

Gaining access to unspoken narratives of people living with dementia on a hospital ward—A new methodology

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Abstract

Background: This is a methodological paper that aims to advance the conceptualisation of participatory research by focusing on the value of capturing and understanding movement as a vital means of communication for older people with dementia in a general hospital ward. Qualitative research involving people with dementia tends to be word-based and reliant upon verbal fluency. This article considers a method for capturing and understanding movement as a vital means of communication.

Method: This narrative enquiry is underpinned by the model of social citizenship that recognises people with dementia as citizens with narratives to share. The study focused on spontaneously produced conversations that were video recorded and analysed through a lens of mobility. This enabled each participant to share what was important to them in that moment of time without always using words.

Findings: The study findings showed that people with dementia have narratives to share, but these narratives do not fit the bio-medically constructed model that is generally expected from patients. Utilising a mobilities lens enabled the narratives to be understood as containing layers of language. The first layer is the words; the second layer is gestures and movements that support the words; and the third layer is micro movements. These movements do not only support the words but in some cases tell a different story altogether.

Conclusion: This methodology brings attention to layers of communication that reveal narratives as a mobile process that require work from both the teller and the listener to share and receive. Movements are shown to be the physical manifestations of embodied language which when viewed through a lens of mobility enable a deeper understanding of the experience of living with dementia when an inpatient. Viewing narratives through a mobilities lens is important to the advancement of dementia and citizenship practices.

KEYWORDS

communication, dementia, hospital, micro-mobility, mobility, movement, narrative, video

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Key points

- Movement and micro-movements are a vital form of communication for people living with dementia.
- Viewing narratives through a lens of mobility enables a more nuanced understanding of people's narratives than just words alone.
- Qualitative methods based on communication strategies other than words have the potential to promote inclusion.
- An acknowledgement of the juxta positioning of hypermobility and micro-mobility may help in providing quality healthcare for people living with dementia.

1 | INTRODUCTION

This is a methodological paper that aims to advance the conceptualisation of participatory research by focusing on the value of capturing and understanding movement as a vital means of communication for older people with dementia in a general hospital. Qualitative research involving people with dementia tends to be word-based and reliant upon verbal fluency. Although observational methods have been used,¹ interviewing is the main method of data collection for researchers, even though dementia is a condition that affects a person's language skills² and capacity to respond to direct questions.³ Participatory research is posited as more inclusive, in that it seeks to engage people with dementia on their own terms, using a range of creative methods. For example, researchers have used photo-voice and video to enable the participation of people with dementia in community-based research projects. In this article, the conceptualisation of participatory research is further advanced by focusing on the value of capturing and understanding movement as a vital means of communication for older people with dementia in a general hospital.

Through the interpretation of movements, video recordings of inpatients with dementia enables access to unspoken narratives. Developing tools through which to understand a person when they are not verbally fluent or have difficulty recalling on demand is important because this potentially enables people with dementia to participate more fully in clinical qualitative research which in turn can lead to improvements in care. Researchers and healthcare professionals commonly operate within a paradigm of verbal fluency. Developing methods based on communication strategies other than words potentially promotes inclusion.

Global non-profit, non-governmental organisations, such as Dementia Action Alliance, Alzheimer's Disease International, the Scottish Dementia Working Group and Alzheimer's Society campaign for increased investment and the involvement of people living with dementia in research. Further, some people with dementia share their stories publicly to raise awareness of the condition. For example, Wendy Mitchell's⁴ book has been on the UK's Sunday Times Best-seller list and Kate Swaffer has a widely read blog.⁵ However, the voices of people with dementia from within acute hospitals have been largely silent. Overcoming the barriers in qualitative research that impede the involvement of less verbally articulate subjects requires new tools and insights.

Studies that have considered the narratives of people with dementia, or which have attempted to understand their experiences, have taken place in long term care or at home where people are comfortable, supported, or at least in familiar surroundings.⁶ When a person with dementia is in an acute hospital they are in an unfamiliar environment, unwell and often without familiar faces around them. Communication with people who have dementia has rarely been studied in this challenging environment.⁷ Integral to the method reported on here is that the narratives were shared in the contextual environment of their happening - an acute medical ward - and thus did not rely on recall of past events.

This narrative study aimed to explore and develop a method that forefronts movements, both big, small and micro, to bring an understanding to what a person is communicating when they cannot rely solely on words. This video method captured people's movements as well as their words, and showed that these movements can be utilised as a lens (a mobilities lens) through which to access layers of meaning within a person's narrative. The narratives were considered as multi layered and textured performances wherein movements were analysed alongside verbal utterances to interpret the narratives and construct an understanding of the person in that moment. This narrative approach not only aimed to challenge the biomedical narrative of the acute hospital, but also to keep the person in focus and value the uniqueness of each individual's experiences at a specific moment in time.

2 | PHILOSOPHICAL ASSUMPTIONS AND THEORETICAL UNDERPINNINGS

Central to this method was inclusion of people with dementia on their own terms, rather than on the terms of the researcher. The study was framed within Bartlett and O'Connor's⁸ social citizenship model for research in which people with dementia can, and should, be actively involved with the generation and translation of new knowledge. Bartlett and O'Connor propose that we reconsider what we regard as evidence, what we research, where we research and how we use the results of research. With direct relevance to this study, Bartlett and O'Connor advocate for the privileging of people's stories; the use of participatory and creative research methods that allow inclusion; a re-examination of the ethical issues underpinning

research with people who have dementia; using a critical lens that considers power dynamics; and finally translating research into practice in a meaningful way.

For those living with dementia the difficulties encountered with expressive language, loss of memory for recent events and disorientation to place and time may limit the possibility of engaging narratively with the world and with others.⁹ Healthcare professionals and researchers expect a different narrative than the one that is often provided. This is especially true in the context of acute healthcare which relies heavily on the biomedical interpretation of a patient's story and the search for the medical "truth".

The biomedical approach to illness works to colonise the narrative of the patient. The ill person not only agrees to follow the treatment that is prescribed, but to also tell their story in medical terms that are expected by the healthcare professional, and to which the professional will listen.¹⁰ Narrative colonisation by medicine is increasingly questioned in a world with a growing number of people living with long term health conditions. The "post-colonial" ill person demands to speak rather than being spoken for, to represent oneself rather than being represented, and rejects the reduction of their experiences to a mere set of symptoms.¹⁰ People want the human, personal aspect of their condition to be understood from their perspective; to be given the space to tell their own story. Where verbal communication is deemed to be difficult, the problem is situated with the person living with dementia, a viewpoint that does not lend itself to the exploration of other methods of expression.¹¹

The method described here involves focusing on the narratives of the moment in the context in which they occurred, and not looking for coherency, authenticity and consistency.^{12,13} The attributes and value of shorter, fragmented narratives¹⁴ were acknowledged, as were the body movements that accompanied them. Expecting to understand the narratives of someone with dementia only through their use of words is to "overlook how bodily sources of agency, grounded in pre-reflective level of experience, are fundamental to the constitution and manifestation of selfhood".¹⁵ Kontos considers the body as a generative source of agency through which selfhood can be reproduced through practical and corporeal actions, in other words, through movements. This in turn can provide a foundation for how people with dementia interact meaningfully with, and are understood by, the world around them.

However clinical practices, and biomedical narratives in particular, are premised on a model of dementia that denies the body an agential role in the constitution and manifestation of personhood¹⁵ because of their reliance upon verbal responses. Thus Kontos' "embodied language" is often misconstrued, misunderstood or not noticed. The use of a mobilities lens through which to view the narrative forefronts the body as a generative source of agency and brings into focus embodied language.

Existing methods, such as Dementia Care Mapping (DCM™)¹ recognise that people with dementia do not always communicate verbally but can be understood through observations of their behaviours. DCM™ is a practice development intervention that has been successfully used within health and social care settings to

support the embedding of person-centred care. DCM™ recognises behaviour, mood and engagement by structured observation of people with dementia in care settings. However, facial and body movements are still envisioned as behaviours with the person placed as a passive recipient awaiting the bestowal of person centred care, rather than as an active agent with rights and abilities.⁸

Focusing on the physicality of communication is novel to a healthcare environment. Within acute hospital wards non-verbal, or embodied communication were not recognised as such, but rather were understood and viewed as acts of resistance, disruption or transgressive behaviour to be managed and limited.¹⁶ Viewing narratives through a mobilities lens places the spoken words in secondary importance to the movements of the participants. Movements are thus no longer viewed as behaviours, but as communicative strategies that require interpretation.

3 | METHOD

This visual narrative enquiry aimed to utilise a participatory approach to data collection in order to gain some insight into the experiences of people living with dementia whilst on a busy and noisy hospital ward.

3.1 | Video and recruitment

The use of video to record the narratives engendered a focus on what the participants could share in terms of narrative, rather than what they could not, as a wider range of response possibilities were captured that extended beyond the narrow range of verbal responses.¹⁷ Video based research that is well designed can yield significant benefits by improving the understanding of healthcare and enhancing communication,¹⁸ yet this method is rarely used within hospitals.

Unlike previous studies where small digital cameras have been used,¹⁹ or video equipment,²⁰ this study utilised a Samsung Galaxy S3 tablet which has a large 9.7 inch screen and good picture resolution. Due to the larger screen size and high resolution picture, the tablet facilitated the participant to review their videos instantly. It was very simple to use and hold and enabled the participant to have a contextual conversation around their involvement. The ability to review the video immediately after filming also enabled people to have a visual understanding of what the research was attempting to achieve which aided the participant's decision of whether to keep the video or delete it. This contextual approach also enabled the main researcher to establish if the participant could understand the concept, and consent to, the video being used in research and education.

Participants were approached by a member of their clinical team who asked if they would like to participate in the research. The main researcher followed affirmative answers by an offer to explain what the research entailed using the contextual prompt of the Samsung

tablet on which was a video of the researcher interviewing her older parents. If a relative was present their consent to being involved was also sought. The conversation with participants was opened with a request to “have a chat”. The ensuing conversations were conceptually understood as being the participant's narrative of that moment and time.

Interview schedules and questions were not used to elicit the narratives as these rely on remembering, recounting and relaying accurate experiences, something that people with moderate to severe dementia often find difficult. Instead, each narrative took place as a conversation that was directed by the participant in context on the ward; was unconditionally accepted, and analysed on an individual basis utilising a lens of mobility.

Study participants appeared to find using the tablet and having an unhurried conversation on topics of their choice a welcome distraction. Ward staff went out of their way to help recruit participants, and engaged enthusiastically in discussions around capacity and consent. Relatives, where present were also keen to see involvement of participants. Thus the actual process of data collection led to an unexpected chance to undertake learning opportunities and conversations with patients, healthcare staff and relatives.

The rarity of use of video in healthcare settings is likely due to perceptions of risk. Risk to the participant and their anonymity; the risk of filming people in the background who had not agreed to be included; issues around consent for people who are often perceived as not having the capacity to make decisions around inclusion for themselves and risk to the researcher. Risk of negative perceptions of the videos by healthcare staff and relatives and blame for including vulnerable people in crisis are very real fears for researchers.

Filming proved to be reasonably unobtrusive, and pulling the curtain between the participant and the next cubicle protected the privacy of other patients, members of staff and visitors to the ward. Following each recording feedback about their videos was elicited from participants. Three participants did not wish to review their video. In common with Hung et al's²¹ findings from their go-along interviews, when videos were played back to patient participants, those participants who did comment, made comments about their appearance in the film, rather than the content of the data. Comments were made such as “Oh I look old, I'm 94”; “I look anxious” and “there's a bruise on my face”. Videos taken in the context of an acute health crisis are potentially upsetting; people do not look their best when they are in hospital due to an acute illness or social crisis, and viewing oneself in this situation, especially if you have visual signs such as facial bruising, can potentially be upsetting.

3.2 | Participants

The participants were aged between 76 and 101 (Table 1) and thus included some of the oldest old.

People were identified as having a dementia diagnosis from their medical notes and were first approached by a member of the ward staff to establish if they would like to hear about the study. If they

wished to hear more, the main author approached the potential participant and showed them the tablet and talked about the study.

This study aimed to be inclusionary rather than exclusionary; therefore a formal cognitive assessment was not used because these have been used in other research to exclude people with dementia.^{22,23} Formal cognitive assessments can also be stressful and feel humiliating to a person who may well know that the questions are simple, and yet find themselves unable to answer. They also add to the burden of questioning that is experienced by patients in the initial days of admission.

People were excluded from the study if they were critically unwell or receiving end of life care which was established by reviewing the notes; or if they were unable to make known and communicate their choices and preferences either verbally or non-verbally.

The ethos of qualitative research is to value individual perspectives, so sample size is considered less important than the depth, richness and diversity of data. Twelve people were recruited to the study but not everyone was comfortable with being video recorded and chose instead to be audio-recorded ($n = 1$) or agreed for the researcher to take field notes as an alternative ($n = 2$). One video recording was deleted as the participant did not understand the use of the video for research or education and the personal consultee could not be contacted. The eight videoed narratives are shown in Table 1.

3.3 | Consent and ethical issues

There is increasing unease amongst qualitative researchers that the ethics process in research is exclusionary rather than inclusionary^{8,24,25} and based around the ethics and consent processes that are designed for clinical trials. This has caused ethics review boards to be tied to the experimental, hypothesis-testing positivist paradigm.²⁶ People who are assessed by a researcher as being unable to negotiate the complex consent process for themselves are often excluded from participating as a result of misguided paternalism.^{22,27}

Obstacles to participating in research include determining mental capacity to provide informed consent and the complexity of the consent process.^{24,28–30} This “exclusionary ethics” prioritises the duties and action of others (the researcher, ethics committees) and further disempowers an already stigmatised group of people by preventing them from participating in research. Alongside Boyle³¹ it is argued here that a more expansive concept of agency is needed in social science theory that is informed by the experiences of cognitively disabled people, rather than the researcher.

The ethos of using inclusionary methods becomes problematic when research processes, such as recruitment and consent to participate, rely on a person being able to understand complex written and verbal information in a relatively short time frame and to be able and willing to sign forms.

It could be argued that this complex process of consent has been designed to protect the researcher rather than the participant, and that it leaves a person affected by dementia in a position in which it is

TABLE 1 Videoed participants, diagnosis and consent.

	Age	Acute condition	Consent for videoed conversation	Consent for use of video in research/education
Albert	97	Chest pain	Participant	Participant
Bert	94	Respiratory infection	Participant	Participant
Elizabeth	82	Chest infection	Participant	Participant
Ivy	101	Urinary tract infection	Participant	Consultee
Jane	84	Fall/Fractured hand	Participant	Participant
Philip	83	Admitted with unwell wife as could not be left alone	Participant	Consultee
Roger	76	Urinary tract infection	Participant	Participant
Rose	94	Decreased use of left arm	Participant	Consultee

almost impossible to consent for themselves, and therefore dependent on the decisions of a consultee. The person is “outpaced” because the information provided is too complex and in a form that is difficult to understand.³²

For this study the main author argued at the Research Ethics Committee (REC) meeting against using the participant information sheet and consent form that had been produced for the purpose of gaining ethical permission to undertake the study. The main author argued that a one-off consent process that was very complex did not enable the participant to properly consent; and that if the process was simplified then more people would be able to consent for themselves. She also proposed to divide the consent process into two parts: firstly to take part in a conversation that would be videoed, and secondly to use the resultant video or audio recordings as data for research and for showing in educational settings such as teaching or conferences.

The resulting REC decision required the researcher to use the participant information sheet and consent form as a check list rather than giving them directly to participants. The committee agreed that process consent²⁵ was more effective than the use of a consent form on a single occasion. It noted however that clear records of ongoing explanation and consent should be kept; this was achieved through a reflective diary. The committee noted that there was no doubt that the research was connected to the impairing condition and it was a rare example of research which targets this group with an aim of understanding them better. The committee agreed that there was an ethical imperative to conduct research of this nature as it should also yield some useful training materials and might lead to positive changes in practice.

Where the participant was assessed by the main author as not having the capacity to consent to inclusion for themselves, then a personal proxy was consulted and the participant information sheet and proxy forms were used.

Making the consent process more accessible, using the tablet as a contextual indicator of what the research entailed and dividing the consent process into two parts resulted in more people with dementia being enabled to consent for themselves because the

information provided to them was accessible. Every participant or potential participant was clearly able to indicate whether or not they wanted to take part in a videoed conversation with the researcher. People were as happy to say or indicate no (for instance by withdrawing from the interaction and closing their eyes), as they were to say or indicate yes. During the course of each conversation it was established if the participant understood that this video was for use in research and/or education and a proxy opinion sought accordingly (Table 1).

Making the consent process a two-stage process also enabled people to take part in what can be an enjoyable activity—namely talking with a person who is not hurried and can give undivided attention. For people that were approached and did not want to take part in the research they often enjoyed a conversation and the opportunity to use the tablet together.

To conform with the regulations of the hospital each participant (or proxy where appropriate) did sign a simple hospital consent form that confirmed that they were happy for the video recording to be used in either research, education or both.

Ethical approval for the study was received from the University of Southampton and the NHS Health Research Authority, South Central—Berkshire REC, reference 17/SC/0625.

3.4 | Analysis

This research method necessitated developing a new way of data analysis that could bring out the nuances of movement that each participant made whilst narrating their story. Schwartz³³ argues that in a world where we are surrounded by ever increasing numbers of visual images, there is an assumption that we have all become visually literate—that we know how to “read” a picture. Schwartz contends that viewing images is not intuitive but is a skill-based activity which does not lend itself to context-free semiotic analysis. As no clear analytic method for this type of data was found analysis was iterative. The main author watched each video soon after completion initially with the sound on. It was quickly recognised that each participant

was making body movements throughout each video. These included large body and hand movements; and tiny facial and body movements (micro-movements) It was also apparent that the general movement and noise of the acute ward (the hyper-mobility) was impacting on each participant's narrative in different ways. These movements were then conceptualised as a "lens of mobility" through which each individual narrative could be explored. Utilising a mobilities lens enabled the videos to be viewed as being constructed from layers of meaning. Three layers of meaning were found within the narratives - the first being words and verbal utterances; the second the larger more obvious movements of the participants; and the third the subtle facial and body movements (micro movements). The movement of people and objects in the ward around the participant was also acknowledged, and conceptualised as environmental hyper-mobility.

The main author undertook the primary analysis and then the initial interpretations were shared with JB and RB who discussed and tested preliminary thoughts, developing and sharing insights as the data collection and analysis progressed.

4 | FINDINGS AND DISCUSSION

As this is a methodological paper only three short video narratives have been selected that best represent the layers of meanings that were found within the narratives. These layers of meaning bring attention to other forms of knowledge gathering, alongside words, by acknowledging that the body is a reliable indicator of the workings of the mind and that through our bodies we perceive our environment and instantly interpret it.³⁴ The power of the following short narrative segments lies in their being shared in the context of the hyper-mobile acute ward. People could respond to the world around them as they experienced it in that moment in time.

A mobilities lens can help to fill the gaps in our knowledge around communication with people when they become less verbally fluent and enable a participatory approach to data collection whereby the narratives are unconditionally accepted. The three following narrative segments illustrate that to enter another's world we need to slow down, observe and accept the person's reality in that moment. To understand that people are using communication strategies, but that interpretation and recognition of these strategies are needed. An exploration of these strategies can help to address the problem that first-person insights of people with complex communication needs are often not collected within research studies and people can be viewed as unreliable research participants.¹¹

It is equally important to remain cognisant of the fact that the data are a representation of one moment in time in one place, and that there is no one stable and unitary interpretation. The videos represent a short moment and space where each person strove to understand and make sense of the other person in the interaction. However, the real issue in this context is around accessing and interpreting the meaning of what is being communicated. Both these issues need to be more clearly described in the context of dementia research.²⁴

4.1 | The first narrative layer—Spoken words (Roger)

Roger illustrates the first and most obvious layer of narrative—the words. Roger is the only participant who overtly speaks of their dementia diagnosis. He succinctly explains that it is not the dementia diagnosis that is a problem for him, but the way that he is then treated by those around him.

Roger had been labelled as aggressive, and during our time together it became clear that he felt that people were avoiding him. Roger chose to lie in bed and not sit in a chair. He was unshaven. He tried throughout our interaction to do up the poppers on his pyjama top. Eventually I offered to help and he told me there was no point as they didn't work. We agreed that nothing seemed to work for him at the moment and laughed a little to relieve the sadness.

R: My memory's a bit clouded because like I have got Alzheimer's disease. Soon as they know you've got Alzheimer's disease a lot of doctors [say] oh well we know all about that and they don't; they don't know what they're talking about because it's only the person whose got it who knows what it's like.

He gestures at me with his arthritic forefinger to emphasise points as we talk:

R: One of the things about it, you see, I am perfectly lucid you know, I mean you listen to me talking:

PC: Perfectly lucid:

R: Yes, yes exactly. But a doctor will come along he'll read on there umm suffering from Alzheimer's disease and he immediately assumes that you're a nutcase. Do you understand what I mean?:

PC: I do, I do understand exactly what you're saying:

R: And it's not true and, and you can't, you can't get through to them. And I'm waiting now for a doctor to come and see me so that perhaps, maybe I might be able to go home today, but it is very unlikely.

Later in the conversation Roger use the phrase "We can't release you today" and I can see that he thinks of himself as a prisoner (of this place? Of his dementia?):

Stories always sit in relation to other stories, and personal storytelling in particular can highlight the powerful linkage between the micro and the macro; narrative scholars must consider this broader terrain in their analysis of the materials they collect.³⁵ As he lies in his bed, moving only his hands to emphasise his words he embodies resignation and despair. He had not wanted to get out of bed when asked if he would prefer to be videoed in a chair: "*there is no point*" he said. Surrounded by the hyper mobility of the ward, doctors come and go to the bed diagonally opposite, but not to his; healthcare professionals move noisily in and out of the bay. The background noise is loud and at times intrusive. Roger's passive position in bed leaves him disempowered by the movement that surrounds him.

Whereas mobility defines the hospital it is immobility of the patient that shapes the processes of the medical care they receive. The patient is rendered a passive, immobile recipient of care provided by a moving, connected professional working in a hospital that relies on the movement of patients through and out of the physical building.³⁶ The hypermobility of the professional is interpretable as a sign of power.

4.2 | The second narrative layer—Macro movements/expressions (Jane)

The second layer of the narrative was the larger, more obvious body movements that people made. Jane's is a story of chaotic movement. The chaos narrative imagines life never getting better, and stories are chaotic in their absence of narrative order.¹⁰

Jane was admitted to the acute medical ward because she had fallen over, and as she had been unable to get up, had remained on the floor until her carer arrived later in the day. She had sustained a fracture of her left hand but is otherwise medically well. She has been placed in a bed facing the nurses' station and people move constantly in front of her past the foot of her bed. The background noise is almost overwhelming.

Jane constantly readjusts her position, makes big back and forwards movements, leans in towards me, rocks sideways and makes expansive gestures to people passing by. Jane seems like the embodiment of the hypermobile environment that surrounds her. She talks in fast staccato unpunctuated sentences and interrupts her speech with sharp, quick bursts of laughter.

Jane starts the conversation with no prompting from me:

J: Yeah yeah. You get fed up you know especially new places I think people like me make you go funny don't they?

Looks directly at me, chin raised, mouth downturned, brow slightly furrowed. Screws up eyes, mouth square shaped, leans towards me with forced laugh lasting seconds. Stops instantly, leans back, mouth downturned, eyes relaxed, chin up, looking behind me:

P: In what way?:

J: It's not my fault I've never had children I've never been married did you know that yeah.

Quick shake of head, lips pursed, brow furrowed, looking at me, raises chin and eyebrows; eyes wide, mouth downturned:

P: I didn't know that about you:

J: You do now, are we talking already?

Face relaxed, small nod, looks down at tablet, back up at me, rapid explosive laugh, stops instantly and looks to left:

P: We are. Talking already:

J: Everybody keeps thinking they put me down as Mrs and I think I'm supposed to pay for.

Looks at me, looks to right, eyes slightly furrowed, mouth relaxed. Looks at me, turns head to left, moves head centre, eyes still left.:

J: The care that I have cos they charge me for it they think that I'm.

Small jerk of head to look at me, mouth downturned; moves head and eyes constantly from side to side as follows movement of people behind me, brow furrowed, mouth tight:

J: Hello.

Sudden exaggerated eyes and mouth wide, hand raised in greeting as someone passes behind me:

J: [mouths] my friend.

Instantly drops hand, face relaxes, still looking behind me, rapidly indicates to right with sweep of hand. Shoulders raise, short forced laugh:

The use of video within the context of the ward enabled the participants to react and respond to their current situation without having to rely on recall of the experience. The word that seems to describe Jane is "manic". At no point is she physically still, and her words feel physically mobile, leaping in topic and place. This fragment of conversation and its accompanying movements takes only 43 s, includes approximately 44 movements and micro movements and changes topic seven times. It is impossible to verbally scaffold³⁷ Jane's conversation as it leaps from topic to topic.

The chaos of the acute ward appears to have become embodied in Jane's movements and words. Jane is constantly distracted by movements of people and equipment, and the conversation is dominated by background noise. Jane needs an activity frame³⁷ that could scaffold her, somewhere quiet with people who had time to converse with her—to "build relationships, connect with me".³⁸ Instead, she is in an environment of noise and movement.

Recognition of this story of Jane's verbal and physical hypermobility can start to explain why people become adversely affected by an admission to an acute hospital. If people cannot stop moving, exhaustion must soon follow. Yet Jane is not physically moving from her chair beside her bed, and the intensity of her movements in the chair are not recognised as a form of communication by the staff around her.

4.3 | The third narrative layer—Micro movements (Rose)

The third layer of narrative was identified when the sound was turned off. It was only then that it was recognised that each participant was making not only the obvious larger body movements and hand gestures, but also very small body and facial movements - "micro movements".

Rose's dementia is quite severe which will have affected her cognitive functions such as planning, remembering and language skills. She is in a new and noisy environment and in the last 2 days has transitioned from her care home to the ambulance, to emergency department and then to the acute ward where she is now. The ward soundscape is of voices, footsteps, equipment clattering, and a phone

ringing. People constantly walk past directly in Rose's line of sight. What Rose hears and sees is movement. Sitting beside her bed wrapped in a blanket Rose is not a part of this movement, she sits apart both physically and metaphorically.

R: Looks down to right and moves a piece of paper to reveal the roll of tissue:

PC: tell me about Manchester:

R: I can only move very slowly:

R: Keeps head and eyes down as she says this:

PC: that must be very frustrating:

R: swallows twice; is holding the roll of tissue with right hand and focusing on it; moves left shoulder to try to tear off a sheet but arm does not follow. Looks down at the roll and then away into the distance behind me, still holding roll in her right hand but looking away:

PC: I can see what she is trying to do with one hand and I take the roll:

R: sees me tearing off tissue.:

R: I want some paper to blow me nose:

PC: there you go:

R: Moves her gaze from downwards to the right, rocks her head twice then looks briefly at me. Blows her nose very carefully using only her right hand, she looks into the middle distance with huge eyes and tiny pupils; slowly puts the tissue down, rests her head on her right hand and rubs her forehead looking down. Raises her head, sniffs and looks directly at me:

PC: Hello?:

R: Holds my gaze for a moment; puts her head back on her hand and rubs her forehead looking down:

PC: I got you your tea Rose:

R: Continues rubbing forehead; stops, looks down to the left and right:

R: thank you:

R: Stops rubbing her forehead; looks down towards the tea mug with head resting on fingers of hand and to the right then briefly in front and up to right then rests cheek on back of right hand:

R: is that tea?:

Rose's movements are small and slow. Rose's story is a micro quest for her cup of tea. The quest narrative¹⁰ gives the ill person a voice as the teller of her own story, as opposed to the chaos narrative where the suffering is too great for the story to be told. The quest narrative speaks from the person's perspective and holds chaos at bay.

Entering Rose's story necessitates slowing down to her speed, a speed that the main author automatically assumed must be very frustrating. However, Rose did not appear to be frustrated at experiencing the world at her pace. Reconceptualising narrative through a consideration of movement has the ability to unsettle

some of our basic ideas of how we come to know the world; Rose's story illustrates that human beings trying to understand other human beings is not a clear cut business.³⁵ Slowing down to Rose's pace can lead to an understanding—a quest for a cup of tea that she cannot find on her cluttered table. The inability to acknowledge the juxtapositioning of hypermobility and slowness may well be part of the challenge to providing quality healthcare for people living with dementia.

5 | CONCLUSION

Within clinical qualitative research there has been limited development of different methods of including people with dementia whilst they are inpatients.^{2,30} This is problematic because lack of involvement can thwart the advancement of theory; hinder practice improvement; and compromise the quality of life of people with dementia and/or delirium³⁹ due to their perspectives and experiences not being included.

This paper explores and develops a research method that forefronts movement to enable people who are less verbally articulate to portray their personhood and convey their narratives to those around them. The narratives run counter to the biomedical form of coherent and succinct narrative, yet these fragmented narratives, which contained both words and movements, elicited valuable insights into what the participants were experiencing in a particular moment in time.

A broader view of communication methods opens out new possibilities for people with dementia to communicate and share their narratives and thus build relationships with those around them. Connecting with another and providing care that is truly centred on the person relies on the building of relationships.³⁸ Relationships are built on mutual understandings, communication and the sharing of narratives about self.

The narratives showed that conversational storytelling is a multimodal event and this needs to be reflected in the methodology.¹⁴ The use of videos in this study revealed layers of meaning that could be established when both words and movements were analysed simultaneously—it enabled the visual consideration of embodied selfhood and how this can be displayed; yet it is important to recognise that these videos portrayed only a tiny fragment of a person's inpatient stay. They illustrated only one specific lived moment in time.

There is a corpus of theoretical work that considers bodies and embodiment,^{15,40} however less work has taken place on the task of grappling with how we translate these theoretical insights into concrete methodological tools and approaches.⁴¹ This research has gone some way to translate the theoretical into the practical.

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CONFLICT OF INTEREST STATEMENT

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICAL STATEMENT

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REFERENCES

- Bradford Dementia Group. *Evaluating Dementia Care: The DCM Method*. Bradford University; 1997. Retrieved from: <https://www.bradford.ac.uk/dementia/>
- Samsi K, Manthorpe J. *Interviewing People Living with Dementia in Social Care Research*. NIHR School for Social Care Research; 2020.
- Abendstern M, Davies K, Chester H, et al. Applying a new concept of embedding qualitative research: an example from a quantitative study of carers of people in later stage dementia. *BMC Geriatr*. 2019;19(1):1-13. <https://doi.org/10.1186/s12877-019-1240-x>
- Mitchell W. *Somebody I Used to Know*. Bloomsbury; 2018.
- Swaffer K. *Creating Life with Words: Inspiration, Love and Truth*; 2019. Accessed 13 March 2023. www.kateswaffer.com
- Kindell J, Sage K, Keady J, Wilkinson R. Everyday conversation in dementia: a review of the literature to inform research and practice. *Int J Lang Commun Disord*. 2017;52(4):392-406. <https://doi.org/10.1111/1460-6984.12298>
- Harwood R, O'Brien R, Goldberg S, et al. A staff training intervention to improve communication between people living with dementia and health-care professionals in hospital: the VOICE mixed-methods development and evaluation study. *Health Serv Deliv Res*. 2018; 6(41):1-134. <https://doi.org/10.3310/hsdr06410>
- Bartlett R, O'Connor D. *Broadening the Dementia Debate: Towards Social Citizenship*. The policy press; 2010.
- Baldwin C. The narrative dispossession of people living with dementia: thinking about the theory and method of narrative. In: *Narrative, Memory & Knowledge: Representations, Aesthetics, Contexts*. University of Huddersfield; 2006:101-109.
- Frank AW. *The Wounded Storyteller: Body, Illness and Ethics*. The University of Chicago Press; 1995.
- Dee-Price BJM, Hallahan L, Nelson Bryen D, Watson JM. Every voice counts: exploring communication accessible research methods. *Disabil Soc*. 2021;36(2):240-264. <https://doi.org/10.1080/09687599.2020.1715924>
- Bamberg M. Talk, small stories, and adolescent identities. *Hum Dev*. 2004;47(6):366-369. <https://doi.org/10.1159/000081039>
- Bamberg M. Who am I? Narration and its contribution to self and identity. *Theor Psychol*. 2011;21(1):3-24. <https://doi.org/10.1177/0959354309355852>
- Hydén L-C. Storytelling in dementia: embodiment as a resource. *Dementia*. 2013;12(3):359-367. <https://doi.org/10.1177/1471301213476290>
- Kontos P. Embodied selfhood in Alzheimer's disease: rethinking person-centred care. *Dementia*. 2005;4(4):553-570. <https://doi.org/10.1177/1471301205058311>
- Featherstone K, Northcott A, Bridges J. Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards and its consequence. *Int J Nurs Stud*. 2019;96:53-60. <https://doi.org/10.1016/j.ijnurstu.2018.12.009>
- Prosser J. Visual Methodology: towards a more seeing research. In: Denzin N, Lincoln Y, eds. *Collecting and Interpreting Qualitative Materials*. 4th ed. Sage; 2013.
- Parry R, Pino M, Faull C, Feathers L. Acceptability and design of video-based research on healthcare communication: evidence and recommendations. *Patient Educ Counsel*. 2016;99(8):1271-1284. <https://doi.org/10.1016/j.pec.2016.03.013>
- Capstick A. Travels with a Flipcam: bringing the community to people with dementia in a day care setting through visual technology. *Vis Stud*. 2011;26(2):142-147. <https://doi.org/10.1080/1472586x.2011.571890>
- Hydén L-C, Örvul L. Narrative and identity in Alzheimer's disease: a case study. *J Aging Stud*. 2009;23(4):205-214. <https://doi.org/10.1016/j.jaging.2008.01.001>
- Hung L, Phinney A, Chaudhury H, Rodney P, Tabamo J, Bohl D. Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. *Int J Older People Nurs*. 2017;12(3):e12153. <https://doi.org/10.1111/opn.12153>
- Shepherd V. Research involving adults lacking capacity to consent: the impact of research regulation on 'evidence biased' medicine. *BMC Med Ethics*. 2016;17(1):55. <https://doi.org/10.1186/s12910-016-0138-9>
- Shepherd V. An under-represented and underserved population in trials: methodological, structural, and systemic barriers to the inclusion of adults lacking capacity to consent. *Trials*. 2020;21(1):445. <https://doi.org/10.1186/s13063-020-04406-y>
- Dewing J. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have dementia. *Dementia*. 2002;1(2):157-171. <https://doi.org/10.1177/147130120200100204>
- Dewing J. Participatory research: a method for process consent with persons who have dementia. *Dementia*. 2007;6(1):11-25. <https://doi.org/10.1177/1471301207075625>
- Denzin NK, Lincoln YS, eds. *Collecting and Interpreting Qualitative Materials*. 4th ed. Sage; 2013.
- Sutton L, Erlen J, Glad J, Siminoff L. Recruiting vulnerable populations for research: revisiting the ethical issues. *J Prof Nurs*. 2003;19(2):106-112. <https://doi.org/10.1053/jpnu.2003.16>
- Beuscher L, Grando VT. Challenges in conducting qualitative research with individuals with dementia. *Res Gerontol Nurs*. 2009; 2(1):6-11. <https://doi.org/10.3928/19404921-20090101-04>
- Wood F, Prout H, Bayer A, et al. Consent, including advanced consent, of older adults to research in care homes: a qualitative study of stakeholders' views in South Wales. *Trials*. 2013;14(1):247. <https://doi.org/10.1186/1745-6215-14-247>
- Benson C, Friz A, Mullen S, Block L, Gilmore-Bykovskiy A. Ethical and methodological considerations for evaluating participant views

- on Alzheimer's and dementia research. *J Empir Res Hum Res Ethics*. 2021;16(1-2):88-104. <https://doi.org/10.1177/1556264620974898>
31. Boyle G. Recognising the agency of people with dementia. *Disabil Soc*. 2014;29(7):1130-1144. <https://doi.org/10.1080/09687599.2014.910108>
 32. Kitwood T. *Dementia Reconsidered*. Open University Press; 1997.
 33. Schwartz D. If a picture is worth a thousand words, why are you reading this essay? *Soc Psychol Q*. 2007;70(4):319-321. <https://doi.org/10.1177/019027250707000401>
 34. Goldman E. *As Others See Us: Body Movement and the Art of Successful Communication*. Routledge; 2004.
 35. Andrews M. Quality indicators in narrative research. *Qual Res Psychol*. 2020;18(3):353-368. <https://doi.org/10.1080/14780887.2020.1769241>
 36. Collins P. Stories of (Im)mobility: people affected by dementia on an acute medical unit. In: Vindrola-Padros C, Vindrola-Padros B, Lee-Crossett K, eds. *Immobility and Medicine - Exploring Stillness, Waiting and the In-Between*. Palgrave Macmillan; 2020.
 37. Hydén L.-C. *Entangled Narratives: Collaborative Storytelling and the Reimagining of Dementia*. Oxford University Press; 2018.
 38. Bridges J, Collins P, Flatley M, Hope J, Young A. Older people's experiences in acute care settings: systematic review and synthesis of qualitative studies. *Int J Nurs Stud*. 2019;102:103469. <https://doi.org/10.1016/j.ijnurstu.2019.103469>
 39. Symonds T, Dadich AM, Collier A, et al. Video reflexive ethnography in hospital with people with dementia and delirium: can it be done? In: *Conference Proceedings: ACSPRI Social Science Methodology Conference*. Vol 12-14. University of Sydney; 2018:130-140.
 40. Kontos P, Martin W. Embodiment and dementia: exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*. 2013;0(0):1-15. <https://doi.org/10.1177/1471301213479787>
 41. Chadwick R. Embodied methodologies: challenges, reflections and strategies. *Qual Res*. 2017;17(1):54-74. <https://doi.org/10.1177/1468794116656035>

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