



Rethinking participation and knowledge: Reflections on qualitative research in technology development for dementia care

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ABSTRACT

The past two decades have seen an intensification of research and development in assistive technologies for people living with dementia. While many of these projects emphasize inclusion, participation often takes place under restrictive conditions: through structured evaluations, usability testing, or proxy-based design feedback. This paper argues that such frameworks limit what kinds of knowledge are recognized as valid and what forms of expression are rendered legible. Drawing on multi-site participatory research projects, the author reflects on moments in which inherited benchmarks of coherence, reliability, and evidence strain against the realities of the field. In these spaces of epistemic friction, where memory fragments, timelines collapse, silences carry meaning, names shift, or questions fail to land, what emerges is not less knowledge but knowledge of another kind. These claims are illustrated through four scenes of epistemic friction drawn from the author's fieldwork. The paper develops a methodology of shared presence: a research stance grounded in attunement and epistemic reciprocity, valuing responsiveness over analytic control and relation over extraction. By treating repetition, silence, ambiguity, and reframing as epistemic resources, this orientation contributes to the rethinking of qualitative inquiry in technology development for dementia care. It also addresses technology development more directly, arguing that when such forms of knowledge are ignored, the results are often technically sophisticated but socially unanchored unusable products. The article thus speaks to broader debates about voice, vulnerability, and epistemic responsibility in the context of health, care, and innovation.

1. Introduction: when knowledge doesn't fit

The past two decades have seen an explosion of research and development in the field of assistive technologies for people living with dementia. These projects are driven by promises of safety, autonomy, dignity, and independence (Bharucha et al., 2009; Ienca et al., 2017; van der Roest et al., 2017). From GPS tracking devices to ambient assisted living systems and socially assistive robots, technologies are envisioned as solutions to the complex challenges posed by demographic change, workforce shortages, and increasing care demands. Policy initiatives and funding programs at both national and European levels have reinforced this trend by encouraging innovation geared toward “aging in place” and the reduction of institutional care (Töpfer, 2016; Daly Lynn, Hynes, & Cullinan, 2019; Federal Ministry of Education and Research, 2015).

My concern is not technology as such, but the logics of research and participation that accompany it. Participation, framed within development timelines and usability criteria, determines which voices are heard and which are silenced. These project logics intersect with common cultural imaginaries of dementia and with the practical demands of

research settings, further narrowing what counts as useable input.

What many of these projects share, however, is not only a commitment to technological development but a particular logic of participation. People with dementia are increasingly expected to be ‘included’, but primarily in ways that align with the timelines and structures of development (e.g. Cole, 2006; Brankaert & den Ouden, 2013; Hendriks et al., 2015; Orpwood et al., 2007). Inclusion often means usability testing, interviews about product design, or assessments of acceptability and feasibility. Those who do not or no longer conform to these models of articulate engagement are quietly filtered out (Bartlett, 2012; Suijkerbuijk et al., 2019). Their voices are replaced by proxy accounts from caregivers, professionals, or designers, and the resulting knowledge base remains narrowly framed by what fits into the affordances of the project structure.

In this sense, participation is not simply involvement, but a form of selection: privileging those who can deliver articulate, linear accounts, while sidelining those whose contributions appear fragmented, affective, nonverbal, or – in our view as researchers – inconsistent; memories that shift from one day to another, or that hold affective truth even when

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they contradict factual accuracy. This selective participation shapes what is recognized as knowledge and what is silently excluded. The exclusions that result from these selective forms of participation are not only social but epistemic, shaping what can appear as valid knowledge and what remains illegible.

These exclusions are rarely acknowledged. They are structural, embedded in assumptions about what counts as useable knowledge and whose expressions are recognized as meaningful. In more than ten years of my own fieldwork, their effects became tangible in several technology development projects between 2014 and 2025, including “JuBot” (2021–2025), “QuartrBack” (2015–2018), “Movemenz” (2014–2015), as well as “Compatibility of technology and networks in home care” (2014). My role included ethnographic observation, the facilitation of co-design sessions, focus groups, and narrative interviews with more than thirty people living with dementia, alongside additional interviews and discussions with caregivers, professionals, and other stakeholders. The vignettes discussed in this paper are grounded in contemporaneous fieldnotes and analytic memos, as well as in qualitative content analysis of audio recordings from these engagements (see e.g., Krings & Weinberger, 2025; Weinberger et al., 2025; Weinberger et al., 2021; Krings & Weinberger, 2018; Weinberger et al., 2018; Krings & Weinberger, 2017; Decker et al., 2017; Weinberger et al., 2016). The issue was not only whether people with dementia could be involved in technology development or in participatory technology assessment. The deeper issue was how our research methods rendered certain forms of presence, incoherent speech, affective intensity, and looping narratives illegible as epistemic contributions.

One moment in particular stayed with me. “I have a younger sister ... How old is she?” The woman I am interviewing pauses, searching for a detail that seems to retreat as she reaches for it. I know her sister has passed away, her husband had mentioned it earlier, but for a brief moment, this fact is suspended. What follows is not silence but a stream of associations: about friendship, drinking, cigarettes, and the habits of someone who is, in that moment, still vividly present: “She had a big circle of friends, they liked to drink. Smoked too. Or ... *does she still smoke?*” She nods, then continues.¹

This was not an isolated moment. In my research, I encountered many such instances. Narratives looped and contradicted themselves; memories surfaced with affective clarity only to dissolve a few seconds later. Facts shifted. Timelines disintegrated. Yet these conversations were not devoid of meaning. On the contrary, they were saturated with emotional coherence, relational nuance, and the effort to hold on, to something, to someone, to self.

This paper begins with a simple provocation: What if we are asking the wrong kinds of questions about validity, evidence, and knowledge in technology development for dementia care? Rather than treating cognitive instability as a methodological problem to be managed, I suggest we take it seriously as an epistemic condition, a mode of knowing that is partial, shifting, and deeply situated. This article emerges from my ongoing engagement with the limits of inclusion and the silence around what cannot be readily translated into useable input. It is not a critique of technology or technology development in dementia care per se, but of the research logic that marginalizes the forms of knowing dementia brings into view. This stance is not neutral. It carries commitments to openness, to co-presence, to resonance as a mode of knowledge, and to solidarity over extractive clarity.

Building on other empirical studies that have reimaged interviews with people with dementia not as sites for extracting facts but as spaces for co-presence, improvisation, and shared sense-making (Angus & Bowen, 2011; Barnett, 2000; Hydén, 2018; Köhler et al., 2024), this article proposes a methodological reorientation. I call this a *methodology of shared presence*, in which meaning arises not from clarity but from

resonance, and where knowledge is not retrieved but formed in relation.

Rather than a conventional paper with separate methods and results, this article is written as a methodological reflection. It interweaves empirical vignettes with conceptual analysis to explore how dementia opens up the logics of participation and knowledge production.

In what follows, the article moves through several stages. I begin by situating dementia research within broader debates on participation and technology, highlighting how dominant logics of inclusion constrain what kinds of knowledge are recognized. I then turn to the epistemological assumptions of qualitative research and show how they create subtle exclusions when working with people living with dementia. From here, I present a series of empirical scenes – fragments from interviews, observations, and shared moments – that illustrate how knowledge emerges otherwise: through looping narratives, silences, gestures, and atmospheres. Drawing on these scenes, I elaborate the idea of epistemic friction and argue for a methodology of shared presence as an alternative orientation. Finally, I return to the questions of participation in technology development projects to suggest what this reorientation might mean for dementia research and for qualitative inquiry more broadly.

2. Methodological struggles: the epistemological frame of qualitative research

Qualitative research is often framed as a corrective to the objectivist claims of positivist science. It values subjectivity, attends to lived experience, and is methodologically open to complexity. Yet even within this openness, certain tacit expectations continue to shape practice, particularly in projects aiming to develop technologies for people with dementia. These are not formal criteria codified in qualitative methodology, but background norms that guide what is often recognized as meaningful data.

Coherence, credibility, and reliability often function as such tacit benchmarks in practice, even if they are not official pillars of qualitative inquiry (Charmaz, 2006; Seale, 1999). Narrative consistency, in particular, holds powerful sway. Interviews and focus groups are commonly evaluated in terms of how well they ‘hold together’, whether they follow a temporal sequence, stay internally coherent, and offer interpretable accounts of lived experience. This standard, while rarely made explicit, shapes how qualitative data are collected, interpreted, and ultimately validated. As Mason (2002) and Charmaz (2006) have noted, researchers often engage in subtle acts of narrative smoothing, reordering or editing participants’ accounts in ways that preserve a sense of epistemic order. These are not merely methodological routines; they carry ethical weight because they delimit in advance whose ways of speaking risk being silenced.

Beneath these practices lie enduring assumptions about how knowledge is produced: that memory can be retrieved, identity can be narrated, and meaning exists in stable, extractable forms. In technology development for dementia care, such assumptions have tangible consequences. Participants are often selected based on their capacity to reflect, recall, and express themselves in ways that align with normative standards of coherence (Bartlett, 2012). Those whose speech is marked by fragmentation, repetition, or confusion are often excluded altogether or replaced by caregiver or proxy accounts (see e.g., Daly Lynn, Rondón-Sulbarán, et al., 2019; Megges et al., 2017). As Brankaert (2016, p. 100) noted: “Attempts in the literature to design by involving people with dementia are marginally successful. Instead, the technology is often only discussed with the informal or professional caregivers”. This reliance on caregiver or proxy-stand-ins further reinforces the assumption that contributions by people with dementia are either unreliable or unusable, not epistemically significant in their own right. Even explicitly narrative approaches intended to open space for subjectivity tend to favor linearity and internal logic. As Angus and Bowen (2011) observe, the prevailing model is still a narrative arc that begins, develops, and concludes: an expectation that leaves little room for discontinuity or

¹ This scene based on interview material collected as part of my doctoral research (data yet unpublished, 2015).

looping. Alternatives exist, but they are seldom taken up. Hydén (2014), for example, has proposed the concept of “collaborative narration”, emphasizing how stories may be co-constructed through affective cues, shared rhythms, and relational scaffolding. Such approaches challenge the privileging of cognitive autonomy and invite a more situated understanding of meaning-making, yet they continue to be treated as exceptions rather than common practice.

The consequences of these methodological preferences are not only technical but ethical. They contribute to what Miranda Fricker (2007) describes as epistemic injustice: a structural devaluation of certain forms of speech, particularly when those forms do not align with dominant norms of intelligibility. In technology development for dementia care, this can mean that persons living with dementia are not simply under-represented: they are systematically disqualified from being seen as knowers.

Instead of asking how to ‘speak for’ people with dementia, the question becomes how to recognize the knowledge they already offer; knowledge that may be affective, partial, nonlinear, or fleeting. Process-consent models, as developed in participatory dementia research, have shown that capacity and engagement can fluctuate and that ethical research practice must be equally flexible (Dewing, 2002). What matters is not stable consent in the abstract but attunement to how people choose to be present in the moment. A similar reframing is needed epistemologically. As Nancy Tuana (2006) argues, dominant knowledge systems do not simply ignore certain voices; they actively produce ignorance by failing to develop categories adequate to recognize what falls outside dominant frames of intelligibility. In the context of technology development for dementia care, this means missing knowledge that is neither abstract nor discursive, but embodied, situated, and shared. To take such knowledge seriously requires more than new techniques. It demands a methodological stance oriented toward presence and resonance, one that values partiality and momentary coherence as epistemically significant.

3. Dementia as an epistemic borderland: rethinking knowledge in qualitative research

What does it mean to speak of ‘knowing’ under conditions of forgetting? In researching with people living with dementia, I quickly learned that knowledge does not disappear when memory falters. It changes form. As recent interdisciplinary research confirms, knowledge in dementia is not simply lost, but reconfigured. It persists through emotional resonance, bodily memory, and socially mediated processes (Fuchs, 1995; Meier zu Verl, 2024; Meyer, 2014; Verl, 2024). Instead of remaining a purely cognitive asset, knowledge takes shape through gestures, rhythms, affective alignment, and environmental cues. Much of what is traditionally labeled as confusion or incoherence could be reframed as ‘narrative creativity’. Stories that double back, shift temporality, or merge people and places are often rich with emotional truth, even when they diverge from factual events or chronological order. In these accounts, temporal and factual coherence may collapse or spiral, but what persists is the effort to make something intelligible in the moment. As Hydén (2011, 2013, 2018) has argued, the focus should not be on narrative coherence, but on narrative performance, on what the act of storytelling does relationally, even when it departs from expected structures.

These performances are often collaborative. In all of my interviews, meaning did not arise from what a person said alone but from how their words interacted with my presence, with long pauses, with their spouse’s interjections, or even with the surrounding silence. Hydén’s concept of “narrative collaboration” (2011) aligns with findings from Meyer (2014), who describes how conversation partners in dementia care routinely take on responsibility for co-constructing meaning, compensating for memory gaps while sustaining the interactional flow. Knowledge, in these encounters, is not transmitted – it is co-produced. This co-production is not only verbal. As dementia progresses, people

often turn toward more bodily-affective forms of communication, such as gestures, facial expressions, or simple physical routines. Recent studies emphasize the increasing role of “embodied knowledge” in sustaining identity and orientation, particularly in care settings, where singing, dancing, or touch-based interactions become meaningful forms of exchange (Meier zu Verl, 2024; Bennett et al., 2019). This borderland, marked by shifting forms of orientation and expression, is also where epistemic frictions become most tangible. Such encounters also resonate with what Law and Ruppert (2016, p. 268) have described as baroque modes of knowing; modes that embrace multiplicity, sensory richness, and nonlinearity, and that resist reduction to linear or singular accounts. In my fieldwork, such dynamics became tangible. One encounter illustrates how such forms of knowing become visible, quietly, affectively, and through the choreography of place and repetition:

When I ask Susanne Berthold² about her daily routines, she points to the door. “There,” she says. “That’s where I know what to do.” I follow her gaze and see a cluster of handwritten notes pinned to the inside of the flat door. Some in shaky script, some crossed out, others newly added. “Sometimes I forget”, she says after a pause, “but I always check before I go.” She touches her chest lightly. “I just need to feel that I know it.”³

I recall this moment not because it revealed a fact but because it illuminated a way of organizing the world relationally and somatically. There was no linear timeline, no narrative reconstruction of morning routines. Instead, there was presence, gesture, repetition, and affect. The door became a site of orientation not only in space but in knowledge. What mattered was not remembering as recall but as ‘re-grounding’, as the capacity to re-enter meaning through place, movement, and habit.

A different encounter with Anna Fröhling, a former professional photographer, underlines another facet of this epistemic borderland:

She welcomed me warmly into her apartment in an assisted living facility and, before we began, thanked me for the chance to participate: “I am so glad I can talk about my experiences. It means a lot to me that you want to hear them.” She spoke with great energy, sometimes looping back or drifting into digressions, sometimes pausing as words escaped her. What emerged was not confusion, but a powerful sense of what mattered most to her: independence, dignity, and the refusal to be reduced to a “Heimkandidat” [author’s note: nursing home ‘candidate’]. When she described how she could no longer manage her camera after forty years of practice – “I once forgot how to even switch it on. This illness takes everything from you” – the grief was palpable, but so was her insistence on being recognized as someone whose voice still counted. Meaning here was not carried by narrative order but by affective insistence, by tone, gesture, and the urgency of being heard.

Such forms of orientation are not isolated occurrences. Artistic and embodied experiences, whether in group settings, care routines, or visual encounters, have been shown to sustain emotional coherence and stimulate self-reflection, even when linguistic expression becomes limited (Bennett et al., 2019). These findings reinforce the view that knowledge does not reside solely in the mind but also in the body, in environments, and in the shared effort to stay in relation.

To frame dementia as an epistemic borderland is to resist the urge to stabilize, diagnose, or rescue meaning. Instead, it invites us to stay with the fragility of expression, to listen not for narrative completion but for

² All participant names in this manuscript are pseudonyms. I chose to work with names rather than codes, since referring to people as numbers would strip away individuality and personhood. In this way, I aim to acknowledge the participants as persons whose presence and voices matter, even if anonymized.

³ The two vignettes are drawn from interview material collected as part of my doctoral research within the participatory project “Project Q” (interview transcript, 2019). The data are not yet published.

resonant presence. This means attuning to the temporal rhythms of disorientation, to the relational labor of being-with, and to the subtle ways in which people with dementia continue to orient themselves in meaning, even as memory disorients them in time. These moments do not lend themselves to citation or extraction. They are often fleeting, inconsistent, and irreproducible. But that does not make them less real. They point to a different register of epistemic engagement: one that values momentary coherence, affective resonance, and the shared effort to sustain something intelligible, however briefly. Dementia, in this view, is not a limit to knowledge but a limit-case for how we define knowing in the first place. It brings us face to face with the tension between narrative and noise, between form and flux. It reminds us that linearity, while comforting, is not always adequate for capturing lived experience in qualitative research, especially when that experience unfolds at the edge of language – across interruptions, silences, and repetitions.

These two encounters hint at what is at stake for qualitative research in technology development for dementia care. If coherence and factual stability continue to function as tacit benchmarks of validity, the forms of knowing that emerge through objects, gestures, affective insistence, or fragmented narratives risk being overlooked. As the examples from my fieldwork suggest, such expressions are not noise but knowledge: they show how meaning is sustained through material anchors, bodily rhythms, and the urgency of being heard. And, what such moments ask of me as a researcher cannot be answered in method sections. They unsettle what I expect to find, how I listen, and what I recognize as knowledge. Attending to them requires not only analytical flexibility but also an ethical stance: a willingness to stay with fragility, to recognize resonance as knowledge, and to resist reducing fleeting presence to methodological noise. I will return to what such moments imply for qualitative inquiry; for now, they signal the need to broaden what we recognize as epistemically significant. In the next section, I turn to these tensions more directly, where epistemic expectation and lived experience diverge, and where research becomes a practice of staying with what does not resolve.

4. Scenes of epistemic friction

Qualitative research in technology development for dementia care tends to presume that data, once gathered, can be made legible. That meaning may be layered or partial, but ultimately reconstructable. In participatory research with people living with dementia, I repeatedly found myself in moments where this assumption did not hold. These were not simply gaps or silences to be filled; they were epistemic frictions, situations in which my expectations met their limits and where the task was not to fix or decode, but to hold presence.

In the following, I present four scenes from my fieldwork that capture such frictions. Each scene is accompanied by a brief reflection: first, on what the encounter revealed to me as a participatory researcher, and what may likewise be instructive for other qualitative and participatory researchers working in technology development contexts, and second, what technology developers might take from it. In this way, the vignettes are not simply illustrations, but moments of methodological and practical insight. Together, they trace different forms of epistemic resistance: temporal, affective, relational, and interactional.

Scene 1: The loop that doesn't close. In one interview, Maria Harman told me the story of her son's visit. She described how he brought cake, how they sat on the balcony, how the sun felt. A few minutes later, she told the same story again. This time the cake was different, it was cloudy, and the second after, he hadn't come after all. Then, softly: "It's always nice when he comes."⁴ I noticed the repetition,

⁴ This vignette is drawn from interview material collected as part of my research within the participatory project "Project Q" (own fieldnotes, 2018). This specific data is not yet published.

but what struck me was not the inconsistency. It was the emotional continuity. Each version held a different texture but the same desire: to stay connected, to share the moment. The loop was not a cognitive failure. It was a way of re-entering a space of relational significance. This pattern was not unique. In another interview, Herbert Feddersen⁵ recounted twice within just a minute how he had once been a band leader. Each version of the story shifted slightly; new details emerged while others receded. What might appear as inconsistency revealed itself as a way of holding on to a meaningful role, replaying it in variations that sustained its presence.

Such looping narratives can be understood as rhythmic performances of meaning, in which identity and relation are re-anchored through affective continuity rather than factual coherence. As Hydén (2013) and Law and Ruppert (2016, p. 268) suggest, repetition here operates as a performative device: it does not reproduce memory but actively re-creates orientation in the present.

For participatory research in technology development, the lesson was that repetition and variation should not be smoothed away as error but recognized as modes of meaning-making. For technology development in dementia care, such moments suggest that systems and evaluation protocols need to accommodate repetitions as a meaningful practice. Instead of treating loops as failure, developers could design for re-entry, allowing people to return to the same point multiple times, in shifting variations, without being penalized.

Scene 2: The silent assertion. In another case, I asked a woman what made her feel safe. She did not respond. The pause stretched. Then she looked at me, blinked slowly, and said: "You're very quiet." Her caregiver laughed nervously. I did not speak. I just waited. A few seconds later, she said: "That's better. The quiet is good."⁶ What emerged in that moment was not verbal content but relational atmosphere. She didn't give me the data I might have been expected. She gave me a condition, an orientation toward safety that was situated, sensory, and already unfolding. There was no answer to record, yet something important had been communicated. An importance that only became clear on a second look, when I realized that her response was less about words than about the atmosphere we were sharing. In that silence, something shifted, not in her, but in how I was listening.

The lesson for qualitative research here is to recalibrate listening: to treat silence not as absence but as communicative presence. For technology development in dementia care, this scene indicates that comfort and orientation are often expressed nonverbally. Developers might therefore consider how devices and interfaces can make room for pauses, quiet, and atmosphere rather than interpreting them as breakdowns or absence of input.

Scene 3: The mismatch we want to fix. There were moments when I noticed myself slipping into diagnostic shorthand. A man repeatedly called his wife by his daughter's name. She corrected him gently.⁷ The third time, I wrote in my notes: "confusion intensifies." Later, re-reading that line, I paused. What I had seen was not simply cognitive decline. It was a moment shaped by intimacy, generational entanglement, and affective habit. Perhaps the daughter's name was more present. Perhaps it had come to stand in for something else. Such misnaming is typically understood as symptom of semantic confusion, as a sign of cognitive decline in which categories of relation begin to blur. Yet from a relational perspective, it can also be read as an affective condensation – a way of sustaining connection through names that overlap emotionally rather than semantically. The reflex to name the moment as confusion had offered me a kind of structure. But it had also closed down other

⁵ This moment was part of an interview conducted 2019 as part of my research within the project "Q" (not yet published).

⁶ This scene based on an interview and fieldnotes from the participatory research project "M" (unpublished data, 2015).

⁷ This vignette is drawn from interview material collected as part of my doctoral research (2018). This specific data is not yet published.

readings. What I had witnessed was not a loss, but a shift: a reconfiguration of relational positioning.

Occasionally, misnaming involved references to people who appeared to be neither present in nor familiar to the participant's current social world. Such moments suggested that relational meaning can extend affectively or imaginatively beyond immediate recognition, reaching into remembered, displaced, or symbolic relations that nonetheless sustain orientation.

The lesson for qualitative research here is that annotation itself can pathologize, foreclosing alternative readings. The task is therefore not to multiply interpretations indefinitely but to delay closure, to stay with the interpretive uncertainty long enough for the social and relational meanings of an utterance to become visible. This means resisting the urge to label or correct too quickly, allowing the interaction itself to indicate what matters before analytic reduction. For technology development in dementia care, this points to the need for systems that can tolerate relational ambiguity. Mismatching should not be automatically corrected or flagged as error; developers could design interactions that acknowledge such moments as part of the relational fabric rather than as defects to be eliminated.

Scene 4: The question that doesn't land. In one interview,⁸ I asked: "What would help you feel more supported in daily life?" Louisa Bredt looked at me for a moment, then said with a gentle shrug, "That's too big." There was a pause. Then, smiling slightly: "Maybe I should ask you that." I hadn't misstepped. My question was clear, respectful, well-intended. But it did not meet her where she was. It hung in the air, structured, abstract, ungrounded. Her response redirected the frame. Not dismissively, but with precision. She had shifted the interaction not away from the topic but toward something more mutual, more present. What stayed with me was not a sense of failure but of recalibration. She had, in effect, refused the asymmetry of the interview form. By redirecting the question, she invited a co-presence that dissolved the usual roles of interviewer and respondent. To 'respond to the moment as it was' meant to re-enter the encounter as an open dialogue, where relevance was negotiated rather than pre-defined.

For qualitative and participatory researchers, this scene offers more than a reminder to remain flexible. It exposes how even well-crafted questions can reinscribe asymmetry by deciding in advance what counts as relevant knowledge. The task is therefore not simply to rephrase or to allow participants to reframe a question in more grounded, emotionally resonant, or dialogic terms but to recognize when inquiry itself has become the obstacle to encounter. Methodological rigor, in this sense, means knowing when to suspend inquiry long enough for relevance to be co-defined. Moments like this underscore that participation is not simply a matter of inclusion but of epistemic reciprocity: the willingness to let relevance emerge between, not within, participants and researchers. For technology development in dementia care, such episodes highlight e.g., the importance of adaptive framing. Developers could derive from this that evaluation and design protocols should allow users to redirect, reframe, or scale down questions. What appears relevant from a developer's perspective may be too abstract in practice; design must remain open to the situational relevance logics of those living with dementia.

Taken together, these scenes draw attention to the gap between methodological expectations and lived expressions. None of them offered what is typically sought in participatory research in technology development for dementia care: a clear narrative, a coherent account, a quote that can stand for something. They could not easily be thematized or coded, nor neatly paraphrased. They did not yield answers. They resisted capture. And yet, they were saturated with epistemic weight, not as 'findings', but as frictions. They represent different dimensions of how meaning is sustained when the usual coordinates of coherence and

control fall away.

They marked those moments in the field when meaning flickers rather than speaks, when presence carries more than propositions, and when the question itself begins to unravel. These reflections also contest a widespread assumption in technology development for dementia care: that when speech is fragmented, looping, or inconsistent, it cannot provide meaningful insight. The scenes demonstrate the opposite, although this may become apparent only on a second look. Their value does not lie in producing coherent narratives or directly useable answers, but showing how knowledge emerges otherwise, through repetition, silence, misnaming, or reframing. What is required is not to dismiss such moments as irrelevant, but to develop ways of recognizing their epistemic weight.

What lingered after these encounters was not clarity in the conventional sense but a quiet tension that refused resolution. They shifted the terms of engagement and left me with a different sense of what it means to listen, to be addressed, to be met by an expression that eludes conclusion. The looped story, the silence, the misnaming, and the redirected question did not yield immediate answers, but they did yield insight, about how knowledge can be sustained through repetition, atmosphere, ambiguity, or reframing, and about what dementia means as a lived epistemic condition. Their lesson was not to extract more content, but to remain attuned, and in doing so to recognize that methods and technologies alike must learn to value such forms of knowing. As Mol (2021) has argued, knowing is never neutral but transformative, it leaves traces on all those involved as they participate in its creation. In this sense, epistemic frictions do not only generate knowledge; they also reshape researchers, participants, and their relations in ways that carry consequences for care and well-being.

As researchers, we often inherit tacit expectations of reliability, validity, and clear evidence. These benchmarks continue to shape what counts as meaningful knowledge, even though qualitative methodology has long moved toward criteria such as credibility, transparency, and context-sensitivity. But what if the field itself refuses these conditions? What if the knowledge we seek emerges not as a claim to be checked but as a resonance to be witnessed? In these moments, the criteria we inherit begin to strain – not because they are wrong but because they are insufficient for the kinds of truths that dementia reveals. Truths that are embodied, affective, relational, and fleeting. These moments do not ask to be verified. They ask to be accompanied. What they offer is not data but direction, not content but contact.

In the following section, I ask what it would mean to take these frictions not as methodological problems but as the ground for a different kind of epistemic practice: one that turns toward presence, resonance, and the ethics of unresolved knowledge.

5. Toward a methodology of shared presence

If the moments I have described do not yield answers in the conventional sense, if they resist coding, coherence, or clear interpretation, then perhaps it is not the field that falters, but the expectations we bring to it. Expectations of validity, reliability, and clear evidence continue to function as tacit benchmarks in qualitative research practice. Yet when the field itself becomes porous, when language fails or fragments, and when presence overrides structure, these benchmarks begin to strain. Such moments mark points of epistemic friction, where methodological assumptions meet the lived realities of the field. The four scenes illustrate how such frictions unfold, revealing the methodological tensions that shared presence seeks to address. Taken together, they show that meaning in technology development for dementia care often emerges not through clarity but through resonance. What appears as methodological tension in the field thus mirrors a broader epistemic pattern: the privileging of measurable, coherent, and ostensibly "trustworthy" data. In technology development for dementia care, this appeal can become an instrument of exclusion.

Often, as shown above, only those participants are included who are

⁸ This scene based on fieldnotes from the participatory research project "Q" (unpublished data, 2018).

presumed to still “make sense” in ways familiar to the researcher (Lloyd et al., 2006, p. 1387). Others, those who speak differently, fragmentarily, or through gesture, are ‘filtered’ out before the research even begins, with the consequence that precisely these modes of expression never enter the frame of research as possible forms of knowledge. Such exclusions are rarely acknowledged. They are often hidden behind ethics forms, feasibility arguments, and assumptions about capacity. But their effect is deeply epistemological: they delimit in advance what can be recognized as knowledge.

This narrowing is well documented. Out of 52 studies analyzed by Bharucha et al. (2009) only eight tested technologies directly with persons with dementia. More recent reviews confirm that although people with dementia are primary users of assistive technologies, many projects proceed *without* directly involving them, relying instead on relatives, caregivers or, experts (Köhler et al., 2024; Giménez, Augusto, & Stewart, 2022; Suijkerbuijk et al., 2019; Brankaert & den Ouden, 2015, for example). Besides this, in several interviews I conducted, relatives or caregivers stepped in to correct or ‘translate’ what a person with dementia was expressing (see also e.g., Brankaert & den Ouden, 2015). While often well-intentioned, these interventions risk reinscribing the very exclusions the literature documents. The methodological lesson is not that participation is impossible but that we require a different posture to make it possible: one that resists the tendency to stabilize, correct, or paraphrase too quickly, or to avoid such situations altogether.

Against this background, what I propose is not a new technique but a methodological orientation I describe as *shared presence*. It begins not with the need for answers but with a willingness to be addressed. It is a research posture that does not extract knowledge but holds space for it to surface: unevenly, unpredictably, relationally. This is not a matter of interpretive generosity alone but of epistemic accountability: a commitment to modes of knowing that refuse to stabilize. The central claim is simple: meaning in technology development for dementia care often arises not through articulation but through co-attunement. It grows directly from the kinds of moments described earlier; moments where repetition became rhythm, silence became presence, and ambiguity became relation. Building on these experiences, shared presence does not prescribe a rigid protocol but implies a set of relational practices and commitments. The researcher cultivates a mindful, caring presence, an attentiveness akin to *Achtsamkeit* that prioritizes listening over directing. It means leaning into silence, following the participant’s lead, and treating pauses, gestures, and bodily cues as significant forms of expression. Participation here is not an add-on but the very medium of inquiry. It also entails a willingness to be influenced, even transformed, by the encounter.

Shared presence requires openness, tolerance for fluidity, and an orientation toward solidarity rather than autonomy. At the same time, I caution against romanticizing resonance and reflect on its limits, acknowledging the affective and moral labor it entails for both researchers and participants. I frame accountability here as a commitment to stay with fragility without reducing it to deficit. Shared presence thus entails epistemic reciprocity: a willingness to let understanding emerge between participants and researchers rather than being imposed by predefined categories. Shared presence therefore involves not only methodological attentiveness but also moral and affective work: listening without rushing to closure, allowing discomfort, and cultivating patience and care as integral to research practice. To acknowledge this means recognizing such capacities not as personal virtues but as professional skills that should be cultivated and supported institutionally. More broadly, it calls for a transformation in how research communities and funding structures value time, care, and relational engagement as legitimate forms of rigor.

Resonance, in this sense, is not a vague metaphor but a concrete mode of epistemic engagement. It describes the capacity of research to remain responsive to what does not resolve and to let insight take the shape of atmosphere, rhythm, or silence. As Reason and Bradbury

(2001) remind us, experiential knowing “is through direct face-to-face encounter ... knowing through empathy and resonance ... a kind of knowing almost impossible to put into words” (p. 170). Such knowledge does not lend itself to generalization but to ethical proximity, to a form of rigor grounded not in distance and control but in attentiveness.

To practice research in this way is not to abandon discipline. It is to reframe it. Rigor becomes the ability to remain with uncertainty, to resist the urge to paraphrase too soon, and to attend to what lingers beneath the surface. Not-knowing is no longer a deficit but a methodological condition. It opens a space where knowledge is not stabilized but negotiated: moment to moment, gesture to gesture, always in relation. Crucially, this also reshapes what we think of as evidence. In a field where many forms of expression slip beneath the threshold of formal recognition, the refusal to speak, the looping of a memory, or the mutual act of pausing may carry epistemic weight. Attending to these forms does not weaken our claims. It honors what dementia reveals about the limits of language, and about the potential of relational ways of knowing.

For technology development in dementia care, this orientation implies a shift as well. Evaluation and design processes cannot rely solely on coherence and proxy accounts. They must engage directly with the fragile, situated, and embodied ways in which people with dementia orient themselves. Repetition, silence, or ambiguous expression should not be dismissed as unusable data, but engaged as signals of how meaning and orientation are sustained in practice. Systems that can accommodate such forms, rather than filtering them out, will be better able to align with the lived realities of those they are meant to support.

This orientation builds on a growing body of research that calls for inclusive, process-oriented, and presence-sensitive approaches in dementia studies (Barnett, 2000; Dewing, 2002; Meier zu; McKeown et al., 2010; Verl, 2024). These perspectives do not dismiss the difficulties posed by memory loss or communicative ambiguity, but they refuse to treat these difficulties as the end of research. Instead, they suggest that such tensions might be the very starting point for rethinking our epistemic commitments. A methodology of shared presence, then, is not a retreat from rigor but its reconfiguration. It does not dissolve responsibility but relocates it, from the pursuit of clear results to the cultivation of ethical attention. It reminds us that in some fields, the most valuable knowledge is not what can be confirmed but what can be carried. And sometimes, the task of research is not to define what is known but to remain alongside what is still becoming knowable. As Robinson (2002, cited in King et al., 2016, p. 24), a person living with dementia and actively involved in research, once wrote: “*What a hugely missed opportunity it would be if people with Alzheimer’s were excluded from the very thing that could be used to gain a fuller understanding of their disease.*”

6. Not less knowing – but knowing otherwise, and more

This article began with a question: What kinds of knowledge become visible when we stop asking research to produce clarity and begin asking it to witness complexity? In technology development for dementia care, this is not a rhetorical gesture. It is an epistemic and ethical necessity. The dominance of technological innovation as a framework for understanding care has structured not only what kinds of solutions are imagined, but also what kinds of knowledge are deemed relevant. People with dementia are expected to be involved, but most often in roles that fit usability testing, design validation, or functionality feedback. This model presupposes a certain kind of participant: responsive, articulate, consistent, cognitively intact enough to ‘give input’.

The consequence is not just exclusion. It is a narrowing of what we allow ourselves to count as knowledge. As the examples in this paper have shown, people with dementia are often most present in moments that exceed the formats of interviews, design protocols, or evaluation forms. These are not moments of data loss. They recall the earlier scenes in which knowledge surfaced through repetition, silence, misnaming,

and reframing, each challenging what counts as useable input and inviting a different mode of attention. They are the beginning of another kind of knowing: one that is affective, fragmented, temporal, and situated. Such knowledge cannot be verified in conventional ways, but it can be recognized. And it requires a methodology willing to be altered by what it encounters.

I have called this orientation a methodology of shared presence. It is not a new technique but a different stance: a mode of research that stays with rhythm, silence, interruption, and gesture. It reframes presence not as an obstacle to knowledge but as its very condition. This reorientation does not demand less knowledge; it demands more – more of ourselves as researchers, more sensitivity to the forms in which others speak, and more willingness to recognize that knowledge often appears where our usual tools fail. Knowing otherwise is not a lack. It is a deepening: a shift from control to encounter, from answers to presence, from content to contact.

For qualitative inquiry, the implication is clear: rigor is not weakened by such forms of knowing but redefined as attentiveness and accountability rather than coherence and stability. For technology development in dementia care, the lesson is equally direct: design and evaluation must be prepared, for example, to recognize repetition, silence, misnaming, or reframing as meaningful contributions. If they are treated as noise, the very insights that could lead to more humane, more accepted, more used technologies will go unheard. This is not only an epistemic loss but has practical consequences. As several studies have shown, a profound discrepancy persists between the benefits anticipated by developers and policymakers and the lived realities and social needs. The result is often products that, despite being technically mature, find their way into practice only hesitantly or not at all (Berridge & Wetle, 2020; Krings & Weinberger, 2022). I argue that these modes of knowing should not remain confined to research. They need to be actively fed back into design and policy processes so that participation is not limited to usability metrics but opens to the situated, embodied, and affective ways in which people with dementia make sense of their worlds. Only then can technology development align with the realities of living with dementia rather than abstract expectations of usefulness or efficiency.

And perhaps this is what dementia research can offer the broader field: not only methodological challenge, but epistemological insight. An invitation to leave the mapped territory of established methods and step into the methodological landscape in which participation and technology development are rethought through, rather than despite, these forms of knowing. The challenge, then, is not merely to involve people with dementia in existing research frameworks but to let their ways of knowing transform what counts as research in the first place. Such a methodological shift inevitably extends into the ethics of research practice. Ethical review systems, after all, are epistemic filters: their logics of evidence, replicability, and risk often collide with the very forms of knowing that dementia brings to view. In protecting participants through cognitive thresholds of consent, they may also exclude them. Yet consent remains essential, and participation must always rely on a person's capacity to agree meaningfully and voluntarily. What is needed is an ethics capable of reflecting on its own epistemic boundaries. One that asks which forms of knowledge and subjectivity are silently ruled out by its criteria. But that is a discussion for another article.

Ethical statement

This article draws on qualitative material generated during three participatory research projects on technology and dementia care. One of these projects, *QuartrBack*, received formal ethics approval from the Ethics Committee of the German Society for Nursing Science (DGP, No. 17-002). The other two projects, *Movemenz* and *Compatibility of technology and networks in home care*, did not undergo formal ethics committee review, as they were non-interventional, exploratory studies conducted within a participatory technology assessment framework. In

both cases, only individuals living with mild dementia were involved, and all participants were able to provide informed consent independently. Consent was obtained after providing clear and accessible information about the aims, methods, and voluntary nature of participation. Throughout all phases of the research, particular attention was given to autonomy, cognitive vulnerability, and relational sensitivity. The study adheres to established ethical principles for qualitative research in health and social care.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author used OpenAI's ChatGPT-4 only for translation purposes, as well as for improvements in readability. The author thoroughly reviewed and edited the content as needed and takes full responsibility for the content of the publication.

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