., & Menzel, F. (2009). *Zur Situation gehörloser Menschen im Alter (SIGMA). Abschlussbericht der wissenschaftlichen Untersuchung*. Universität zu Köln.

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, *24*(6), 829–849. https://doi.org/10.1017/S0144686X04002375

Kusters, A., De Meulder, M., & O'Brien, D. (2017). *Innovations in Deaf Studies: Critically Mapping the Field*. Innovations in Deaf Studies: The Role of Deaf Scholars, 1-53.

Johnson, P., Cawthon, S., Fink, B., Wendel, E., & Schoffstall, S. (2018). Trauma and resilience among Deaf individuals. *Journal of Deaf Studies and Deaf Education, 23*(4), 317-330. https://doi.org/10.1093/deafed/eny024

Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Multilingual Matters. https://doi.org/10.21832/9781853595479

Lakoff, G., & Johnson, M. (1980/2003). Metaphors We Live By. University of Chicago Press.

Lane, H. (1992). *The Mask of Benevolence: Disabling the Deaf Community*. Alfred A. Knopf.

Lieberman, A. M., Hatrak, M., & Mayberry, R. I. (2014). Learning to look for language: Development of joint attention in young Deaf children. *Language Learning and Development, 10*(1), 19-35. https://doi.org/10.1080/15475441.2012.760381

Meek, D. R. (2020). Dinner table syndrome: A phenomenological study of Deaf individuals' experiences with inaccessible communication. *The Qualitative Report, 25*(6), 1676-1694.

Merleau-Ponty, M. (1962). *Phenomenology of perception*. English translation C. Smith. London: Routledge & Kegan Paul.

Mühlhoff, R. (2014). Affective resonance and social interaction. *Phenomenology and the Cognitive Sciences, 14*(4), 1001-1019.

Narvaez, R. F. (2006). Embodiment, collective memory and time. *Body & Society, 12*(3), 51-73. https://doi.org/10.1177/1357034X06067156

O'Brien, D. (2021). Theorising the Deaf body: Using Lefebvre and Bourdieu to understand Deaf spatial experience. *Cultural Geographies, 28*(4), 645-660. https://doi.org/10.1177/14744740211003632

Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a Culture*. Harvard University Press. https://doi.org/10.4159/9780674041752

Parker, J., Young, A., & Rogers, K. (2010). "My Mum's Story." *Dementia, 9*(1), 5-20. https://doi.org/10.1177/1471301209353987

Parma, C., Doria, F., Zulueta, A., Boscarino, M., Giani, L., Lunetta, C., Parati, E. A., Picozzi, M., & Sattin, D. (2024). Does body memory exist? A review of models, approaches and recent findings useful for neurorehabilitation. *Brain Sciences, 14*(6), 542. https://doi.org/10.3390/brainsci14060542

Pfau, R., Göksel, A., & Hosemann, J. (Eds.). (2021). *Our Lives - Our Stories: Life Experiences of Elderly Deaf People*(1st ed.). De Gruyter.

Pfau, R., Steinbach, M., & Woll, B. (Eds.). (2012). *Sign Language: An International Handbook*. Mouton de Gruyter.

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

Rantapää, M., & Pekkala, S. (2016). Changes in communication of Deaf people with dementia: A thematic interview with a close family member. *Dementia: The International Journal of Social Research and Practice, 15*(5), 1205-1218. https://doi.org/10.1177/1471301214557183

Schild, S., & Dalenberg, C. J. (2012). Trauma exposure and traumatic symptoms in Deaf adults. *Psychological Trauma: Theory, Research, Practice, and Policy, 4*(1), 117-127. https://doi.org/10.1037/a0021578

Shapiro, L., & Spaulding, S. (Eds.). (2024). *The Routledge Handbook of Embodied Cognition* (2nd ed.). Routledge. https://doi.org/10.4324/9781003322511

Sullivan, P., Brookhauser, P., & Scanlan, J. (2000). Maltreatment of Deaf and Hard of Hearing children. In P. Hindley & N. Kitson (Eds.), *Mental Health and Deafness* (pp. 149-184). Whurr Publishers.

Summa, M., Koch, S., Fuchs, T., & Müller, C. (2012). Chapter 26. Body memory: An integration. In S. Koch, T. Fuchs, M. Summa, & C. Müller (Eds.), *Body Memory, Metaphor and Movement* (pp. 417-444). John Benjamins Publishing Company. https://doi.org/10.1075/aicr.84.31sum

Supalla, T. (2020). Transforming the expression of collective memory in Sign Language. In P. Boudreault (Ed.), *Deaf Studies Digital Journal, Vol. 5: Selected Papers from Deaf Studies Conference Transformation 2020*. https://doi.org/10.3998/15499139.0005.013

Van der Kolk, B. (2014). *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*. Viking Press.

Van Steenwyk, I. (2008). Going, going, but not gone: The impact of social and technological influences on the Australian Deaf community. *Anthropology Matters, 10*(2). https://doi.org/10.22582/am.v10i2.38

Varela, F. J., Thompson, E., & Rosch, E. (2017). *The Embodied Mind: Cognitive Science and Human Experience*(Revised ed.). MIT Press.

Veditz, G. (1912). *Ninth Convention of the National Association of the Deaf and Third World's Congress of the Deaf*. Philosophicus Press.

Verheggen, T., Enders-Slegers, M.-J., & Eshuis, J. (2017). Enactive anthrozoology: Toward an integrative theoretical model for understanding the therapeutic relationships between humans and animals. *Human-Animal Interaction Bulletin, 5*(2), 13-35. https://doi.org/10.1079/hai.2017.0011

Vogel, H. (2015). *Gehörlose Opfer der Zwangssterilisation und der "Euthanasie" in der NS-Zeit* [Documentary movie in German Sign Language and spoken German, with subtitles]. https://www.euthanasiegeschaedigte-zwangssterilisierte.de/dokfilme/film-gehoerlose-opfer-zwangssterilisationen-und-euthanasie-ns-zeit/

Woll, B., & Ladd, P. (2011). Deaf communities. In M. Marschark & P. E. Spencer (Eds.), *The Oxford Handbook of Deaf Studies, Language, and Education, Vol. 1* (2nd ed.). Oxford Library of Psychology. https://doi.org/10.1093/oxfordhb/9780199750986.013.0012

Young, A., Ferguson-Coleman, E., & Keady, J. (2014). Understanding the personhood of Deaf people with dementia: Methodological issues. *Journal of Aging Studies, 8*, 62-69.

Warburg, A. (2010). *Werke*. Suhrkamp.

WHO - World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. World Health Organization. https://iris.who.int/handle/10665/259615

Zaurov, M. (2003). *Gehörlose Juden: Eine doppelte kulturelle Minderheit [Deaf Jews: A double cultural minority]*. Peter Lang.

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Ich, Lisa Magdalene Stockleben, geboren am 19.11.1988, versichere eidesstattlich, dass ich die von mir vorgelegte Dissertation selbstständig und ohne unzulässige Hilfe angefertigt, die benutzten Quellen und Hilfsmittel vollständig angegeben und die Stellen der Arbeit einschließlich Tabellen, Karten und Abbildungen, die anderen Werken im Wortlaut oder dem Sinn nach entnommen sind, in jedem Einzelfall als Entlehnung kenntlich gemacht habe sowie dass diese Dissertation noch keinem anderen Fachbereich zur Prüfung vorgelegen hat. Die Promotionsordnung ist mir bekannt. Die von mir vorgelegte Dissertation ist von Prof. Dr. Wolfgang Mann betreut worden.

Köln, 26.09.2025

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