SSM - Qualitative Research in Health 2 (2022) 100103

Contents lists available at ScienceDirect

SSM - Qualitative Research in Health

journal homepage: www.journals.elsevier.com/ssm-qualitative-research-in-health

Fragile storytelling: Methodological considerations when conducting ethnographic fieldwork among people with Alzheimer's disease

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ARTICLE INFO

Keywords:
Dementia
Alzheimer's disease
Ethnography
Narratives
Deteriorating language

ABSTRACT

The purpose of this article is to discuss the possibilities and challenges of qualitative research for studying the lifeworlds of people living with dementia. Historically, people with dementia have been widely neglected within qualitative research, being considered too incoherent or unintelligible. Though this has been contested, methodological challenges remain. Building on fieldwork among people with Alzheimer's disease in Denmark from 2019 to 2021, we argue that ethnographic methods have the potential to grasp the non-verbal presence and interaction crucial for describing "the moods" of social encounters and people's "signature". Yet, at the same time, the people who participated in the study were still trying to tell stories, highlighting the importance of also paying attention to their verbal expressions, however fragmented they may be. We use the term "fragile stories" and "fragile storytelling" referring to how people with Alzheimer's easily become distracted from the topic of conversation. Fragility implies the possibility of breaking, if not handled with care. Losing one's words risks derailing attempts to tell a story, and hence the sense of coherence and continuity, while also challenging the conversational partner's ability to properly relate to the story being told. Doing fieldwork among people with Alzheimer's highlights the fact that knowledge creation is an ongoing dialogic process, in daily life and in research. With inspiration from the concept of wayfinding (see Ingold 2000), we propose that the researcher must go along with the fragile stories by continually attuning to the person with Alzheimer's shifting modes of being. By doing so, the researcher can help the stories come into being by not just being present and listening with patience, but through guessing and filling in.

1. Introduction

The field of dementia is dominated by medical research dedicated to finding a cause and a cure. Yet, more than 200 investigational programs have failed or been abandoned within the last decade, and only one new drug has been approved by the US Food and Drug Administration within the last 19 years (Danish Dementia Research Center, 2021a; Yiannopoulou et al., 2019). In the absence of new effective treatments, the World Health Organization (WHO) highlights the urgent need for research into quality of life, care and the inclusion of people with dementia – both societal and in research (WHO, 2021, p. 16).

Qualitative research potentially plays a crucial role in improving our understanding of life with dementia and dementia as a socially embedded phenomenon affecting the individual, the family and broader society (Carmody et al., 2015, p. 1013; Steenman et. al., 2006, p. 723). But how do we get insight into the lifeworld of people who are losing their ability to participate in verbal interactions? Their memories fade, they increasingly have difficulties finding the right words at the right time, and their sense of time and place wanes. People with dementia challenge qualitative methods. Life-story interviews, narrative understandings and even participant observation become difficult.

The purpose of this article is to discuss possibilities and challenges of qualitative methods for studying the lifeworld of people living with dementia. Our starting point is a study of people with Alzheimer's disease, followed through ethnographic fieldwork in Denmark from 2019 to 2021. At the beginning of the study, the research participants were in the early stage of their disease, but as the study covers 2.5 years, we followed how their disease progressed to the middle stage - and for some of them, also the late stage. In other words: we studied people who were in the process of losing their language but were still trying to tell their story.

Up until the 1990s, the voices of people with dementia were widely neglected within qualitative research. People with dementia were

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https://doi.org/10.1016/j.ssmqr.2022.100103
Received 17 December 2021; Received in revised form 7 April 2022; Accepted 12 May 2022
Available online 17 May 2022
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considered incoherent and unintelligible, as discussed by Murphy et al. (2015, p. 801) and Lloyd et al. (2006, p. 1392). Instead, research focused on describing dementia from the perspective of their caregivers (ibid.). While it is indeed important to shed light on how dementia affects the family and wider network, the use of proxy-accounts cannot replace the positions and experiences of people living with dementia. Neglecting their lifeworld adds to the stigma and risk that people with dementia be further excluded and silenced (Murphy et al., 2015, p. 802; Herskovits, 1995, p. 152). Furthermore, failing to do so entails a risk of delivering inadequate care and support (Lloyd et al., 2006, p. 1388).

Since the 1990s, more attempts have been made to include people with dementia, though a literature review shows that people with cognitive impairments and dementia are still often excluded from geriatric research with no further explanation or reflections (Taylor et al., 2012). Within the field of medical anthropology, in which this study is inscribed, the question of how to access the perceptions of people with dementia has been discussed (cf. Collins, 2021; Driessen, 2018; Kontos, 2005; Pols, 2005). Most of these studies were carried out in nursing homes and looked at how residents with dementia, whose language had deteriorated considerably, use their bodies to display personhood and agency. Jeanette Pols (2005) calls for studying “patient positions” rather than “patient perspectives” as a way to include enactment of preferences made by people with aphasia or cognitive impairments. Annelieke Driessen (2018) has studied “enacted appreciations” of residents in Dutch nursing homes. She shows how they use their bodies to communicate with few or no words, which activities they want to engage in. Recently, Pippa Collins (2021) has argued for a total abandonment of the interview in research with people with dementia, favoring conversations led by the person with dementia. She proposes to video-record conversations to capture bodily movements of the research participants (ibid., p. 213–214).

Some anthropological studies have looked at ways to interpret the verbal expressions of people with dementia. Lone Grøn (in press) proposes to understand the at times incomprehensible answers of her interlocutors as “responsive events”, that is, events in which a space for interaction is created. One stays with the utterances of the other and tries to build on them with interest and appreciation, even as one struggles to understand the meaning of the actual words. Anne Basting (2006) has shown how collective storytelling workshops create meaningful ways for self-expression for people with dementia. Here, participants told non-linear stories about pictures shown to them by facilitators, which nevertheless allowed for an integration of past and present and an avenue for self-expression. Athena McLean (2006) has argued that life stories of people with dementia do indeed serve to create coherence and meaning for the narrators in the present, even when their stories lack facticity. In her article, McLean retells a coherent and well formulated life story that lacks historical facticity but which anyway teaches the reader why this person is in a nursing home and feels abandoned by her family. However, the reader is not being given insight into the role of the researcher in its retelling.

Building on these discussions, we argue that ethnographic methods have the potential to grasp non-verbal presence and interaction and that this is crucial when trying to understand the lifeworld of people with Alzheimer's. Yet, at the same time, we argue that the content of conversations remains important, even when the language is deteriorating. The people who participated in our study were trying to get their stories across. They asked for help to do so. We refer to their storytelling as fragile, and discuss methodological questions of how to listen to and participate in these attempts to get stories across to conversational partners.

2. Material and methods

The article is based on a study of people diagnosed with Alzheimer's disease living in Denmark. Approximately 87,000 people live with a dementia illness in Denmark, a country with a population of 5.8 million (Danish Dementia Research Centre, 2021b). Dementia is an umbrella term covering more than 100 different diseases. Alzheimer's disease accounts for nearly two-thirds of all incidents above the age of 65.[1] The typical duration of Alzheimer's is 8–10 years. Typically, the first symptoms are memory lapses, and struggles to find the right words. Symptoms worsen over time, resulting in the person becoming increasingly dependent on others in all daily activities such as communicating, eating, going to the toilet, changing clothes, and so on. (Danish Dementia Research Centre, 2021c).

Ida conducted 12 months of ethnographic fieldwork among people with Alzheimer's disease and their family members in 2019–2021. Hanne occasionally visited her in the field. The data collection was divided into three blocks: first, 7 months from February to August 2019, then 4 months in fall/winter 2020, and finally one month in the summer of 2021.[2] In total, Ida followed people for 29 months and witnessed how their disease developed from the early to middle - and for some also late - stage of Alzheimer's. Five key research participants were visited regularly in their homes: three women and two men, aged between 57 and 84 years. All had been diagnosed one to two years before the study and lived at home, managing life relatively independently. Two of them lived with a spouse, two alone. One man lived with two tenants. In addition, Ida did 11 semi-structured interviews with eight other persons with Alzheimer's.

Ida noticed early on that many research participants felt uneasy about being interviewed. It reminded them of the cognitive tests they had done to get their diagnosis and the sense of failure they had felt then. They often put a lot of energy into “performing well” during the interview. They wrote notes beforehand, listened closely to the question, and tried their best to answer. And they felt exhausted afterward. Their difficulties in answering questions in a formal interview and the uneasiness it caused them made Ida abandon this method after the first interviews. She started focusing on participating in different activities. Typically, she would spend half a day with them, talking, drinking coffee, and participating in activities they enjoyed, such as going for walks, knitting, painting, and accompanying them on a shopping trip. Towards the end of the fieldwork, Ida recorded some conversations with research participants in order to look closely at the exchange of words taking place even when the research participants' language had become limited indeed. Furthermore, Ida conducted seven semi-structured interviews with six family members of the key research participants.

In addition to the fieldwork done in the homes of the research participants, Ida participated in different activities available for people with dementia: a weekly exercise team, a five-day retreat for 20 people with dementia. She also did observations at a Memory Clinic in Copenhagen, to get a sense of the diagnostic procedure for dementia.

All procedures of the research project were performed in compliance with relevant laws and institutional guidelines, and has been approved by the appropriate institutional committee(s). Conducting qualitative research among people with cognitive impairments such as Alzheimer's requires careful ethical considerations (Sherratt et al., 2007). Yet, it seems that people with Alzheimer's and other dementia illnesses often end up being excluded from participating in research by those ethical measurements that are designed to protect them from harm (Alzheimer Europe, 2019, p. 7). This is particularly an issue in relation to informed consent. Research projects on life with dementia are often rejected as ethical committees are not convinced that one can obtain informed consent from participants with dementia (Dewing, 2008). In addition to obtaining initial written consent from all participants, Ida therefore also

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[1] For people younger than 65 years, Alzheimer's disease accounts for around 35–40% of all dementia incidents (Danish Dementia Research Centre, 2021b).

[2] The second part of the fieldwork took place during the COVID-19 pandemic. Ida followed the official guidelines of the Danish Health Authority when visiting a research participant. Fieldwork was paused in late December 2020, one month earlier than planned due to a steep increase in numbers of COVID-19 cases. Instead, Ida met with her key research participants again in the summer of 2021.

pursued an approach referred to as “process consent”, specifically designed to enable people with dementia to make known their preferences concerning participation (ibid.). Process consent entails that at each stage of data collection the researcher reminds the research participant of the purpose of the study and the right to withdraw at any time. None of the participants withdrew from the study. All names of people and places have been changed. The presentation of results in this article is structured around one key research participant, Susanne, whom Ida followed for longer than the rest of the participants. Her husband, Erik, has read and approved the use of her story, since Susanne is no longer able to read it herself. Repeatedly, when she was still able to communicate, Susanne made it clear to Ida that she wanted to participate in the study and that she hoped others could learn from her story.

3. Analytical framework

Dementia challenges European and North-American understandings of what it means to be a person. As discussed by Taylor (2008), people with dementia are seen as losing their personhood when they can no longer recognize their loved-ones or speak coherently. The close association often made between personhood and cognitive skills turns cognitively impaired people into “living dead” (Kaufman, 2006), and “slowly drowning in a sea of forgetfulness” (Driessen, 2018). Medical anthropologists have joined other academic, clinical, and lay fields in a critique of this conflation of personhood with cognitive skills, a critique that has been referred to as “the personhood turn”: an attempt to rediscover the “person lost” within the logic of dementia (Cohen, 2006; Leibing, 2006). These scholars argue that identity, selfhood and personhood are manifested and invoked through interactions with others, and do not rely solely on cognitive skills (Basting, 2009; Driessen, 2018; Gjødsbøl & Svendsen, 2018; Herskovits, 1995; Kaufman, 2017; Leibing, 2006). In other words, the understanding of a person cannot be reduced to what one learns through verbal interactions. The researcher must also step into the person's social life: into social relations as they come into being and are maintained and changed in everyday interactions (cf. Hastrup, 2004).

Ethnography has a long tradition of valorizing both participation and observation, and of creating descriptions that attempt to put into words the silent dimensions of the social, the taken for granted and the prelingual, to elicit tacit knowledge and give voice to the voiceless (Hirschauer, 2007). Ethnographic description puts something into words which did not exist in language before. However, ethnographic research also relies heavily on the spoken word, not only when writing, but also while in the field. The literary turn of the 1980s (Clifford & George, 1986) further amplified a discursive practice that gives priority to the spoken word. In addition, the spoken word creates an illusion of “raw data”, that is seductive when, in interdisciplinary collaborations and disseminations, the researcher is confronted with requests for “evidence” (see e.g. Hirschauer, 2007 for a discussion of this). Recordings of interviews and the use of quotations have thus for various reasons become well established methods in ethnographic research.

When researching life with Alzheimer's we are reminded of the need for methods that do not prioritize the spoken word and to revisit what ethnographic methods and descriptions can contribute with, when studying people whose language is deteriorating or absent, as many scholars have indeed done (see above). However, the language of our research participants is exactly *deteriorating*, not absent. We are trying to understand the lifeworld of people who attempt to keep verbal interaction alive. Who – at least at times – try themselves to create a coherent verbal narrative, but fail. How can we attune our methods to going along with them?

3.1. The narrative quest and problems with experience

Life is in quest of narrative (Ricoeur, 1991). Telling about one's life is a process of meaning making. When life's many incidents are transformed into one story, a sense of coherence and meaning is created, as Ricoeur has argued (ibid, p. 20). Storytelling gives us a sense that even though we do not determine the course of our lives we at least have a hand in defining its meaning, as Michael Jackson puts it (2002). In making and telling stories, Jackson continues, we rework reality to make it bearable and renew our faith that the world is within our grasp (2002, p. 16–17).

In the 1980s and 1990s, anthropology became increasingly influenced by phenomenological scholars and “experience” has in many instances replaced social structures and cultural models as anthropology's primary object of inquiry (see e.g. Turner & Bruner, 1986). The stories people tell are considered a gateway to people's experience (see e.g. Good, 1994). Robert Desjarlais has reflected on this use of experience as a universal and authentic entity, and on the assumption that experiencing is something we all do all the time (Desjarlais, 1997, p. 10). He argues that “experience” results from a specific cultural articulation of selfhood, namely, a sense of self as possessing depth, interiority, and stability, and the capacity for transcendence (ibid., p. 13). This understanding of experience as an inwardly reflexive process cohering through time has been reinforced by the notion of narrative (ibid., p. 17).

Desjarlais further argues that experiencing - tying things together through time - is just one among other modes of being in the world. He suggests “struggling along” as a way to describe another mode of being that he encountered among mentally ill homeless people in Boston. “Struggling along” entails a sense of disruption and displacement, lack of focus, lack of meaning, and a way of being that is not tied to temporality and continuity. Struggling along involves a more fragmented sense of self and a sense of living in a diffuse and external rain of distractions that sometimes prompt a retreat from the world (ibid., p. 22). A good day for someone who is “experiencing” may entail the novel integration of personal undertakings, and build on elements of novelty, continuity, transformation, plot and movement. In contrast, a good day for someone “struggling along” might instead be a day where one temporarily overcomes one's burdens and makes time go by in an eventless manner. A day that builds on contingency, convenience, equilibrium, and stasis (ibid., p. 22).

Narratives, however, do not only help us create continuity and coherence. Stories are also told to make sense of ongoing situations and are guides for future action (Garro & Mattingly, 2000, p. 17). Being an actor means trying to make certain things happen, to bring about desirable endings, to search for possibilities that lead in hopeful directions (Mattinly, 1998, p. 813). We want our stories and actions to get us somewhere. Endings, however, are uncertain. We know we will encounter obstacles on the way and narrative time is thus marked by suspense and an acknowledgment that things may turn out differently than one anticipated (Mattingly, 1994, p. 814). We live life in suspense and life's indeterminacy extends backwards as well as forwards. We may need to reinterpret the past and revise our desires for the future. Narrative time is a time of uncertainty as well as potentiality.

Phenomenologically inspired scholars have thus emphasized both the continuity and the openness implied by experience (Desjarlais & Throop, 2011) and we suggest that people with Alzheimer's who fail to get their stories across are therefore challenged on both their sense of continuity and coherence and their orientation towards the future, and hence their ability to act towards desirable endings.

3.2. Fragile stories and other modes of being

People with Alzheimer's undergo a progressive loss of sense of time, place and words, hence they lose the ability to tell stories and thereby to create meaning and coherence over time as well as orienting themselves towards the future. They lose the sense of having a hand in defining the meaning of life, of where they are heading, and their sense of belonging to the larger collective (cf. Jackson, 2002). But they do not stop trying to get their stories across. They fluctuate between different modes of being as their disease progresses, but also on a daily basis. They have “good” and “bad” days, and good and bad moments within the same day, where the symptoms of the disease are more or less pronounced – where words come more or less easily and where stories are more or less easily derailed.

What Desjarlais reminds us, is to avoid assuming the existence of a coherent, well-rounded and deep sense of self. And to avoid assuming that "experiencing" understood as the ability to create coherence and continuity is the only – or even the predominant – way of being in the world. Sometimes the suspense of the present and the potentiality of the future weigh more heavily than making sense of the past. Sometimes one tries to create coherence, but struggles to do so. At other times one is content not trying to not try to do so, and maybe even to lose one's sense of self in nature or in the company of others. We suggest that life, generally speaking, consists of both "experiencing" - of moments of coherence and others of openness and potentiality - and of moments of "struggling along". But also that life with Alzheimer's can be understood as an accentuated and constant oscillation between experiencing and struggling along, or maybe as a continuum of modes where one increasingly finds oneself in a state more akin to struggling along than to experiencing, or even a state of being in which one neither experiences nor struggles to do so.

We use the term "fragile" and talk about "fragile storytelling" to refer to the fact that people with Alzheimer's easily become distracted from the topic of conversation. Fragility implies the possibility of breaking or destroying something. Like a crystal glass that risks splintering, if not handled with care. People with Alzheimer's try to tell their stories, they engage their listener in guessing games, and they at times withdraw, become quiet and fix their gaze elsewhere – and then a bit later they try again, with a new conversation and new stories. In order to accompany people with Alzheimer's into their lifeworld and grasp their shifting modes of being, we propose that researchers have to go along with these "fragile stories" and that this means not just being present and listening with patience, but also guessing, filling in, and helping the story come into being. Doing fieldwork among people with Alzheimer's highlights the fact that knowledge creation is an ongoing dialogic process, in daily life and in research.

Before returning to the methodological implications of going along with the fragile storytelling we will present some of the results from the study.

4. Results

The following presentation of the study's results is structured around one person: Susanne, whom Ida followed closely for 2.5 years. Some participants in the study were more talkative than others, but they all struggled to get their stories across. Susanne was particularly insistent on telling stories, even as her language deteriorated considerably, and since Susanne is the person whom Ida followed for the longest period, she has a particular rich material on how Susanne's struggles developed over time. However, the discussion that follows the presentation of Susanne's struggles also draws on material from the rest of the fieldwork.

Ida (and later also Hanne) is present in the account below. We argue that making the researcher present is necessary, as it provides a means to capture the many uncertainties and unknowns in interacting with people with Alzheimer's. This has also been argued by Joao Biehl (2013) in his book about a person whose voice was annulled by a psychiatric diagnosis (2013, p. 20). Understanding is an interpretive and dialogic process and through Ida's uncertainties of how to interact, and what she did – or did not – understand, we see the contours of Susanne's lifeworld.

In 2016, at the age of 54, Susanne, a former art teacher in primary school, was diagnosed with Alzheimer's disease. Ida had difficulties apprehending that Susanne was sick when she first met her in February 2019. Susanne had thick curly hair dyed red with henna, wore bright clothes and had strong arms and exuded vitality and charisma. Her vivid green eyes had an intensity to them. Susanne lived with her husband, Erik, with whom she has been for more than 20 years, in a small, rather primitive, but cozy house in the countryside. The walls of their home were covered by Susanne's art: big colorful paintings of naked people dancing.

Susanne has three adult children, none of them living at home. In 2019, Erik worked part-time, while Susanne had stopped working due to her disease. Since Susanne could not be on her own for longer periods, Erik had arranged with their wide network of family and friends to keep her company, when he was not around. Susanne started attending an activity center for people with dementia in January 2020, five days a week. The center was closed when the first COVID-19 lock-down was announced in Denmark in March 2020 and Erik could no longer manage having Susanne at home. In the summer of 2020, she moved to a nursing home.

We present material from Ida's time spent with Susanne in a chronological order, allowing the reader to see how the ethnographic methods continuously had to be attuned to the progression of her Alzheimer's, and consequently her loss of words.

4.1. *Painting together: details and the larger picture*

During my first visit to Susanne and Erik's home in 2019, Susanne showed me an old circus wagon they used as an atelier and a guest room. She proudly pointed to the many tubes of paint in all sorts of colors. Brushes were neatly organized in old jam-jars on the shelves. It looked inviting but untouched. "I have stopped painting ever since that Alzheimer's came", Susanne said. "I cannot remember how to paint."

I suggested that we paint together,[3] and Susanne immediately agreed. During one of our first painting sessions, Susanne realized that she had left her glasses in the main house and we went to get them. "What am I doing?" she exclaimed upon reaching the house, pressing her fingers against her forehead, rubbing her temples as if they were hurting. A crease appeared between her eyebrows. I reminded her that we had gone to the house to get her reading glasses. "Oh yes", she replied, and started looking for them.

Deciding on a motif to paint took nearly an hour. Together we leafed through a glossy art book, admiring great expressionist painters' work, their use of colors, contrasts, and shapes. Sometimes Susanne stopped and used a brush with black paint to follow the lines of the images, not worrying about ruining the book by painting directly on it. Finally, she stopped at an image portraying a man in a small room, painted in yellow. The man leaned awkwardly to one side, held one hand to his head. His face expressed pain or despair. A messy black and yellow cloud hung above his head. With no further explanation, Susanne tore out the page from the book and said: "This is the picture we are going to paint."

After some time, we paused and looked at the canvas. We had painted the man's legs and upper body and it had taken us hours to get this far. Susanne had been going back and forth between the painting and the tubes of colors. "Where was I?" she had asked herself many times. I repeated, eager to proceed with the painting: "Maybe you could paint the lines of his head with black color?" "Yes, great idea", she said, dipped her brush in the black paint, and then turned to the canvas. She looked at it for a while, waved her brush slowly in the air, following the lines of the lower part of the body already painted. "So this is his hip, and then he does like this with his arm", she commented and mimed his position using her own body. We shared a laugh. Susanne then started painting the small hat, but not the head. She returned to the table, took a new

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[3] Within the last two decades, there has been a surge of art-based interventions in dementia care (Shakespear et al. 2019, Bellass et al., 2019). Art practices are claimed beneficial for people with dementia biomedically and therapeutically, as well as improving quality of life and self-care (Jeong, 2020, 362,; Basting, 2018; Selberg, 2015). While we acknowledge that art-practices can provide creative and more socially inclusive ways to express personhood, this research project did not pursue an art-based approach, as such. At times, Ida did engage with art-based activities, like with Susanne who as a former art teacher enjoyed art in her life. Yet, these activities sprung from the interest of the research participants, and was not a general theme of the research project. Ida also participated in activities suggested by research participants that were not art-based.

brush, painted his feet with a yellow color. Took a step back, looked at the painting and pointed to the black hat floating in the air. “Did I do that? What is it? Is it his hat?”

Susanne noticed the details of the motif in the book and on the canvas. She commented on shapes, shades, colors, and individual parts of the motif, but not on the motif as a whole. While painting, Susanne time and again asked for help to create an overview. “So this is his shoulder, these are his arms”, she said while using her own body to imitate the man's body posture. She had difficulty connecting the different parts of his body on the canvas. But she continuously commented on the details of the painting, added colors of gold to make shades more visible, noticed the few places with red, and then added red to the canvas. The floor below the yellow man had been painted blue, but at some point she said: “That is a boring blue”, and started mixing different colors/shades of blue to make it more vivid. Returning to the painting after a coffee break, Susanne pointed to the curves of the man on the painting: “This is a funny thing”, she said. “It is like Alzheimer, it also goes up and down.”

During the early phases of Ida's relationship with Susanne, conversations would be possible though words would sometimes go missing and Susanne would get confused. What the painting sessions made clear to Ida was that Susanne had trouble seeing the bigger picture, the motif as a whole. She dwelt, instead, on details. Though she had difficulties connecting the details to each other, she was able to connect them to that which mattered in her life, such as comparing the curves of the man to the way her Alzheimer's goes up and down. See Fig. 1.

4.2. *In the museum together: sensorial and emotional links*

After a couple of months of painting together, Susanne and I took the bus to the National Gallery of Denmark. I found it difficult to engage Susanne in a conversation that day as I did most days by then. While crossing a street, I asked her what was on her mind. The road was noisy, cars drove by fast, a woman spoke loudly on her phone, and I was painfully aware of how distracting all of this was to Susanne. I asked about Susanne's participation in a retreat for people with dementia: “Did you speak with anybody about Alzheimer's, while you were there?” I asked. “Some”, she said. “And how was that?” I continued, and she replied: “Some have it a lot, others a little.” “Okay, so it differs from person to person”, I said, struggling to find a way to continue the conversation: “Yes”, Susanne said and the conversation came to an end. I did not know how to ask in a way that would keep the conversation going and Susanne did not take any initiative to start a conversation. Neither did she seem to find the silence awkward.

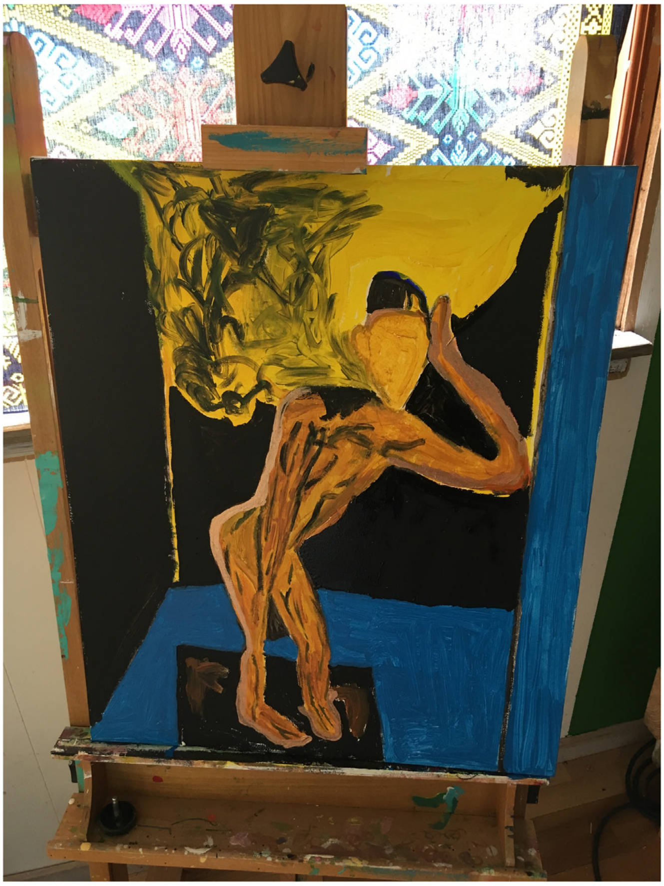

Fig. 1. Photo of the painting Susanne and Ida made together. Painted with inspiration from “Alone in room” by Ernst Ludwig, in 1915.

The silence felt awkward for me, though. Did Susanne not hear my questions due to the noise around her? Or did she forget the question before coming up with an answer? Or did she not understand the question in the first place? The idea that qualitative questions should be as open-ended as possible did not seem to work. We were together, doing nothing but walking and not keeping a conversation going, as was the case during many of our walks at this stage. They were a constant reminder of how much one-on-one interaction is based on verbal interaction. How hard it is to give space to the silent person, to not insist on keeping the conversation going. It increasingly became a challenge for me to deal with the uncertainty of never knowing whether I had understood or not. Of never being able to ask Susanne to explain or confirm my own understanding.

That day in the museum, something different happened, though. When entering the exhibition, a dramatic change occurred. Susanne suddenly became the one doing the talking. She embarked upon long and complicated stories evoked by the paintings. Memories and emotions tumbled down on her.

In the first room hung a big painting of a schoolyard with children playing. Susanne caught sight of it through the glass door, before even entering the room. She ecstatically exclaimed: “Wow, how cool is this?” and then she started narrating a long story about her mother's brother who died when somebody was a child. Someone who was mistreated. She told of a child who had to sleep in the filthy hay: “How could you do that to a child?” she asked indignantly. I looked for something in the painting that could help me follow Susanne's trail of associations. Perhaps, I thought to myself, was it the other painting, the one with the cows, that had sent Susanne's thoughts off in the direction of filthy hay? Or was it the painting of the children in the schoolyard? Susanne seemed troubled and waved her arms in front of her head as if she needed fresh air. “Uh, I am being reminded of that, no, now we have to … new … I need to see something new.” Resolutely she entered the next room, filled with brightly colored paintings. “Wauuuw. This is so great!” Susanne exclaimed. She approached a painting of a woman dressed in yellow, in a blue frame. “The color on the frame is so cool”, she exclaimed. Then a painting of a snow-covered cabin at the edge of a forest. “Have I told you that I have a small house? From my father. That could be my house right there”, she said, “mine is also situated next to a pine forest.” “And it also gets covered in snow?” I asked. “Yes, well then we …” I tried to help her continue the sentence: “… then you clear the snow?” “No”, Susanne insisted. “No … we …. ” Susanne moved her arms and legs as if walking into the snow with skis on. “Oh you ski!“, “Yes!” she said, with a happy laughter.

Over time, conversations with Susanne became increasingly difficult but words and her desire to tell a story would still resurface, triggered by emotions or sensorial memories. Ida tried her best to go along with Susanne as she was carried away by associations arising from the colors and shapes and paintings on the walls of the museum.

4.3. *Going for walks: on a guessing trip*

During a visit to Susanne and Erik's house in August 2020, just a couple of weeks before Susanne moved to the nursing home, Susanne tried telling me a story. “Yes, we were out bathing, me, Laust [Susanne's youngest son] and his lady. We drove down to … Also we went swimming without clothes. And then, when we got out of the water, it was just gone. Completely gone!” She gave me an astonished look, clearly surprised herself: “I do not know what it was that had disappeared”, she said. “It was a big thing.” Susanne indicated a large square with her arms. I tried to guess. “Was it a beach towel?” No, it was not a beach towel. Susanne seemed sure of that. “It was …” she started, while letting her hands slide across her upper body. “A bathing suit?” I suggested. “Yes …” Susanne said, not completely convinced, yet satisfied that a term had been agreed upon. I asked what happened. Susanne replied that she did not know: “All of a sudden it was gone. It was all new and … It was really annoying”, she said.

In some ways, Susanne stood out from the rest of the research participants. Even in her late stage of Alzheimer's she was insisting on getting her points across. She expected me to continue guessing even as words became fewer. It felt as if I was sent out on a mental memory game, which required that I mobilized all my knowledge about Susanne's life. Susanne's cat once went missing near her summerhouse. She had told me the story on earlier occasions, but with time it was told with only two words: “cat” and “summerhouse” and I had to help her make the link between the two words. Susanne also involved her husband Erik in guessing games. I talked with him about this and he described how he would sometimes become “mildly desperate” when sent on a guessing trip through their 23 years of relationship.

With time, the work of guessing took up a larger part of Ida's conversations with Susanne. A work of guessing that would have been very different had Ida not by then known a lot about Susanne's life, met relatives, friends, and professional caretakers in her life and followed her over time. Susanne continued to be particularly insistent upon this, but it was also the case for the other research participants. Ida was made to play a much larger role in conversations with them than what is normally expected in qualitative interviewing.

4.4. In a cafe: fragile conversations

After Susanne moved to the nursing home, the Danish government imposed the second lockdown in the fall of 2020. However, Susanne was allowed to go on trips outside the nursing home. Therefore, during this period, Ida picked her up on her carrier bike every second week. They spent time together, at first in cafés, and after these were closed, due to further restrictions, in parks with woolen blankets, hot tea, and lots of warm clothes. Susanne's language had become very constrained by this point, and Ida became more and more frustrated with herself. In her fieldnotes, she struggled to recall the conversations that had taken place. Ida therefore decided to try out recording bits of her conversations with Susanne. She was motivated by a need to document the fact that the words exchanged did indeed make little sense and to be able to properly describe the ways in which Susanne's sentences were fragmented. In the following we present Ida's fieldnotes from the meeting, as well as extracts from the raw transcription.

Excerpt from Ida's fieldnotes:

> Today I have decided to focus on everything other than seeking meaning in the words spoken by Susanne, but my search for meaningful sentences was difficult to let go of. I tried to be present in the silences that filled almost as much as our exchange of words. The silence felt awkward, though it didn’t seem to bother Susanne. And I couldn’t help asking her questions along the way: “Are you OK about being here with me?” I asked. She nodded in response and I was once more reminded of my constant need to use the spoken word as a way of verifying my sense of a situation. I failed to trust my impression that Susanne did indeed seem at ease and not bothered by the silence.

Settling at our table at the café, I asked Susanne if she wanted a bun, or perhaps a croissant? My question confused her. I asked again. She looked at me, still confused. “Croissant?” I asked. “Did I say that?” she replied. “No, I asked you if you wanted a croissant.” Eventually I came to the conclusion that she wanted a bun and a cup of tea. I got up to order.

When I returned to the table Susanne immediately started talking. She clearly had something on her mind that she wanted to share with me. I asked if I could record our conversation on my phone. She agreed and though I could not be sure that she had understood my questions, I decided to do so, since she had previously approved of all of my different requests to document the progression of her disease.

I: So you and Erik talked about not being together?

S: Yes, yes. But it's like it is good again.

I: Good again?

S: Yes, yes [Silence].

I: You were mad at him last time. You felt like he didn't take it seriously that you had problems with your legs?

S: Yes?

I: Are you still angry with him?

[Long silence]

S: … Yes. Yes … It's not because I have to have … Yes, yes, yes, yes.

I: But it's better now?

S: What?

I: You and Erik are better now?

S: Yes.

… …

S: Yes … [Silence for 10 s] We are with … When we're going …. Yes … Together with … [Silence for 20 s]. But we actually also get … uh, down there, where I live now? Yearh yearh …

I: Yearh?

S: So there must also be …. [Susanne mimics someone with his/her mouth too full, as if food is falling out, perhaps vomiting]

I: Is that how the others look, or? [Me thinking that she might be imitating the others residents]

S: And Erik … I think maybe we should be down in our real house …

I: Yes, that would be nice [Me not understanding what she is referring to]

(…)

I: Is it hot? [I asked about the tea]

S: Yearh [Laughs] At first I thought it was a piece of … When I did this … That it was a sausage! [Pointing to the small biscuit next to her cup of tea]

I: Well, yes it looks like that too, same color and shape.

S: We have not quite figured out what we need, because we have so, there are so many.

I: For Christmas? [Me guessing the theme to be Christmas since she talked about Christmas on the way to the café]

S: Yeaerh. [Silence for 10 s]

I: Was there something about you being in the hospital and having your legs checked?

S: Yearh!

I: How did it go?

S: Mmmm, yearh, yearh. They must … they must. Yes. I have that too … So before, before … there I have had something like this.

I: At the hip?

S: Hips! Jaer. Mmm. [Silence for 30 s], yearh, mmm.… I think that Laust and those who want to join.

I: Yearh? [Me not sure what we are talking about now]

S: So if they do not want.. Yearh [Silence for a minute]

S: Yearh, Laust? He has a … and …. Yes … Like mmm … who has such a one who arranges. Also because I have something like that with me, over there all the …

I: Yes yes yes?

S: So … Laust? Laust? He found this woman who was … So then when I got up there. She was really really …. . It was crazy. Crazy! Mm!

I: Is that right?

S: Yes, very nice woman.

I: Did she do something with her hands, massage you or?

S: Mmm yes. The whole back, yes, yes.

I: Well how nice.

S: He is so sweet, Laust.

I: He is a good boy.

S: Yes.

I: He takes good care of his mother.

S: Yes.

(…)

I: [breaking the silence] What are you thinking about?

S: Oh … I think that …. I do not know. Yeah, so they are kind of okay somehow. But it is a place where I cannot … yes … Yes.

I: Yes? [Without understanding]

S: Mmm, mmm, yes, mm … yearh.

I: And how do you feel about that? [Without understanding]

S: Not so good.

I: I can understand that.

S: Yes. Yes. They have …. Now have … and running around all the time and all the time. That. Yes.

I: Do you know why you should live there? Why you had to move there? [Me guessing that the topic is now the nursing home]

S: It was … It was me and what is her name? Cecilie? Yes.

I: You were going to live together, was that not the plan? [Cecilie is a friend who also has Alzheimer's who moved into the nursing home before Susanne. Together they had made a plan to live at the same nursing home, so Susanne followed Cecilie]

S: Yes.

I: Do you know why you could not live at home anymore? Or can you explain why you live there now? [Me finding it difficult to ask a clear question]

S: Now? Yes. Yes [Silence for 30 s]

I: Have you and Erik talked about why you should move to Kærholm [The nursing home]?

S: What? Yes. First, it was like that we could get … aerrh … yes.

I: Yes?

S: Yes [Silence for 15 s]

I: But that's not the case anymore?

[Long silence for 1 min and 10 s]

S: What is it? [Susanne picks up a piece of cake next to her cup of tea]

I: It is a small piece of cake.

S: Mmm! [Enjoys quietly]

[Silence for 20 s]

S: Laust?

I: Yes.

(…)

I: Did Erik sleep at your place last night?

S: Yes, right now it's good.

I: That's good, because before you were sad, but now it's good?

S: Yes yes mmm, mmm [Silence for 20 s]

I: You know I'm doing this project about having Alzheimer's. And I think like you, you can experience the loss of some things. Things, words, the home you know.

S: Yes.

I: You can feel the losses?

S: Yes, I can feel them.

Fieldnotes continued:

> Most of the time, Susanne sat quietly in the armchair across from me, her legs crossed, her gaze fixed somewhere behind me. I tried to follow her gaze, but did not get the impression that she looked at anything in particular. She seemed concerned. Thoughtful. She often said: “yes, yes, yes” to herself and nodded as if a conversation was taking place in her head. She also used facial expressions, imitating somebody vomiting, or as if food was falling out of her mouth. Was she trying to tell me that the other residents are disgusting? “It is a place where I cannot”, she said, but did not finish her sentence. During our one hour long stay at the café, words were exchanged, but more than words defined our encounter. Her brow was furrowed, her gaze fixed on something distant. She herself was not distant. She seemed to think a lot. About what? I have no idea. We went from talking together to a bit of silence, to sudden heartfelt laughter. From there we went to more silence, and suddenly she started crying. She leaned forward, hid her head in her hands. I leaned forward and squeezed her arm. She said it was difficult and tears rolled down her cheeks. I asked why she was crying. I wanted to make her stop crying. Feared that my visit had somehow made her upset. Feared that my questions made her think of sad things and I wondered whether we should do fun things together instead of trying to talk, but the COVID-19 lockdown had not made this any easier. How could I distract her? Was it my job to distract her? I thanked her for sharing her thoughts with me. She nodded. Our meeting that day left me with a feeling that there was nothing but losses left in Susanne’s life.

The transcription of the conversation does not in any way do justice to the interaction that took place in the café. The many changes in mood, the glances shared. Ida noticed that when listening to the recording she could hardly hear the laughter they had shared. But the transcript does show us things that may otherwise have gone unnoticed. We see how difficult it is for a person who does not have Alzheimer's to remain silent and to accept that a story remains unfinished. It also shows us how difficult it can be to avoid asking abstract questions. And only when reading the transcript do we see how Susanne often did respond to Ida's questions, though not according to narrative logic. We are being given insight into the emotional jumps she made, for example through her references to Erik and to Christmas and whether her son, Laust, would be there.

4.5. Last encounter: art that makes you happy

On Ida's last encounter with Susanne before ending fieldwork in the summer of 2021, both Erik and Hanne (the second author) joined them at an art museum north of Copenhagen, situated in a beautiful park. Erik and Susanne arrived in high spirits on one of the nursing home's tandem bikes with four wheels, all smiles and laughter and having fun riding a bike like that together. Susanne had not seen Ida for three months, but her joy at reunion was unmistakable. Hanne noticed how with the few words Susanne still had left, the warmth of her voice, and the glances she cast, she expressed genuine happiness and eagerness to catch up with Ida. She hugged Ida several times. With a proud air, Susanne said that her son Laust was doing something “big”. Erik explained that Laust had started at the University this month. Preparing to enter the museum, Erik – as always impressively sensitive to Susanne's changes of mood – noticed an unease in Susanne. He took her aside and returned to let Ida and Hanne know that it was all a bit much and that Susanne would prefer to sit in the park instead. Hanne and Ida went to get coffee and cake and while relaxing in the foldable beach chairs in the park, Ida decided to give Susanne the gift she had brought to thank her for her participation in the study.

Hanne caught sight of Susanne's excitement and the title of the book concurrently. Susanne's face lit up and her green eyes twinkled when the words, “Art that makes me happy”, appeared underneath the wrapping paper. “That was me!” she repeated several times, with unmistakable glee in her voice, and Hanne thought to herself that what Susanne meant was that this was the perfect book for her. A book about art that makes you happy. A book that she and Ida had looked at together at a previous encounter. A book that reminded Susanne of Ida and of a relationship that clearly evoked happy feelings in her. But maybe, Ida later suggested, her words, “that was me”, could also refer to the woman in the painting on the front cover, a naked woman seen from behind as she spreads out her arms and prepares to jump off a small rowing boat into the clear water on a beautiful summer day. “That was me”, Susanne had said, pointing to the book, again and again, and then spreading her arms like the woman in the painting, about to jump. So maybe her words did indeed refer to this woman and to the sense of freedom, delight, and well-being that a warm summer day on a rowing boat with good friends can give you. Whatever brought forth her joy, Susanne's reaction left no doubt in Hanne that she felt seen and understood in her relationship with Ida and Ida's choice of gift for her.

5. Discussion

When researching life with Alzheimer's, you cannot count on your research participants to help you explain or put into words a situation that you have observed or participated in. But comprehending the life-world of others cannot be reduced to a question of whether one can make sense of their sentences or not. How then do we catch sight of the contours of a lifeworld in heightened oscillation between experiencing and struggling along? What modes of attention and practices are needed to grasp the shifting modes of experience of people with Alzheimer's?

We suggest that it entails the ability to go along with the silence of the social and the fragility of stories. To be able to go along with the fragile storytelling of a person with dementia requires a skilled performance akin to the one Tim Ingold refers to as “wayfinding” (2000:219-220). Wayfinding, Ingold suggests, is “a skilled performance in which the traveler, whose powers of perception and action have been fine-tuned through previous experience, ‘feels his way’ towards his goal, continually adjusting his movements in response to an ongoing perceptual monitoring of his surroundings" (ibid. 220). Ingold contrast this to the use of cartographic maps, that depicts a static world, detached from movements, flow and sounds (ibid.:242) While Ingold's wayfinding attends to what it means to find one's way through a physical place or landscape, we suggest that wayfinding resembles storytelling more than map-using (cf. Ingold, 2000:219). When journeying into the lives of people with Alzheimer's, the researcher must tune into the person's shifting modes of being. The researcher must do so based on her previous experience with the person, continually adjusting her movements in response to the other person's movements between verbal and non-verbal presence, between searches for coherence and for openness, and at times into states of diffuse and external rains of distractions that may prompt a retreat from the world (cf. Desjarlais, 1997:22). In the following, we will suggest ways in which this can be done methodologically.

5.1. Being present in the silence of the social

Life is about more than the exchange of meaningful stories. People can spend days together without saying much. Ordinary life contains nonsense conversations, whether one has Alzheimer's or not. Even conversations with little or no content confirm togetherness and belonging, and maintaining a sense of belonging is indeed of major concern to people living with dementia (Glavind, unpublished result).

In writing about her own mother's Alzheimers, Janelle Taylor (2008) describes how their conversations seemed to go nowhere. The same topic was repeated many times, answers were inaccurate or even incomprehensible. But that was not the point, Taylor argues: “The exchange itself is the point” (ibid., p. 327). And as mentioned, Grøn suggests that we talk about “responsive events” in which a space for interaction is created even if we fail to understand the actual utterances of the person with dementia (in press). Not only the semantics of a word, but also the pragmatics matter, that is, the action of uttering the words, the tone, and the tempo and rhythm of words being exchanged create an intersubjective space between conversational partners (cf. Hastrup, 2004, p. 113–152), like when Ida and Susanne exchange the words “yes, yes, yes” and a mood of mutual recognition was created in the space between them.

In addition, we need to include that which happens beyond words and utterances, such as body language, like when Susanne imitated the woman's posture on the front cover of the book, her brow furrowed when talking about the nursing home, and the pride with which she showed Ida her many tubes of paint in the circus wagon. It also goes for the sense of togetherness that cannot be caught by the recorder and requires a description. When Ida listened to the recording of the time she spent with Susanne in the café, she could hardly hear the laughter they had shared. She recalled Susanne's laughter as longer, more heartfelt, and she also remembers laughing herself, though this cannot be heard on the recording. The recording does not adequately reflect the interactions that took place in silence, the many glances shared, or the many changes of moods. Tine Gammeltoft reminds us to attend closely to such subtle aspects of human life, that is, not just to words, but also the feelings, sensations, and forms of life that belong to nonverbal registers (2018, p. 591). Inspired by Heidegger, she uses the term “mood”, to designate the assemblage of intersubjective affective states in a social situation. A mood is neither simply “inside” nor “outside” individuals, but refers to “the way of being there with one another”, like a melody setting the tone, drawing us into the grief or joy of others (Heidegger in Gammeltoft, 2018, p. 583–584). When Ida describes the sense of loss and grief that permeated her encounter with Susanne on that cold winter day, as well as the sense of togetherness in the café, she brings fleeting aspects of human life into language and analysis. Inspired by Gammeltoft we may say that she was attuned to, that is, she was open to and soaked up, the atmosphere (cf. Heidegger in Gammeltoft, 2018, p. 583), and described the moods that laid the foundation for her encounter with Susanne that day.

In addition to describing the moods of social encounters, we suggest, inspired by Zoanni (2018), that we also pay attention to the “signature” of a person. People with cognitive disability are often defined by their inability to enact or cultivate “a voice”, Zoanni argues (2018, p. 72–73). But they anyway foster a clear sense not only of their basic humanity, but also of their singular personalities, which emerge through a confluence of patterns of behavior and practices and other people's response to these. They have what he refers to as “signature” (ibid., p. 72), a distinctive embodied mark of being in the world, an imprint elaborated and stabilized through living in relation to others (ibid., p. 73). Signatures are not always clear or easy to read, but they are recognizable and they make people socially legible, even when verbally illegible. Susanne increasingly lost her “voice” but her “signature” remained strong. Her big, curly red hair remained a symbol of her charismatic personality, even when it faded into shades of gray. With her insistent gaze, her persevering attempts to tell stories, her vivid response to colors and shapes, Susanne positioned herself as a creative person filled with emotions and stories, even when lacking the words to express them.

We thus call attention to the importance of participant observation as a method when doing research on life with dementia, the purpose being not only a search for intersubjective meaning making, but also participating with patient co-presence to call forth and describe the silence of the social, the moods of social encounters, and the signature of people who are losing their voice.

5.2. Contributing to fragile stories

Life may well be about so much more than words. But it is also about words. As we have shown above, it continues to be important for people with Alzheimer's to express themselves verbally – and they ask others to help them do so. These efforts at conversing and telling coherent stories have to be handled with care, due to what we refer to as the fragility of their stories. We do not know to what extent the thoughts of people with Alzheimer's can be said to be fragile, but we do know that their practices of telling stories are fragile. They struggle to make links between separate elements and hence to create continuity and coherence.

When Ida asked follow-up questions it would often lead the person in a new – and for Ida unexpected – direction. In particular, questions that were broad or abstract would rarely be answered. The research participants would maybe listen to the question, and start thinking about it, but not answer. Maybe they did not hear the question properly or maybe they forgot it before figuring out what to answer. Sometimes they seemed to answer a whole other question than the one they had been asked. When

Ida asked Susanne at the café if Erik had spent the night at the nursing home, Susanne answered that they were doing good now. And maybe it was indeed an answer to Ida's question, though some steps in her line of thought had not been immediately obvious to Ida. Things had not been going well with Erik since Susanne moved to the nursing home. She was confused about having to move. She was angry at him for not spending all of his time with her. But recently, she and Erik were doing alright again. Maybe that was what she had tried to say.

In sum, stories were easily derailed by the loss of words, other people's (wrong) guesses, frustrations over one's own failure, distractions in the surroundings like noisy roads and people on their cellphones. Conversations felt fragile as not just the sentences were fragmented due to missing words, but also attempts to link sentences and events and create coherence and openness towards the future. Susanne failed to connect the different parts of her story like she failed to link the hat to the man's body in the painting. She held onto details, to the shade of blue and the body's curves – but had difficulties holding on to the larger picture. However, the details she did hold on to were often of immense significance in her life, and touched on existential issues such as her relationship to Erik, her husband and primary caretaker. In the transcript from the café, we also see that while in the midst of answering questions about something else, Susanne repeatedly returned to her son Laust, and to questions of who would be together for Christmas. Her utterances were not always answers to questions posed to her. They were rather associations to those she holds dearest in life. At other times, the links made by Susanne were evoked by sensorial impressions. Motives, colors and shapes in paintings could bring forth memories from Susanne's childhood, so profoundly that she lost her breath. Ida's knowledge of Susanne's life story made it easier for her to go along with these sensory impressions, which usually did not make sense, if detached from her past life experiences (cf. Pink, 2015). Ida knowing that Susanne owns the summerhouse of her childhood made it possible for her to help Susanne connect the details to a larger picture or story, even if presented in just a few words like cat, cabin, and pine trees.

Grasping emotional and sensorial links were at times difficult for Ida in situ. In her fieldnotes she complained that the fragmented sentences impeded her understanding, making it difficult to properly recall and account for the words exchanged between her and Susanne. The lack of coherent narratives being exchanged made it difficult for her to recall their conversations. We all “struggle along” (cf. Desjarlais, 1994) when coherence and meaning cannot be constructed. Recording and transcribing became a tool for Ida that helped her catch sight of links made by Susanne that may otherwise have gone unnoticed.

Listening to fragile stories thus means taking note - not of the person's lack of overview and their inability to see the larger picture - but of those details that they hold on to. We should inquire how such details are linked to larger emotional and existential issues in their lives - like Susanne being concerned about her relationship to her husband, Susanne seeing the resemblance between the curves of the man in her painting and her Alzheimer's going up and down, and Susanne repeatedly returning to thoughts about whom she would be spending Christmas with. Fieldwork is, among other things, an act of listening to the moments when facts falter, says Stevenson (2009) – or, as we suggest, when coherence falters and existential uncertainty is communicated through emotional links between incomplete and fragmented sentences.

While in the field Ida did not only listen, though. She also put a lot of effort into helping Susanne find missing words and creating stories. Listening to fragile stories implies acknowledging the inherently intersubjective nature of all knowledge (cf. Hastrup, 2004). In everyday conversations, we all do our best to fill in and guess to help people with whom we are having a conversation get their stories across. Comprehension is an ongoing dialogic process unfolding over time. Conversations with people with Alzheimer's accentuate the dialogic nature of knowledge production. The need for the other party to fill in and to guess is heightened, while the information provided that can help the other person guess and fill in is reduced. Though we can never be entirely sure what our guesses and attempts to fill in do to the person's story, we as qualitative researchers try to qualify the guesses, drawing on our long-term engagement with and prior knowledge of the research participants and to take the stories in directions that seem to make sense to the research participant.

Susanne's insistence on delivering her points forced Ida to help her search for the best ways to reach the ending of a story, and often Ida would put a lot of effort into the work of guessing. Yet, the act of guessing also entailed the risk of destroying the story altogether. Proposing a wrong word could lead to new associations, a completely different topic of conversation, and leave the original story unfinished. Instead of guessing, Ida could try to hold back, wait and see if the research participant would end up finding the word. This, however, at times felt unethical for Ida, as the participant would then be left “hanging there”, exposed in his/hers search for the word. Sometimes she would help the research participants reach their point by proposing a sentiment as a conclusion to the story. Ida would maybe ask (depending on how she interpreted Susanne's body language): “… and this made you upset?” or “and you liked that?“, and Susanne would then maybe agree and seem satisfied with this. In the most difficult stories, where Ida had no clue what Susanne was trying to say, she would simply say “yes, yes, yes”, as Susanne often did herself, thereby communicating a sense of togetherness and a willingness to go along. Listening is indeed also a way of being present and taking part in a conversation. Guessing and helping the conversations move on, thanks to one's prior knowledge of the person as well as simply listening and confirming one's presence, were ways in which Ida tried to go along with the research participants, helping them get their stories across.

5.3. Doing qualitative research with people with Alzheimer's

We suggest that finding our way (cf. Ingold, 2000) as researchers into the lifeworlds of people with Alzheimer's raises particular kinds of possibilities and challenges for qualitative methods. In qualitative research, the prevailing idea is that questions should be as open-ended as possible but when interviewing people with Alzheimer's open questions risk derailing and closing down the conversation. Another prominent idea is that the qualitative researcher should let the research participant talk as much and as freely as possible, with the researcher saying even less than in everyday conversations (cf. Spradley, 1980). However, people with Alzheimer's need the researcher to be an active participant in the conversation. Filling in and guessing become research tools. These tools cannot be used, though, without the researcher having some prior knowledge of the life of the research participant - of significant people, places and activities in their life - that can be drawn upon to guess and fill in. How much and what kind of prior knowledge the researcher should have about the research participant to make qualified guesses, will vary from person to person. To some degree, ignorance about the research participant's prior life can also be seen as beneficial. Driessen and Ibáñez Martín (2020) have made a similar argument in describing the case of Ms. Jansen, a former vegetarian, who to her family's distress now highly appreciates eating meatballs at the Dutch nursing home, where she resides. The authors raise the important question of how care professionals should attend to this change in preferences: Should Ms. Jansen be cared for as she was, or is now? They write: “sometimes knowing the resident's past may help to provide care and to understand the resident better. Sometimes, it may complicate things instead.” (ibid., 255). In that sense, both knowledge and the lack of knowledge of the person's prior life creates a risk of essentializing the person, keeping him or her in a static form based on the past, instead of the present. Even though the researcher should avoid asking open-ended questions to people with dementia, it is important for the researcher to maintain openness when filling in and guessing.

Being present in everyday life, taking part in social interactions, as well as being patiently present in silences, making room for ruptures, uncertainties, and unfinished stories instead of demanding meaning in any given situation, will all provide the researcher with knowledge about the person with Alzheimer's that can be used when guessing and filling in. Ethnographic descriptions displaying the non-verbal and the silence of the social, could entail an exploration of bodily movements, patient positions, or enacted appreciations, as discussed in the introduction (e.g. Driessen, 2018; Pols, 2005), but also, as we have suggested, of moods of social situations (Gammeltoft, 2018) and the signatures of people (Zoanni, 2018). We furthermore suggest that in addition to presence and ethnographic descriptions, the recording of fragmented conversations can be a useful tool, both in terms of helping the researchers remember conversations in which there is little narrative coherence, and in the researcher's search for emotional logics.

In sum, qualitative research among people with dementia requires being present in the silence of the social, and describing the moods of social encounters and people's signature while also taking part in the dialogic construction of fragile stories by actively filling in and guessing. If we do not do so, we risk further muting people who are already socially marginalized and excluded from research.

Finally, we argue that these methodological considerations are also relevant in relation to other cognitive conditions. While not all cognitive impairments are characterized by a loss of words and sense of time, we hope that researchers can take inspiration from our approach, by making adjustments to ethnographic methods needed to find their into the life-worlds of the people they study.

6. Conclusion

Studies have suggested that people with dementia are silenced and overlooked in research because of their communicative challenges (Herskovits, 1995; McLean, 2006). Sociologist Roma Chatterji proposes that we look at the challenge the other way around: perhaps the lack of voices of people with dementia in research is due to researchers' inability to listen (Chatterji, 1998, p. 357). We have in this article suggested how researchers can become better at listening. By calling the storytelling of people with Alzheimer's fragile, we want to emphasize the obligation of the qualitative researcher to handle it with care, or they risk breaking it. By entering a game of careful guessing combined with careful listening to moments of uncertainty and disconnections, and to emotional and sensorial links, we will be better able to see the contours of the lifeworlds of people with Alzheimer's and at the same time give them a chance to remain part of social interaction and storytelling, thereby upholding a sense of agency and belonging.

Author statement

The first - and corresponding - author is responsible for funding acquisition, project administration, formulation of the research project and for the data collection and data curation.

The second author supervised the first author and took part in the development of research goals and aims and the design of methodology. She occasionally visited the first author in the field and discussed the results and the analysis with her.

Both authors participated on equal terms in the conceptualization, writing, reviewing and editing of the manuscript.

Ethical statement

All procedures of the research project were performed in compliance with relevant laws and institutional guidelines, and has been approved by the appropriate institutional committee(s).

Summary of declaration of interests

Ida Marie Lind Glavind is employed in the Danish Alzheimer Association. The Danish Alzheimer Association has not been involved in the research project's design or development of the submitted article.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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