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In search of epistemic justice. Dialogical reflection of researchers on situated ethics in studies with people living with language and/or cognitive impairment

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A R T I C L E I N F O

Keywords:
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A B S T R A C T

Background: Academics aim to understand the experiences of people living with cognitive and/or language impairment in their search for epistemic justice. Methods that do not rely solely on verbal information (e.g., interviews, focus groups) but also employ an attunement to the non-verbal - such as participant observation and creative methods, are seen as a suitable way to do justice to people's non-verbal interactions. However, in practice, researchers still experience ethical issues in everyday encounters with participants with cognitive and/or language impairment even when trying to address epistemic issues while employing such methods. This article aims to demonstrate 1) the importance of attending to the non-verbal in order to prevent epistemic injustice in research and 2) how a case-study approach and discussing ethical dilemmas with peers may help to unpack some of the ethical tensions that the researchers experience.

Aim and methods: This article focuses on ethical dilemmas the authors encountered during their research projects in the past. Three cases chosen by the authors illustrate these dilemmas. Dilemmas are presented as auto-ethnographical written accounts, which were discussed during ten retrospective dialogical sessions (60–90 min) organized by the research group consisting of six academic researchers.

Results: Ethically sound research, in which older people living with cognitive and/or language impairment are engaged, entails much more than following procedures about informed consent, privacy, submitting a proposal to an ethics committee, and using suitable methods and techniques. Ethical issues in these studies relate to everyday situations in which researchers tried to do justice to the knowledge of people who have difficulties expressing themselves verbally, but were challenged by what they have initially experienced as 'having it wrong,' 'not knowing,' and 'losing something in translation' in their practice. Finally, we learned that the interactions the researchers encountered were complex. They had to constantly evaluate the appropriateness of their approach, balance rational and intuitive forms of interaction and interpretation, and consider ways of communicating the research findings.

Discussion and conclusion: Approximating epistemic justice in research with people with cognitive and/or language impairment requires extra effort in daily research routines. Sharing everyday ethical issues via case stories and reflecting on these issues encourages moral learning and brings new knowledge about the craftsmanship of researchers. Especially the collaborative and dialogical reflection helped the researchers to dig deeper and find words for intangible processes that often remain unaddressed. However, sharing stories about ethical issues requires mutual trust and safety because sharing and reflecting may bring discomfort, messiness, and uncertainty.

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Introduction

People living with cognitive impairment due to brain disorders, such as Alzheimer's disease and related dementias (Gilmore-Bykovskyi et al., 2019; Taylor, DeMers, Vig, & Borson, 2012), or language disorder, for example, aphasia (McMenamin, Tierney, & Macfarlane, 2018; Townend, Brady, & McLaughlan, 2007), are significantly underrepresented in health care research (Prusaczyk, Cherney, Carpenter, & DuBois, 2017). Researchers experience barriers in involving these people because their experiences are difficult to understand (Brooke, 2019; Doody, 2018). Another challenge concerns the methods which are often used in healthcare research. Questionnaires, structured interviews, or focus groups depend on the verbal proficiency of the respondents. They offer little possibility to explore the experiences of people with cognitive and/or language impairment and what is meaningful to them. For example, Joseph Webb and colleagues describe that such a methodology is a 'misfit' with the participant population of people with dementia (Webb, Williams, Gall, & Dowling, 2020). The method of interviews also has its limitations. They rely on abstraction, recall, and verbal reporting (Beuscher & Grando, 2009, cited in Phillipson & Hammond, 2018). Creative methods are a more appropriate way to gain insights into the lifeworld and experiences of older people with cognitive and/or language impairment (Fleetwood-Smith, Tischler, & Robson, 2022; Krøier, McDermott, & Ridder, 2022). These methods are less verbal and rational, do not focus on accurate chronological reconstructions, and try to attune to the state of mind and self-control of people living with cognitive impairment.

A review of arts-based methods in dementia research (Phillipson & Hammond, 2018) demonstrates how researchers use these methods to promote inclusion and create space for self-expression. According to the review, between 2010 and 2018, only four out of the twenty-four identified studies involved older adults with 'severe' or 'late-stage' dementia. The reasons for not including this group in the study were communication and memory problems and difficulties with informed consent. This indicates that procedures, methods, and techniques, including arts-based methods, cannot fill the knowledge gap about experiences of people who have difficulties expressing themselves verbally. The problem is, however, not just a technical one but an ethical conundrum. This implies that better techniques and methods will not solve the problem that we hardly know anything about the life-world experiences of people living with cognitive and/or language impairment, and that they are perceived as not having a voice. As some authors have argued (Young, Lind, Orange, & Savundranayagam, 2019), researchers working with individuals who live with cognitive impairment and/or language issues need to evaluate and revisit their research practice in order to address this issue of epistemic injustice.

Epistemic justice (Fricker, 2007) refers to people's fundamental human right to speak, be heard, and be believed. Epistemic injustice is the "wrong done to an individual specifically in their capacity as a knower" (Fricker, 2007, p. 1). This means that academic researchers and professionals do not have a monopoly on knowledge to define the world, even though much authority is granted to them in our Western culture, where the authors of this paper live and work, because of their professional knowledge, claimed neutrality and objectivity. Moreover, epistemic justice is grounded in a horizontal epistemology (Abma, 2020), meaning that academic knowledge, practical wisdom, experiential expertise, and artistic knowledge are equally valued and complementary in their world representations. We, the authors of this paper, see epistemic justice as a normative and moral horizon of research and the morality we want to keep an eye on in all of what we are and everything we do; our emotions, relationships, interactions, actions, and reflections. As previous studies suggest, we have seen that epistemic justice is not self-evident in the process of doing research (Abma et al., 2022; Abma, Groot, & Widdershoven, 2019; Groot & Abma, 2021; Groot, Haveman, & Abma, 2020; Woelders, Abma, Visser, & Schipper, 2015), and that epistemic injustice in research with people with cognitive and/or language impairing conditions could occur easily.

Researchers often have to deal with 'everyday ethical issues' (Walker, 2007) to approximate epistemic justice. These issues are based on 'situated ethics' (Simons & Usher, 2000). Situated ethics emphasizes that the good always depends - e.g., good care or good research - on the particularities of a given situation, i.e., time, place, person, and culture-specific. These 'everyday ethical issues' could be seen as 'moments that demand moral considerations and ethical choices that arise as part of a researcher's daily practice' (Rossman & Rallis, 2010, p. 379). So, ethical issues are not only the large ethical dilemmas, like euthanasia or abortion in healthcare or fraud in science. In practice, there are also always smaller everyday issues that are ethically charged and require attention from professionals.

Individual and collaborative reflections on everyday ethical issues from the experience of researchers, who may find themselves in a position of power to research participants with cognitive and/or language impairment, is essential. It is in line with the growing attention to the need for reflection on the ethics of the professional research practice and the plea for epistemic injustice (Abma et al., 2017) and the skills and sensitivities of the researcher in how one uses oneself as a knower. This article has two aims. The first one is to highlight the importance of attending to the non-verbal in order to prevent epistemic injustice in research. The second objective is to demonstrate how a case-study approach and a discussion with peers about the ethical dilemmas may help to unpack some of the 'everyday ethical issues' (Walker, 2007) that the researchers experience in the field, especially, but not exclusively, if they are used to rely on "verbal' methods and communication. This article provides a thick description and analysis of three case stories in which ethical issues arose.

Methods

Terminology

In this article, we would like to recognize the personhood of each of the research participants by not labeling them and not reducing them to diagnosis categories but recognizing the complex reality within which their lives unfold. However, we would also like to acknowledge the nuanced relational, epistemological, and ethical context of the research encounters discussed in this study. Thus, throughout the article, we use different terms - 'people living with cognitive impairment,' 'people living with language impairment', and 'people with cognitive and/or language impairment'- in order to highlight that working with each category of impairment may generate different epistemological and ethical challenges in research. We acknowledge that having a language impairment does not necessarily mean that people cannot express themselves or that they lack the capacity to consent. Similarly, cognitive impairment does not necessarily compromise a participant's ability to express themselves, including their capacity to consent. At the same time, having a certain form of cognitive impairment may cause impairment to the person's capacity to express consent even if their language is not impaired.

As will be illustrated by our cases, the ethical challenges faced while conducting fieldwork with participants with language impairment can be similar to dilemmas that often characterize research with those living with cognitive impairment. At first glance, this renders hardly discernible the difference in ethical challenges involved when dealing with different types of impairment. However, an ethnographic encounter, based on a 'deep dive' in and an attunement to people's lived worlds, can help contextualize fine differences. As such, it is particularly helpful in highlighting different ways and the context in which choice is expressed by participants. Paying attention to these subtle differences highlights the value of this study not only for research methods but also for ethically-oriented research practice. Indeed, an open, multisensorial, and flexible approach may prove extremely valuable when assessing, understanding, evaluating, and discerning consent of participants living with a condition that may impair - or appear to impair - their capacity to express choice and consent.

Overview

The purpose of this study is to reflect on everyday ethical issues researchers encounter in their practice with people living with cognitive and/or language impairment. Everyday ethical issues involve more than gaining consent. It involves a set of complex values such as dignity, autonomy, integrity, and well-being that occur daily during the research process. Given the highly complex, contextualized, and relational nature of moral dilemmas in this kind of research, we have opted for a narrative and dialogical methodology. Concretely this means we used case stories to develop an ethical understanding (Banks & Brydon-Miller, 2019). Below, the details are presented.

Method and procedure

The design of this study is based on a combination of (collaborative) auto-ethnographic writing (Chang, Ngunjiri, & Hernandez, 2016; Ellis, Adams, & Bochner, 2011) and ten reflective online group discussions (Lenette et al., 2019; Råheim et al., 2016). The group discussions and writing took place from November 2021 to January 2023. The writing topic was experiences of everyday ethical issues in research projects with people with 'severe' or 'late-stage' dementia,' including aphasia. We elaborated on the nature of the ethical issues, the experience of researchers at those moments, and the effort the researchers made in dealing with these 'ethically important moments' (Guillemin & Gillam, 2004).

We used a participatory process in the reflective discussion and collaborative writing. The participants were all researchers who were asked to share their experiences from completed and ongoing research projects in which they worked with older people who live with cognitive and/or language impairment. We acknowledged the importance of our frames of reference (Abma et al., 2019) in discussing and writing about these issues. All felt responsible for providing a communicative space (Habermas, 1987) in which the participants felt safe, open to transformational learning, and stimulated towards creativity. Transformational learning is based on 'mutual recognition,' 'reciprocal perspective-taking,' and a 'shared willingness to learn from each other' (Abma et al., 2019). In the sessions, participants challenged each other to focus on difficulties they had encountered rather than on narrating the research projects in detail.

The first author invited the participants and moderated the group discussions. We focused on the reflection of stories drawn from a few research projects, see Table 1. These were projects in which four authors were involved, from developing a study design, conducting the fieldwork, data analysis, and publication of the study. All studies were approved by (medical) ethics boards. The participants of the studies were people with a cognitive and/or language impairment, see Table 1. The first author transcribed the audio-recorded meetings. In our analysis, we identified that the concept of 'epistemic justice' (Fricker, 2007) would be most helpful for unpacking this particular set of stories. Epistemic justice is our normative horizon in our research work and a compass to evaluate our practice. The analysis based on epistemic justice allowed for attention to the diversity and variety of reflections of the researchers on each case and the common themes. This concept was a normative horizon to calibrate our work on a scale of goodness.

Table 1

Overview of the empirical research project included in the reflection, including the target group of the study and the authors.

Project	Group of older adults involved	Researcher in the empirical example/ author	References to articles
Study about the remembering process and its meanings in later life	Among others older adults living in a long-term care facility, most often with cognitive impairment and language impairment	Third author	Bendien, Brown, and Reavey (2010); Bendien (2010)
Study about collaborative engagement with an artistic film installation		Second author	Swinnen, Kamphof, Hendrikx, and Hendriks (2022)
Study on the value of aphasia centers for people with acquired brain injury	Older adults living with language impairment	Fourth and final author	Woelders, van der Borg, Schipper, & Abma (2018)

Author-team

The authors of this article are early- ($n = 1$), mid- ($n = 2$), and late-career ($n = 3$) academic researchers. All are women who have conducted qualitative research for the past two to 20 years, among others, with people living with aphasia and/or dementia in the Netherlands. The authors are educated and specialized in several disciplines, i.e., organizational anthropology, cultural science, speech therapy, communication studies, cultural gerontology, applied theater studies, nursing, and medical humanities. All work in the field of health care research. The authors all use a research approach that is normatively grounded (participative action research and responsive evaluation) and is aimed at epistemic justice (Fricker, 2007) for people who are marginalized in society and research. All were colleagues for at least two years, and most have already worked 8–10 years together. Some of us have published on research ethics in our Ph.D. studies (Groot, 2021; Woelders, 2020). For others, this was the first opportunity to reflect on the ethics of a research process. The cases selected in this article were from authors who did not have a supervisor-student relationship.

Results

Below we share three examples of auto-ethnographic writing that describe the ethical dilemmas of researchers, along with the context of the case. Case commentaries of all authors follow every case description. The presentation of case examples follows the empirical cycle: the first deals with data collection, the second with data analysis and interpretation, and the final focuses on translating the non-verbal results into an article for an academic journal.

Case example 1: Feel awakened by a touch or keeping it 'professional'?

The following example addresses a fundamental ethical issue of power play in research where people with cognitive and/or language impairment, who we as researchers choose to work with, may become a simple means to an end; these study subjects help us reach our academic goals. What really happens to these people during the process and what the encounter with the researcher/ intervention can mean to them may become less relevant, which should be considered a serious ethical issue to anybody working with vulnerable groups of people. The research took place in the context of the experiment carried out by the Foundation Humanitas in Rotterdam. This foundation provides living and care centers for people from 0 to 100+, emphasizing dementia care, care for people with somatic care needs, and palliative care. In 2006 the organization engaged in a somewhat unexpected experiment. Humanitas decided to create a Reminiscence Museum in the cellar of its headquarters. The idea was rooted in the notion of reminiscence work, the well-established intervention that stimulates lively recollections from the past based on various stimuli like, for example, old-fashioned objects, but the approach that the organization took was different in terms of scale, procedure, and, as it would become clear later, the impact of the initiative (Bendien et al., 2010). A large space, divided into 14 rooms, had been made available in the cellar of the care facility and filled with old-fashioned paraphernalia, varying in styles and historical periods. One theme united the space: the museum was set up as a home, with an entrance, several bedrooms, a kitchen with three worktops from the 1900s, 1940s, and 1950s, a bathroom, sitting- and dining rooms, and even a small grocery shop from the first half of the 20th century. The museum was supposed to become a place for lively interaction between different generations and where older people could collectively or individually share their memories with each other or with the volunteers. Even before the museum was officially opened, a Ph.D. thesis project commenced with a research question about the meaning of remembering practices in later life. A version of the researcher's (third author) observation that follows has also been used in the Ph.D. manuscript (Bendien, 2010).

> *In the beginning of my work on the Museum project I saw the Museum rather as a therapeutic intervention, especially useful for people with dementia. I did not realize from the start that the remembering process deeply touches the issues of identity and wellbeing and shapes an important part of human interaction and development at any life stage. The museum visitors who came from the psychogeriatric department were patients to me: they lived in the long-term facility under supervision of the nursing team and needed daily physical and medical care. That is why any effects of the Museum on their visits were automatically worded in terms of handling and treatment. That was the period of data collection, and I was fervent about doing it right. At that point I researched the museum; the people who visited were important as means to an end.*
>
> *On the 22nd of November 2006, a couple of months after my project had started, I invited a resident of the long-term care facility to visit the Museum. Mr. Sharp (fictitious name) was 79 years old; he was diagnosed with aphasia and used a wheelchair. I introduced myself and asked him whether he would like to visit the Museum with me. He kind of nodded. I took it for a yes, and we went downstairs. We started the round in the grocery shop. I asked him some questions, and he did his best to remember things and provide the correct answers. His replies were never sentences, mostly one-worded, but the words were the 'right' ones. Initially (at least this is what I thought at that moment), his facial expression did not change very much. I made sure to stand right in front of him while showing things and taking the time for him to work out his answer. We were clearly working on my thesis: I was curious and investigative, actively gathering live material for a book, while my conversational partner seemed to be an isolated person, I thought, within himself and merely complying with the situation. We moved to the sitting room, and he suddenly showed an interest in the music that was playing on the old-fashioned radio. It looked like the recognition struck him. From my side, I was struck by the way the Museum could work. In the kitchen I put an old-fashioned coffee grinder into his hands. He did his best to turn the handle, but it seemed to be too heavy for him. 'Too heavy', I registered… And then he reached out to me and touched my hand.*
>
> *In my experience, Mr. Sharp could not do very much. His touch was what I would call non-intrusive. He did not hold his hand steadily, but moved it softly, which gave me the impression that he was stroking my hand. He smiled in a friendly manner, which in fact looked encouraging. At that moment, I did not realize what had happened, but everything had changed from one moment to the next. I started looking at his face twice as often, in order to follow his gaze and anticipate what he was recognizing. It dawned on me that he was not at all silent, as I had been thinking only moments before. His eyes, his expression, and the subtle motion of his lips, everything in his posture was talking to me all the time. But I had not seen that at first, since I had been busy with my research agenda. I followed his gaze and pushed his chair to an old bakelite telephone. When I put the heavy receiver in his hands, he looked almost delighted. He touched the sturdy object, and I saw this stroking motion again. We moved on, and his look stopped me at the school corner. I took one of the old copybooks, and anticipating his desire, I placed it into his hands. He held on to the copybook tightly, constantly touching and stroking the old object, with a shadow of a smile lightening his face. It took quite some time before I felt we could move on again. The next stop he wished to make, which he made clear to me somehow, was in front of the wardrobe in the bedroom. Once again, I followed his gaze and took a stiff shirt collar from the shelf. That time he not only tried to show how you closed it but also reached in the direction of his neck, where he wanted it to be placed. He did the showing while I did the talking. We were a team. We were conversing.*
>
> *Finally, it was time for us to return to our daily lives. We were waiting together in front of the lift, when he retook my hand, brought it to his face, and let it lie on his cheek for some time. I thought he was saying thank you by softly stroking my hand, and I, armed with all communicative power of language, did not know better than to stroke him back and hold him tight.*

Case commentary of all authors

The essence of all commentaries related to this case is the notion of revelation followed by transition of doing 'good' research. Each of the authors reflected on the temporal character of the case with its culminating moment of self-reflection experienced by the researcher. Researchers used different terms for this critical moment: 'an apparent twist,' 'letting go and claiming space to notice another person,' or 'a disruption of self-centeredness,' the notion inspired by Levinas (1987).

Another uniting element in all comments was the transition that the researcher undergoes herself. She had first acted according to the script based on power relations in which she was the principal knower. However, eventually, she found a more 'relational and horizontal' way of mutual action, which went 'beyond the verbal.' This meant 'leaving your comfort zone,' allowing 'wonder and emotional connection' to guide you through the research process.

Finally, the comments referenced the 'moral appeal' to not 'use another person in your investigation' but follow 'humanity and compassion'-principles instead. This last idea reveals that the correct way of doing research (following procedures) can also become the wrong way concerning epistemic justice. Some researchers pursue their academic goals without taking into consideration whether their research did any good to people they have encountered and whose behavior they have observed. They are usually asked by medical ethical commissions only about harm. They should use self-reflectivity more often and thoroughly scrutinize their work and learn from it.

Case example 2: Breaking the intimacy and togetherness, or not?

As a researcher, the second author was involved in the project 'Beyond Autonomy and Language: Towards a Disability Studies Perspective on Dementia'. We studied innovative artistic and technological practices in and outside dementia care, including poetry, visual arts, theater, and clowning. We felt it was crucial to include people living with dementia as co-producers of knowledge in our project as well as to bring their abilities to the attention of society at large. In the last part of the project, we collaborated with the Limburgs Museum, whose ambition was to bring their special collection of amateur films on the region's history and culture to vulnerable older people living in residential care facilities. With filmmaker Joel Rabijns, we developed three films based on the archive material of the Museum, with the purpose of showing them on three psychogeriatric wards of a residential care facility. The gained insights in our study served as input for the selection of the footage and the editing choices. Instead of focusing on reminiscence, we wanted to appeal to people's imagination. We aimed to support residents living with dementia in their personhood by sharing images that they might be able to relate to enjoyably and nurture their senses and receptivity. We also wanted to learn about the value of this type of arts intervention from the engagement of participants during the film sessions (Swinnen et al., 2022).

The films were shown in three psychogeriatric wards of a residential care facility. We did ethnographic research by participatory observation to study how people engaged with the film screenings. There were seven sessions in total (2.00–4.00 pm). The set-up in each ward was in a separate half-open room in the hallway, visible from three adjacent corridors. Parts of the space were shaded off. In one window, a screen was installed, which closed off one side of the room, creating a space of intimacy, according to researchers, in the passage of the ward. The residents were free to come to 'the space.' They could walk in and out. Residents in wheelchairs were approached about whether they wanted to go there. Family and caregivers were walking with residents (with or without wheelchairs) in the corridor so that they could see the film screen/film set. We, the researchers, invited them verbally and with hand gestures. They were free to enjoy. Here follows the filed note of the researcher on one of such visits:

> It is 4 o'clock, [time to stop the screening, agreed with the staff of the residential care].
>
> *There are still two ladies sitting there, in a wheelchair. They have been sitting quietly for some time now, watching the movie screen. I notice no verbal or non-verbal responses to the film images. We just sit together. I experience a 'cozy' atmosphere in the corner. Do they feel the same? I get up and ask the ladies if I could stop the movie. They nod. I hesitate. Have they understood what I asked? Stopping the picture feels like I am taking something away from them. I postpone it.*
>
> *I sit down next to them again and after a while I begin to chat about the footage. Maybe there will be a response, on which I can experience whether they still enjoy watching. There is hardly any reaction. I hesitate to turn off the projector as long as they have their gazes fixed on the projection screen. Earlier, a caregiver said she would come and get the ladies. What am I going to do? Shall I wait until they are fetched, or shall I share with them the 'dismantling' of the film setting and the breaking of the intimate atmosphere? I stay with them for a while. I try to let go of the film images and my reactions to them, and just try to be there in the moment. Quietly the images move in the quiet togetherness.*
>
> *After a while, it's a quarter past four, I take the initiative to stop the image and to take down the canvas. I feel like I am forcing them to look at it. Both ladies remain seated in the same position and watch my movements. I feel uncomfortable. What's on their mind? There didn't seem to be any change. They seem to be resigned. Breaking off the film cloth changes the light, brings in the 'outside world,' and the feeling of being enclosed disappears. I experience very strongly how the atmosphere of togetherness and intimacy is broken. Do I sense this feeling in the look and attitude of the ladies? Do I see a little change in their look? Does this 'dismantling' also bring a 'back to reality' feeling to them?*

Case commentary of all authors

All commentaries related to this case focused on the difficulty of knowing or understanding the other person. For example, comments used terms such as 'no relational alignment,' 'relational uncertainty,' and 'that you cannot know the other person.' The comments raised questions such as: 'When can there be danger of understanding the other in terms of 'appropriating the other person''?

Another element in all comments was the focus on uncertainty. The questions were: 'What is good?' 'What consequence does your choice have for these people?' Are we as researchers sometimes allowed to trust our feelings, or does this potentially harm the participants?' The research team members questioned the focus on 'allowing not-knowing' and 'embracing and letting go of your questions and expectations' and being able to be with people 'in the moment' during research.

In the comments, there was also a focus on reflections on doubt. Questions arose: 'How to deal with reflecting on your choice, with uncertainty about the power balance in the situation?' and 'What does it mean, as an ethnographic researcher, to interfere in decisions?' 'Are you guided by reason or feelings/intuition?' This last question, in particular, led to friction and insight that ethical issues occur precisely in this intermediate area. For the author, doubt gave direction to search 'what is good to do.' The researcher's main concern was that she could never be sure how to interpret the behavior and expressions of the participants. Researchers use all their senses to perceive a person's behavior and mood. Then their cognition reflects on the experience on a sensory level and articulates it in words. So a researcher combines experience and reason, but one can be left in the dark about perceptions and interpretations. Validating one's own interpretations as usual with a member check is not possible.

Case example 3: Translating the unsayable into words or searching for other means of expression?

In one of our studies, we (the third and final author) and our research team wanted to understand the value and meaning of care and support in aphasia centers from the perspectives of people with aphasia and their relatives. What does the support of the center mean to them? How does it help people with aphasia to increase participation? How does it help to lead a meaningful life? This case provoked many questions for the researchers. How to understand people's experiences when they cannot verbally express themselves? What about informed consent? And how to do a member check to check whether they agree with our interpretations of what they bring up? How to connect with them and open up for their experiential knowledge while meeting the classic guidelines and procedures in the academic context? It was apparent that we had to find creative ways to do our research and some courage just to do it and learn along the way and learn in everyday practice. The fourth author wrote down her fieldnotes:

> *Up to this day, I cannot find the words to express my feeling of being in the aphasia centers. My colleagues and I felt very connected to the people with aphasia we met. We tried to communicate with them, although we could not rely on verbal expressions, like we used to do. It seemed paradoxical, but without words, we felt more connected. Relating to each other seemed more intense. Maybe this can be expressed by this poem by a person with aphasia that I read during the study in one of the magazines from the patient organization:*
>
> *Even though the words were hidden*
>
> *The heart spoke*
>
> *Although the words were hidden*
>
> *The eyes said*
>
> *Words were hidden*
>
> *It reacted*
>
> *The words*
>
> *I saw all of you:*
>
> *The eyes, the skin, the touches,*
>
> *It said enough, and so much more.*
>
> *We experienced that we needed to use other approaches and methods to know about the experiences of people with aphasia. We had to use non-verbal ways of expression. We tried creative forms, like for example making bricolages, about the question what the aphasia center means to them, we tried to communicate in non-verbal ways, and used our bodies and our eyes.*
>
> *But how do these ways of working fit in the academic context? How could I write an academic article and publish this work in an medically oriented journal while doing justice to the knowledge of people who could not express themselves verbally? How could I present the expressions of*

> *people with aphasia without (a lot of) words? Can knowledge be 'valuable' when it is not tangible? Is knowledge less valuable when it cannot be expressed verbally? For example, within the framework of the medical science journal to which I decided to submit our manuscript did not allow us to present photographs of a bricolage that expressed the experiences and the meaning of the provided care in the aphasia center for people with aphasia. The framework only allowed textual expressions founded in rational logic and definitions, numbers and tables. But how to present a feeling or an experience that is not measurable? That cannot be easily expressed in a verbal way? I felt like I had to make a lot of effort to make our work 'fitting' into the academic system. So I had to meander between the formal procedures within our research (like the quality guidelines for member check and the required medical information about respondents) without denying or undervaluing them, and the urge to bring in other than textual accounts and information. I strongly felt that the issues mentioned above should be reflected on. And I felt an urge to share what we learned during our study about the experiences of people with aphasia. It enriched our understanding of what was happening in a more profound way than the academic paper can do. I tried to stretch the boundaries of this framework, driven by the wish to bring in experiential knowledge from the perspectives of people with aphasia themselves. Therefore I argued openly about these issues with the reviewers. In fact, I raised the ethical questions regarding the common procedures and the framework. Not by denying them or the importance of it, but by bringing up questions in relation to epistemic justice. In the end, we could upload one of the photos as an appendix. Unfortunately, in the published digital version only the subtitle of the photo can be seen, not the photo itself.*

Case commentary of all authors

Most commentaries focused on the almost activist act of this researcher who decides to present non-verbal data in a bio-medical journal as a move towards epistemic justice. Her action was described as an 'act of resistance', a 'fight' in which she 'stands for the meaningful ways of interacting with people with aphasia' and even puts 'something on the line for it'. One of the commentaries referred to Foucault's parrhesia or free speech (1983) in this case. Parrhesia means 'boldness, truth-telling or free speech' and is about discourse and truth. With this notion of parrhesia, Foucault (1983) raises important questions: 'Who is capable of telling the truth? What are the moral, ethical, and spiritual conditions that give someone the right to present himself as, and be considered as, a truth-teller? On what topics is it important to tell the truth?' Parrhesia thus connects questions about knowledge, truth, power, and morality. Parrhesia is a way of raising an issue of social or epistemic injustice (Abma & Woelders, 2023), as in this case.

Another essential note in the commentaries was how we, as researchers, are involved in the process of losing meaning in translation. Researchers play an active role in translating the non-verbal interaction they encounter into the academic text they want to publish. The researchers' agenda and positionality play a role in this process. Can one justify this loss, or is it preferable to allow your peer researchers to help and therefore influence this decision?

It is also worth pointing out that two of the commentaries also referred to professionalism in their comments. This raises the question: what is academic professionalism in relation to other ways of knowing, like, for example, less clear-cut, messy, embodied, and experiential knowledge? One comment discussed the importance of the value of the humanistic approach in this case.

Discussion

An important result of our collaboration is that our dialogical reflection on the presented cases is an ongoing process, which does not end with the publication of this article. Each time our research team came together, we challenged ourselves and each other with new questions in search for ways to do epistemic justice to the people with whom we do our research. In reference to the three cases, the dialogical reflection sessions allowed us to identify several aspects of conducting research with people with cognitive and/or language impairment for which we were not fully prepared when we embarked on each of the respective research projects but which can be considered crucial for achieving epistemic justice. As bearers of professional knowledge and experience, we began our studies intending to do 'good work.' We understood 'good work' as following research procedures, being attentive to the wishes of the people we worked with, and sharing our findings through publications. However, through group conversations during which the ethical conundrums related to each case study were foregrounded, we learned that at various stages of our projects, we struggled with feelings of 'having it wrong,' 'not knowing,' and 'losing something in translation' in our practice. These feelings occurred after experiencing dilemmas around the 'cognitive vs. intuitive,' 'right vs. wrong,' and 'language vs. other sensorial ways of communication.' See Fig. 1 for the summary of the meta-analysis of the commentaries on the three case studies.

We learned that to search for epistemic justice, each of the researchers had to acknowledge the complex interactions they encountered and therefore had to reflect on the appropriateness of their original approach, balance rational and intuitive forms of interaction and interpretation and evaluate ways of communicating the research findings. As researchers, we need to allow for getting it wrong. Acknowledging uncertainty about losing something in translation and fallibility, including on a moral level, is essential. It allows to acknowledge that researchers are not 'above' research participants, including in the contexts where researchers are often considered experts or authority. Moreover, another person may hold different values than a researcher, and the latter has to consider that in research work.

The analysis of the dialogic sessions revealed the uncertainty of the researcher's position associated with her work, especially where it involved research with people with cognitive and/or language impairment. We also demonstrated that using a participatory way of working with colleagues as critical friends may help in doing 'good work' in this field.

Conclusion

In search for epistemic justice

The cases in this study highlight the ethical challenges related to the use of non-verbal ways of communication in research that involves individuals with cognitive and/or language impairment. It demonstrates that research approaches that foreground non-verbal communication (as an object of study, methodology, or way of presenting research output) are not deprived of ethical ambiguities. These everyday ethical issues are inevitable and cannot always be fixed. All the ethical issues in this study were not foreseen or addressed by the checklists of the Institutional Review Board. We learned that to diminish epistemic injustice, researchers working with people with cognitive and/or language impairment need to evaluate the appropriateness of research approaches like Webb and colleagues already stated (Webb et al., 2020). Webb and colleagues plea about a misfit and seek more creative methods. However, moral uncertainty and dilemmas can remain or can even become more tangible when someone cannot speak according to the norms within the academy and culture, e.g., cannot speak coherently, when words have no direct relation to intentions, and/or there is cognitive impairment. In those situations, academics become aware that the relationship between knowing, cognition, language, and communication is very complex. This study shared examples of typical situations in which reflection was helpful to highlight the importance of attending to the non-verbal to prevent epistemic injustice in research. Our search for attunement to each other, as a person and researchers brought us uncertainty if we could 'hear' and 'interpret' the findings of these people.

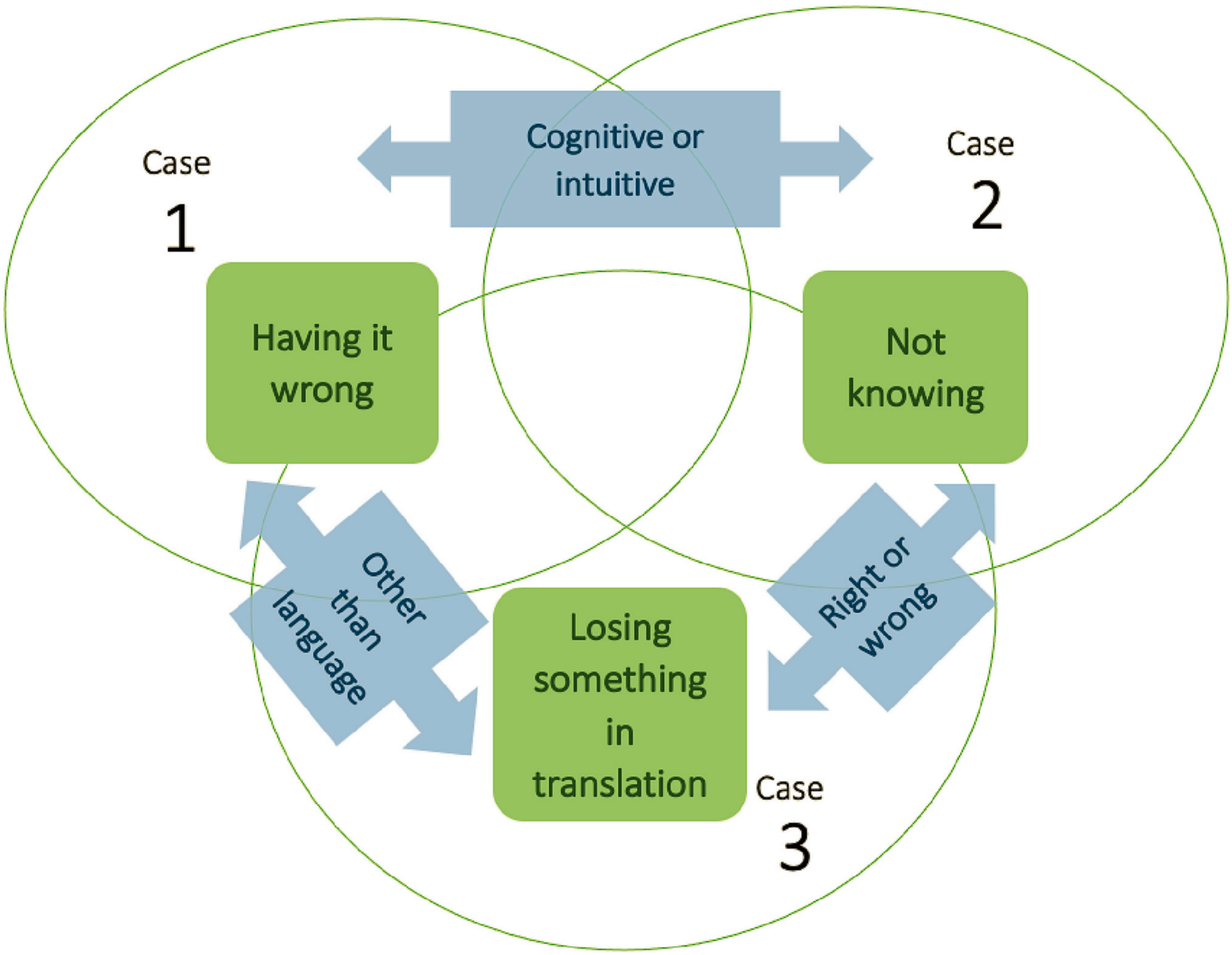

Fig. 1. Summary of the meta-analysis of the three case studies.

So, not only creative methods but also a dialogue among ourselves, is a pathway for epistemic justice. Dialogue among researchers can enhance awareness and a moral learning process (Woelders, 2020). This focuses on balancing rational and intuitive forms of interaction and interpretation and evaluating how to communicate the research findings.

Being aware of everyday ethics in research resonates with Rossman and Rallis (2011), who argue that the focus on procedures in research comes at the expense of a full engagement with the ethical and relational aspects of research with people, especially those living in vulnerable circumstances. These authors describe that this focus is a convenient misapplication of the technical use of the methodology. They underscore the importance of researchers being moral practitioners and reflecting on everyday ethical issues. Based on this study, we not only question the focus of researchers on methodology of data collection but also on the way we share our knowledge. Dealing with everyday ethics asks for dialogical ethical reflection on epistemic justice in all stages of the study.

Space for dialogical ethical reflection

The three cases in the study suggested that academic researchers could benefit from working with colleagues, creative professionals, and arts-based methods. The assumption that people who participate in research can express themselves through their voice and language does not hold in this context; researchers must go beyond verbal communication to fulfill their commitment to epistemic justice (Young et al., 2019). It is crucial for researchers to be aware that there are also different ways of gathering or generating knowledge besides the verbal way. These different ways could also be valuable in gaining insights into people's experiences. It is valuable to use embodied and creative research approaches that incorporate all the senses (sound, vision, touch, smell, proprioception) or work with artists who have acquired these competencies during their professional training. It could open a new perspective on interaction with people with cognitive and/or language impairment. Working together in research also brings 'investigator triangulation' (Frambach, van der Vleuten, & Durning, 2013), not only in the sense that two or more people see and interpret 'better' but see and interpret differently. It sheds light on the skills and sensitivities of the researchers and demonstrates that some issues are complex – or perhaps even impossible – to make sense of. We argue that it is essential to think about the composition of the team that is equipped in the best way to conduct a study with people with cognitive impairing conditions, both in terms of competencies and their training. Especially a team with diverse competencies could stimulate a creative research process: the more perspectives there are, the more methods and insights can be generated. Especially if there is a dialogue between these different insights, it can be valuable for approximating epistemic justice.

Sharing everyday ethical issues via case stories and reflecting on these issues individually and collectively can encourage moral learning and bring new knowledge about the craftmanship of researchers. Especially the dialogical reflection in this study helped the researchers to dig deeper and find words for intangible processes that often remain unaddressed. Several authors have already recognized the value of the case study approach in discussing research ethics (Banks & Brydon-Miller, 2019; Brightman & Grotti, 2019; Pels, 1999). However, this study showed the value of the dialogical reflection between the authors of the cases and other colleagues. This case study approach is rarely applied in dementia research.

We recommend creating more space (in budget and time) for reflection on ethical issues and their complexity to prevent epistemic injustice of, among others, the group of people with cognitive and/or language impairment. Working ethically means making space for 'not-knowing,' 'discomfort,' 'emotions,' 'relationships,' and 'affective embodied signals.' Only then you can create space for reflection on moral challenges in research. This includes the freedom to speak up and the courage to create open spaces for the knowledge of people in the margins (Woelders, 2020). Researchers must dare to reflect, for example, on their role and position in the academic world, question existing frameworks, and whose knowledge is excluded, how and at what stage of the research cycle this happens, for example, the pathic knowledge (Van Manen, 2016) of the other person not speaking or struggling to articulate things clearly. This can be challenging. We noticed the value of discussing these topics first with a group of senior researchers without hierarchical academic relations. From there, discussing these topics with our PhDs is also easier. Being an example for them is an essential step because it shows that being open and vulnerable is also a part of academic work with a strive for epistemic justice. However, most importantly, the researchers should try and create spaces for an open debate and exchange within their own professional communities where such a conversation may take place regularly.

In this study, we experienced the value of dialogic reflections in sharing our stories about ethical issues. It required mutual trust and safety because sharing and reflecting may bring discomfort, messiness, and uncertainty. We propose focusing more on professionals' personal development and moral sensitivity through reflections and peer dialogue. Ethics collectives, for example, this ad-hoc group, but also the more structurally embedded group like the Ethics Group of the International Collaboration of Participatory Health Research (ICPHR) and the Ethics Collective of AgeNet (AgeNet, 2021), are helpful for reflection and dialogue with peers. Sharing dilemmas and exchanging perspectives support researchers in their ethical professionalism.

Limitations

Dutch researchers conducted this study in their national research context. Furthermore, the approach of this study emerged as we went along. In retrospect, we would have liked to go into more depth with each other. For instance, by creating a physical, communicative space to analyze the cases face-to-face with each other, perhaps also using arts-based methods. Finally, we would have liked to do this study not only with the researchers involved but also with someone from medical ethical review boards and perhaps from the patients' association. This heterogeneity in the participants of the dialogical reflections could have deepened the dialogic reflections.

Declaration of Competing Interest

No potential competing interest was reported by the authors.

Data availability

Data will be made available on request.

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