Different Ways of Being, Doing and Telling in Qualitative Research: Lessons From d/Deafblind Studies

Annmaree Watharow[1] and Sarah Wayland[2,3]

Abstract

Traditional qualitative inquiry research methods exhort us to look for the 'good' story tellers who use metaphors to describe their experiences, emotions, and events. This privileges abled-bodied individuals, meaning that without full individual accessibility for people with disability is not achieved. The objective of this paper is to present a case study on inclusion of research participants who live with deafblindness. This case study posits where qualitative story telling spaces currently are; whose voices occupy these narratives; what is said and how it is said: and the performative aspects of the qualitative inquiry currently. Research including people with disability is reflected in the evidence base, however the question that if qualitative methods don't seek to explore and understand these differences, epistemic injustices will be perpetrated. The case study reflects on a research project whose methodology sought to solicit hospital experiences for those living with deafblindness. The Australian study of 18 deafblind participants with wide ranging communication needs, shared in-depth narrative inquiry stories told in: 'snapshots' of moments of disempowerment; through sign and vibrotactile communication; usage of the strong verb with metaphor rarely present except to exclusively describe instances of dehumanisation. Narrative inquiry method when used with people who are deafblind is predominately chaotic with some tense instability for non-signing participants. Emphasis is via repetition, altered pitch and expletives. Touch centricity is fundamental. Dissonance is evident between words used and stories told. The thematic analysis identified a need to reflect epistemically across the creation of any qualitative project from beginning to end, focussing on what is being said and how it is being said or signed or felt. The conclusion of the paper provides a roadmap for future projects to ensure improvements in the enhancing of awareness of different ways of being, doing and telling in qualitative research methods.

Keywords

qualitative research methods, deafblind, dual sensory impairment, dual sensory loss, multi-sense disability, disability, epistemic injustice

Author Positionality

This article explores the process of understanding participant stories and ways of telling these, through the researcher-as-audience lens. It is important that we clearly articulate where we stand in the research space as these points shape trust building, truth telling and meaning making around what is said and even unsaid. Author one is part-insider as lived experience researcher with lifelong deafness and acquired blindness, and part-outsider as clinician and academic. Author two is an ally, research supervisor and academic. Our collective position in this project is that everyone gets every assistance and access requirement are met, no matter the time, cost, or difficulty. This is the necessary first step but as this article explains, it is

[1]Centre for Disability Research and Policy, University of Sydney, Australia
[2]Faculty of Medicine and Health, University of New England, Australia
[3]Manna Institute, Regional University Network, Australia

Corresponding Author:
Sarah Wayland, Faculty of Medicine and Health, University of New England, Parramatta, Armidale, AU -NSW 2351, Australia.
Email: swaylan2@une.edu.au

not enough to elicit stories, we have to understand what is being said by people who have diverse ways of expression.

Introduction

Qualitative research requires continual reflection on, and refinements to, the ways in which representation of and engagement with people whom the research is designed to benefit. Qualitative methods can limit participation by not providing for accessibility. By failing to recognise participants with different ways of 'being' qualitative method adjustments may need to be made to do the 'doing' of the research. Without extra investment to reach what we may refer to as 'hard to reach' audiences i.e. people with communication needs, we can unintentionally or intentionally exclude these voices. Without attention to these needs and differences we cannot capture the myriad and nuanced ways participants tell their stories. When research fails to seek out, acknowledge and understand these rich (differently told) narratives of lived experience of disability, the evidence base is thinned, silenced, or distorted. We argue these stories of difference matter to determine or shape health policy.

> "If our institutions and systems actually serve and benefit people living with disability, we need to seek out, listen to and disseminate the voices of those users of services at the heart of the system/s under examination" (Watharow, et al., 2023, P 17).

Theoretical Framework

Fricker's (2007) concept of epistemic justice and power is used in this article to underpin our quest to reduce injustice, exclusion, and silencing of stories told by those living with disability generally, and in this article, deafblindness specifically. An epistemic injustice occurs when agents are wronged in their capacities as knowers (Fricker, 2007). People living with disability, including deafblindness, are the expert-knowers of their own impairments, conditions, and experiences; they are the ones who know if social systems and institutions are providing benefit, not the providers of those services. If research does not seek, understand, and value these lived experiences then an epistemic injustice occurs. If we fail to consider different ways of telling of this expert-knowledge, we are limiting the capacity for the community to be beneficiaries of the stories and the knowledge generated.

We believe qualitative researchers (and indeed all researchers) must collaborate and coproduce with people living with disability. Fricker asserts that without such immersion to develop 'testimonial sensibilities' we cannot grow the 'perceptual awareness' needed to understand storytellers and their ways (Fricker, 2007).

Asking the question '*why does it matter whether accessibility is provided, methods are adjusted, and consideration is given to different ways of telling and understanding?*' We say that an epistemic injustice occurs when participants are not

asked, are not heard, and are not made legible. By not conducting inclusive research, failing to provide accessibility at all stages for all people in the research space and/or by not understanding different ways of being, doing, and telling, we are guilty of epistemic and testimonial injustices and perpetuating inequities in research. When we engage in these injustices we limit additions to the evidence base, which then limits inclusion in public policy, teaching resources and simply erasure of diverse voices in the knowledge base. Promoting better outcomes for D/deafblind communities requires an informed and truthful evidence base on the expert-knowers.

A previous article (REDACTED) examined how important the provision of accessibility for different ways of being, and methodological adjustments for conducting research are to avoid ableist practices, exclusions, and assumptions. In this article, we provide insight into the preparedness for researchers to not only do we need to challenge ideas of accessibility, ableism, and methodological adjustments but we also need to turn a lens to how stories are performed and told. The focus on previous work by Berger and Lorenz (2016) demands that showing how research is undertaken, is the innovative approach provided by this paper. The emphasis being that people living with disability are disproportionately disadvantaged in almost all social domains and in community participation more broadly. People living with deafblindness are amongst the most marginalised (World Federation of the Deafblind, 2018). This disadvantage:

> "Equips people living with disability, and other marginalised persons, with unique epistemic insights into the nature of their own exclusion. Given this, any project which aims to mitigate instances of disadvantage and discrimination needs to avoid committing epistemic injustices against these populations. Failing to do so constitutes both an act of injustice against knowers with epistemic insight but just as crucially, directly weakens the capacity for any such project to realise its stated goals." (Watharow et al., 2023, p.12).

Being d/Deafblind

We use 'deafblindness' in this article as an umbrella term to include all those living with co-occurring hearing and vision loss such that one sense cannot compensate for the other. Other terms include dual sensory impairment, dual sensory loss, multi-sensory impairment. We use the Nordic definition and an abridged summary of the explanatory notes that accompany the definition to anchor this article.

"Deafblindness is a distinct disability. Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology" (Nordic Centre for Welfare and Social Issues, 2018). From the explanatory notes, key complexities of deafblindness see Table 1, noting

Table 1. Key Complexities of Deafblindness.

- Distinct and complex disability
- Hard for each sense to compensate for the other
- Time consuming
- Energy draining
- Activity limiting
- Participation reducing
- Information is received in fragments
- Communication, access to information and mobility are affected
- Tactile sense is critical as a conduit of information
- Communication technology, assistive devices, interpreters and adaptions to the environment may be required

Reference: Nordic Centre for Welfare and Social Issues.

that irrespective of the list, human assistance and support remains critical to access to information, mobility, and safety (Watharow, 2023, p. 69).

Deafblindness is a complex disability with complicated ways of being, doing and telling. Undertaking qualitative inquiry then requires different ways of 'doing' the research (preparatory processes, immersion, partnerships with disabled people's organisations, accessibility and accommodations, extra funding, and more time). The research space may be physically bigger with more people carers, support workers and interpreters for example and, service animals and assistive technology. The narrative outputs; the 'telling', are diverse too, and differ from the sighted hearing in myriad ways. This is the focus of this article, to examine some of the ways of 'telling' stories with this population. Without understanding these, researchers, protectors, policymakers, practitioners, and community cannot access their epistemic insights. Without research that truthfully reflects these experiential realities, our social, legal and health supports for example run the real risk of being less beneficial, expensive, and more irrelevant. The loss, distortion, or failure to comprehend these insights is an epistemic injustice and further marginalises people who live with deafblindness or other disability.

From the beginning of any research project, a commitment to ensuring accessibility needs of participants and their lived experience are addressed research is required. If accessibility is not achieved, the research project cannot consider itself inclusive of different ways of being, doing and telling. The first step in planning a research project is to understand and embrace the ways stories are told by people with disability and differences. The next section of the article explores the potential performativity of qualitative research and what that informs us about different ways of telling.

The Traditional Qualitative Narrative Inquiry

Qualitative inquiries cannot simply relate to spoken and written stories. They must include visual performance, signing, and tactile elements such as touching and vibration. Events and emotions can be expressed in permutations of multiple modes and sometimes these ways are different too, from one individual, culture, or group to another. Sometimes different modes of telling occur within the one interview.

Early work by Kitchin (2000) notes that qualitative research involving people with disability should be 'disabled-friendly' in terms of utilising emancipatory research approaches to give voice to marginalised people. More recent work by Berger and Lorenz (2016) in their book 'Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World 'notes that the intersections between disability research and qualitative research methods rarely explores the 'showing' of how to conduct research, rather it emphasises the value of qualitative research as an activity of social justice to highlight lived experiences. The insistence that research focused on disability centres the inclusion of people with lived experience (or questions that seek to better understand the needs of people with disability) rather than dismantling methods of qualitative research is required to ensure that research does not exclude people through the accessibility barriers of the chosen approaches. Acknowledging and dismantling barriers for research participation ensuring that those referred to as 'hard to reach' requires reflective practices in research design to consider both the population of participants as well as the accessibility of research tools utilised to collect data. Research insights, about the ways in which people process sensory input and communicate, provides research design with the opportunity to shape the ways in which data is collected (Alper, 2018). As qualitative research keeps pace with challenging ableist methods and embracing neurodiverse ways of communicating (including dual sensory impairments and other communication disability) so to is the need to provide space for participant inclusion of those who are 'nonverbal, bodily, sensory, emotional forms of communication and dialogical competence, or by using augmented communication strategies such as gestures and nonspeech vocalisations (Nind & Strnadová, 2020; Teachman et al., 2018). Knowledge of inclusive research with people with profound and multiple disabilities, (what Gjermstand et al., 2022, refers to as a sensory-dialogical approach) is a welcome addition to academic research.

Reflecting upon this movement in methodological understandings this paper examines this state of knowing and provide an example of how, within the complexity of living

with deafblindness we hear from those who tell their experiences, events and emotions sit uncomfortably alongside conventional ideas of what constitutes a 'good' narrative.

We acknowledge that narrative inquiry seeks to appreciate human experience "by understanding how the individual story has been put together within the mind of the teller" (Minichiello et al., 2008, p. 276). Traditionally, for sighted-hearing researchers, as Bernard (2013) writes: "Good ethnography is, at its best, a good story, so find trustworthy informants who are observant, reflective, and articulate – who know how to tell good stories – and stay with them" (p. 173). Likewise, Hamilton and Bowers (2006) insist that "theoretical richness requires a bias towards individuals who have had an experience and are able to express themselves concerning it" (p. 824).

Favouring the eponymous 'good' storytellers (i.e. those able to articulate their stories simply to the researcher) empower native speakers, the sighted hearing, educated and articulate over other communicators and forms of communication. This favouritism may harm those who are less privileged, leaving their insights unsought and unheard.

Method

This research project sought to explore the hospital experiences of people living with deafblindness in Australia. The process of conducting, analysing, and reflecting on this project, is used as an exemplar of different ways of being, doing and telling (Watharow & Wayland, 2022), with the present article examining closely the 'telling'.

Eighteen participants living with deafblindness (multiple impairment causations, diverse communication modes and heterogeneous living realities) were engaged with full accessible for the individual support in a narrative inquiry about their hospital experiences. Ethics approval No. REDACTED, informed consent was obtained with all information sheets, consent forms in formats chosen by and accessible to the individual.

The following process was utilised to ensure informed consent, noting that people with sensory impairment often find information sheets and consent forms too long, confounding and potentially intimidating. They are usually in non-accessible formats. For this research, plain English information sheets and consent forms were available in several formats: standard, large-print, very large-print, braille and electronic. These sheets varied in page extent according to format and font size. In addition, academic jargon to a minimum. All sheets, forms and interview guides were vetted by a peer researcher who works with the deafblind—to check for appropriateness and cultural-linguistic ease. Because Likert scales are deemed problematic (World Café, 2017), they were removed from an early draft of the interview questions. Questions with multiple concepts were broken down; for example, *Did you feel anxious or distressed?* became two questions: *Did you feel anxious?* And *Did you feel distressed?*

Following consent being achieved, participants were interviewed in the locations of their choosing with the supports, aids and interpreters needed and chosen. Interviewees could choose the mode of interviewing: virtual (2), National Relay Service (an Australia wide phone service for people with a hearing impairment) (2) face to face interviews (14). Interpreters were required for eight interviews.

Through an observational reflective analysis, that allowed the primary researcher to focus on 'doing and being' in the interviews, the recognition by both authors to add insights by 'telling the story of the story' to augment the very thin knowledge platform of some of the ways of telling by this diverse population was identified. Reviewing the literature was an iterative and evolving process that sought to provide a theoretically informed and located rationale for the research question and design as well as being informed by the data analysis itself and the themes that were subsequently generated (Braun & Clarke, 2006). These differences within differences which lie outside the traditional realms of qualitative methodologies are now explored.

How Stories are Told

The experience of undertaking qualitative interviews for this project provided insights that relate to what it means to 'tell' a story through the experience of a dual sensory impairment, meaning that the story telling wasn't just reliant on unaided retelling by an unassisted participant. Narrative vehicles included written email correspondence, relayed telephone exchanges, signed (visual and tactile), first and second languages, and spoken forms. One key difference from sighted-hearing qualitative inquiry is the need for and presence of testimonial support i.e., storytelling aides and aids.

The non-embodied elements of a narrative interview are the components that evoke a performance in a reader's mind (Berns, 2014). There were a heterogenous array of performative elements observed in this project that demonstrated diversity within diversity. These elements included: touch centricity, visual and vibrotactile elements and a dominance of chaotic narrative styles. There were different ways and frequencies of emphasis: repetition, the use of the strong verb, the emotional descriptor, the interesting use of metaphor and its otherwise absence, characterised some stories and not others. The importance of the inclusion of the metaphor was situated in the awareness that those affected by sensory loss use many phrases and metaphors to describe how they experience life. The progress of the storytelling by participants who are D/deafblind notes that no one gives a 'hero'-style illness narrative as Woods (2011) where the patient overcomes all odds and emerges victorious, rather the descriptors as metaphors elucidate the story and allow the listener to engage in the difficulties of seeking health care. Finally, the marked dissonance was evident between some words and events; meaning that the participants stories are centred in a place of being accustomed to discrimination and poorer levels of

service and treatment, their words take on contradictory meanings. 'Good' may mean 'I survived', not 'I received quality care and communication'. There is dissonance at work too in how most participants noted the care and communication failures eclipsed the rigours of the diseases, surgeries, and injuries. Words of distress are commonplace in most stories (89%). Finally, reflections on the interviews on hospital experiences provide insights into the ways in which qualitative interviews must be attuned to different narrative elements and meaning making. Individual elements are now considered.

Touch-Centricity

Touch can be central to how a story is told by people with deafblindness as it becomes a principal conduit of information. For some who may be nonverbal it is also the principal way they are able to tell stories. All participants in face-to-face interviews used touch to access the environment e.g., touching doorways, tables, and chairs. Touching support people and interpreters was common and necessary too. Touching white canes and service animals was also important in communicating information about the environment for half of the participants. For some, touching the researcher (author one) and or accessibility assistant was a part of the narrative events, for example, to indicate emphasis or agreement. Tactile signing and or the deafblind manual alphabet are used by almost one half of the participants. Two participants are learning tactile sign language and two are manual alphabet users if communication is faltering or concepts require clarifying. Tactile communication in interview settings takes longer to conduct and share with the researcher which requires communication mandated by rest breaks. Identification of these experiences means that the researcher needs to be comfortable with methods that will stop-start-stop. This is a normal part of social life for many who use these methods and not an artificial or imposed complexity.

Testimonial Support

The majority of interviews (16) featured additional bodies and voices. The role of any and all of these added voices was to unpack, relay and assist participants to communicate. Many of these extra voices actively contributed to narratives in order to corroborate, add contextual detail and support the participants in telling their experiences. These 'others' bear witness to the system failures, and few successes, that directly impact the participants. Being attuned to the need to watch for taking over and talking over by the additional people present for interviews, no examples where the principal narrator (the participant) was not prioritised, were noted. Interestingly, all the extra voices were either invited by the participant or requested permission to contribute or clarify any missed words or nuance from the sharing of the stories.

Some examples of added voices in the research conversation demonstrate the ways in which clarification or story 'add ons' offered insight without removing the primary focus of storytelling away from the participant.

A participant's support worker interposed to say, 'This is (support worker name), we think they give her medication and restraints to calm her down.' In another interview, the interpreter asked, 'Could I please interrupt?' then explained the difference between interpreter funding in public versus private hospitals, in addition to ensuring agreement from the participant as to how the clarification enhanced their storytelling. This pertains to the participant's two diverse experiences: disempowerment in the public system and empowerment in the private. The participant nodded their head in approval and signalled 'yes, yes, yes' in Auslan, during this exchange.

One partner, of a participant, leaned towards the iPad during the interview, saying, '(Name of partner) speaking … it's not just the doctor and nurse. It's everyone: the allied staff, the food staff, and cleaners— they all need education and awareness.' Sometimes, a participant invited their interpreter, communication-guide, or partner to speak, because they have often been intimately involved in the hospital spaces, sharing and hearing about experiences, either visiting or as the professional interpreting in hospitals.

The interpreter for one participant said, '(interpreter name) speaking' and told of their frustration of waiting four or more hours for the hospital to approve their interpreting services— requests go through 'this person and this person and this person.' This interpreter spoke also of when she was (finally) engaged to interpret, the staff did not know how to use interpreters and would say, 'Tell (the participant) what will happen' while looking at the interpreter. The interpreter would say, 'Hang on! Don't talk to me. (The participant) is your patient.' The participant then took up the story, saying this happens, 'Again, again, again.' The co-construction of the narratives allowed for the primary focus to exist with the participant, and then the additional interpreters, support persons or others enhanced the tone, meaning and urgency of some of the storytelling approaches.

Visual and Vibrotactile Elements

Exaggeration of visual signs to indicate magnitude of event or distress was common in eight interviews. Kinaesthetic performances of narratives by those participants were observed. One participant placed their hand in front of their face to indicate distress at being pulled along by 'aggressive, aggressive staff.' this movement was captured by the accessibility assistant as well as by the limited vision of author one (the movement obscured the lips, so lip reading was not possible).

Another participant placed their index finger on the side of the temple to indicate I am thinking. Hands are used to display emotion with hands on hearts, in the air, shaking and or wringing of hands. These interviews were very much performed as well as told or communicated. This indicated that video would be useful as well as audio recording, as a future

recommendation. There likely are many more examples of visual performance failed to capture with just field notes, this is noted in the recommendations section of the paper.

By contrast, tactile performative elements were absent from the remote interviews via national relay service or email; perhaps, those who need multiple sense communication choose face-to-face contact.

Narrative Styles

Participants, as with all qualitative research approaches, choose what to tell stories to tell and how. The qualitative interviews demonstrated a range of narrative styles. What was important to embrace was a reminder that predominating is the 'chaos' narrative where linear and ordered progression through an experience of health-related events is largely absent. This is not to be confused with Franks (2010) narrative typology of chaos which relates to the illness experience. Participants are often overwhelmed by negative events and wanting to emphasise these as significant by revisiting and reinforcing how dehumanisation, negative touch and lack of communication mar and maim the patient experience shared.

The exceptions to temporal chaos narratives are:

1. The therapeutic emplotment exposition utilised by four participants with health care backgrounds (allied health, nursing, nursing assistant). In these they follow the classic medical progress from past history to the history of the present illness then diagnosis, treatment, complications, discharge and what happens in the post discharge space.
2. The narrative style in the two email interviews followed more traditional plotting of 'this happened followed by this'. Perhaps those choosing email had proficient written English and were able to better order their narratives. A larger study will be needed to clarify these issues of language. The two national relay chats were like the face-to-face narratives with disordered emplotment and repetition of key events.

Again, notably the medical detailing is there just to contextualise the placement of problems with access to information, communication encounters and staff transgressions and failures. Disordered narratives are the norm (12 interviews). One participant groups experience by date, as if their mind holds a catalogue of entries indexed by year and event. This story moves back and forth in clearly marked time periods, as cards were located for events. These events are striking in that they are about moments of disempowerment not disease progression. So, this participant didn't narrate any admission from beginning to end but rather said: 'they sedated me on (date)' or 'took my cane off me (date)' or 'just left me there (date).' The dates on which these things happened are not ordered by time from past to most recent. Instead, they are grouped into 'like' events such as restrictive practices on different admissions.

Another participant, who has post-traumatic stress disorder (PTSD) from multiple institutional abuses (including hospitalisations), offers experiences as snapshots in nonlinear order, often falling into present tense. They describe an event from one time in brief, quickly followed by another in a different time. They know what happened but do not relay it in traditional narrative style. These are episodes too of restrictive practices, forceful touch, humiliation, and degradation.

Through reading and re-reading the transcripts and putting events on cards, a narrative of experiences were constructed. As to whether this is an amalgam of many experiences or montage of one, the former seems most likely. This participant exhibited signs of distress, saying, 'I can't talk more about this.' They paused, self-settled then talked about another event. This particular interview underscored the importance of debriefing to leave participants in a positive emotional state.

Another participant tells the story of one admission in collage fashion, with failures concerning interpreters as a central motif. The hospital's failure to book an interpreter, the interpreter's failure to turn up, the interpreter's failure to stay, the hospitals and interpreter's failure to apologise, and everyone in the system's failure to recognise the consequences for this participant. It takes many rereads of the transcript to understand the linear events that occurred across five days, again putting details on cards, checking, and rechecking their sequence.

For three other participants, the narratives centre around the failure of staff to assist in toileting by answering buzzers in a timely fashion or providing orientation to bathrooms. The narratives keep returning to the moment or moments where they are in their beds or on the floor, soaked in excreta; "they left me there to piss myself" from one, "I just lay there, waiting, wating, waiting. Sometimes I wet myself. And I cry." These events are repeated again, punctuating the narrative upending linear progression.

Yet another participant has multiple layered experiences as a patient, a carer, and a visitor. They experience barriers in all roles. These are only possible to navigate by dividing into roles and events e.g., this is from when they were visiting their spouse, this is from the accident, this is from going to outpatients. Again, not a linear narrative but illustrative events centring around accessibility, communication, and mobility; barriers to entry in hospital (signs, lifts and absent tactile); barriers to finding loved ones in their right beds when moved around; barriers to receiving and giving information (not knowing what is going on with themselves or their spouse); barriers to finding staff (solution: stand at the nurse's station until they turn up because 'they always do').

Still other participants tell stories as serial single episodes of disempowerment or empowerment, rather than a plotted narrative. This method of storytelling is common to most participants. What is remembered is not the flow of medical and surgical patient life but the indignities, harms, and barriers. 'Not knowing what is going on' is the predominate state.

The Strong Verb

All narratives featured strong verbs even the few 'good' experiences of healthcare communication (the focus of the Doctoral study) underpinned by a commonality that those living with D/deafblindness experienced the ubiquity of forceful touch in everyday health interactions. The following are examples, highlighting the verbs describing negative touch and other experiences in hospitals. Tense varied depending on if instability was present. Tense instability is not a feature of the email exchanges, or the signed interviews where the convention is to indicate time at the beginning of the grammatical construction of the story. Tense instability is most noticeable in the chaotic narrative style. Several non-signing participants slipped into present tense when detailing distressing experiences. This slippage was not noted by the researchers during the interviews for the study. Revisiting the transcripts again after a narrative course allowed the researchers to be more attuned to devices of language.

The verbs associated with episodes of negative touch experiences (unwanted, forceful and or unexpected touch) included:

Attack.
Drag/ged/ging.
Force/d/ing.
Grab/bed/bing.
Held
Lash.
Manhandled.
Poke/d.
Pull/ed.
Push/ed/ing.
Shake/ing.
Shove/d.
Take.
Touch/ed/ing.

Emotional Pain

Words (verbs and adjectives) denoting emotional pain were common: frightened, panic, anxious, brutalised, crying freaking out, frustrated, confused, pain, traumatised, terrified. Of these, frightened was the most common descriptor appearing in 16 of 18 narratives, followed by anxious and panic in 12.

Adjectival Associations

Several participants made word associations: a staff member doing their job is 'nice' or 'lovely' but one who, by attitude or action, gives poor or no care is 'mean' or 'unkind'. Further, one participant described the smell of the perfume worn by a 'nice' nurse, so this smell takes on sensate associations, and is comforting and reassuring. When asked to consider how hospital experiences could be improved all participants requested that staff be 'kind' and by this they clearly meant, provide care and communication, and do their jobs.

Metaphors

Linear stories and metaphor-laden narratives are valued in traditional qualitative inquiry as mentioned previously. For the deafblind participants engaged in this project two striking observations were made: the absence generally of metaphor (and similes). Metaphors and similes however were very much present when describing experiences of dehumanisation. Some examples from the interviews are:

A participant in her experience of being sedated in order to receive a health intervention referred to herself as *'I'm in the too-hard basket'*, so too were the reflections articulated by others like *'I felt like a bird in a cage'*- relating to an experience of being trapped or controlled whilst in a health care setting, with three using the term to describe their time in hospital. The descriptions mirrored historical information seen previously in a disabled people's organisation as well as finger spelled (deafblind manual alphabet) in a video from 1991. This powerfully reinforces the value of cultural immersion and partnerships with these organisations to gain testimonial sensibilities to layer understandings of the 'telling', another role of qualitative research in sharing hidden stories.

Other metaphors spoke to the speed at which people with D/deafblindness were cared for in healthcare settings; 'all those mouths going 100 miles an hour and how I just couldn't understand what they were saying' was the experience in a recovery ward which led to security being called to hold the confused patient down, as told to the researcher. Others spoke of losing agency noting '(the deafblind) are just cattle class", or '[we are just] pulled along like a dog on a leash' as shared by four participants.

Finally, the care received by health professionals was referred to as 'it's a lucky dip', meaning that care was allocated as a random offer of a staff member being 'mean' or 'kind'. Participants used the metaphor of being 'a paper doll' to reflect on the dehumanisation they experienced in hospital.

In those interviews marked by a dearth of metaphors strong verb and emotional pain descriptors were the prevalent devices of the narratives. It was important to note that the majority of participants left school early (prior to 14 years old) or were schooled in dedicated institutions for the education of deaf and or blind children. One participant received a limited education at an institution of children with cerebral palsy. It would be remiss to identify how educational attainment may have explained the ways language was used by the participants.

Emphasis

Participants used diverse forms and sensory modalities to emphasise their experiences. Participants with limited traditional communication capacity were able to utilise emotive

Table 2. Use of Repetition in Interviews.

Repetitions:

No, no, no' (Auslan sign repeated in the air, in response to 'Did you have an interpreter?')

'They (the doctors) just **talk, talk, talk'**

'It isn't right, not right.' By one participant and another who combines phrase repetition with exaggerated visual sign such that the interpreter flagged a change in emotional range by relaying:

'I've taken in the medical report a number of times, with me, and they've never ever read it. **Never**. **Never**.'

'Deafy, dumby, deafy, dumby' participant repeating chanting of children at school

'I don't like that; I don't like that and I just push them away.' Participant relaying an unexpected needle or physical examination and says this repeatedly in the narrative going back to those negative touch events

'It's more tiring than trying to recover, having to start at Ground Zero all the time. Same thing again. **Same. Same. Same. Same**.' Referring to the constant need to re-educate professionals

'They didn't always communicate with each other, so you'd have **to start again, start again.'** Referring to the failure of staff to hand over important information such as the deafblindness itself and the communication methods preferred by the participant.

language, words, and phrases alongside physical/visual/tactile actions to demonstrate the complexity of their stories.

There was much repetition to emphasise the extent of the events and emotions. The repetitions punctuated most face-to-face narratives meaning that linear progression could not always be sustained. In several cases the repetitions imbued the narrative with a sense of temporal chaos. (Table 2).

Repetition could take the form of repeated oral or signed statements. Emphasis could also be seen and or felt in visual or tactile sign language where signs are exaggerated to indicate a bigger, larger, more extreme emotion or event. Some verbal participants emphasised their narratives with voices rising or falling in amplitude. Sounds and expletives were also used to emphasise events and emotions. Further observations in the visual and vibrotactile elements, have been described below.

Repeated Words and Phrases

In twelve of the participant interviews was the repetition of 'waiting. waiting. waiting' to denote the common experience as people with deafblindness wait all the time: for services, for interpreters, to be allowed out of bed, for buzzers to be answered, to find out what is happening. By repeating the word waiting the participants are mirroring the long passages of time they spend in limbo. Repeating the upsetting details of a story was a common marker of distress in the face-to-face narratives but not present in the interviews that were conducted by email in written English.

Theatrical and Quickened Signing/Gesture

For eight participants, their signing would get more theatrical and quickened when emphasising distressing parts of story. One participant banged on the table at several junctures to reinforce their point about feeling abandoned.

One non-verbal participant was observed with their fists clenching and moving in the air repeatedly signing 'no, no, no' in Auslan. They were referring to the absence of help from staff. For tactile sign users e.g. hand over hand or deafblind manual alphabet, banging on the table is a social norm for indicating both turn-taking and emphasis. In one interview, when relaying how no interpreter came for five days, the participant banged the table repeatedly. The vibration sent its own message of distress, felt by all present.

Some participants touched the researcher's hand (author one), signifying emphasis of a particular point; for example, four participants touched author one's hand while the interpreter was relaying what was said, moving in a 'yes, yes, yes' motion tactilely. This underscores the importance of contemporaneous research note taking by lived experience researcher and accessibility assistant to enhance reflections on content and meaning. These actions also demonstrated the participant agreeing with the interpreter (the participant knows and trusts the interpreter to relay accurately as they have chosen this person themselves).

Voices

Participants who are verbal and/or oral English speakers often raise or lower their voices to make a point. One raises their voice when saying 'I had **no idea** what the treatment plan was'

Conversely, one participant spoke in a whisper 'I don't like hospitals.' Author 1 doesn't hear the whisper, but later reads the words in the transcript with the notation of its quietude, and the accessibility assistant also notes the drop in volume.

Keening sounds came from one nonverbal participant (a rising pitch sound when discussing their anxieties and fears, underscoring their depth). This sound was not made when they signed about pleasant events such as meals or excursions with support workers.

Expletives

Participants occasionally used expletives as a device to highlight their frustration at repeated health system and staff failures. One participant said, 'it was terrible, you just have to

repeat yourself all the time, every time you saw someone you'd have to say: "bloody read the file" but they don't'. Another snapped, 'I was so sick and tired of this, so I asked the question, "Have you got an interpreter? If you don't have an interpreter, then fuck off."'

Dissonance

Dissonance is understood here to mean a discrepancy between a word used and the event it describes. Experiences may be characterised as 'good' 'smooth' 'okay' when an examination of the events contained in the interviews illustrates that the experiences are clearly not so.

An example (and the majority displayed this dissonant effect) is when one participant describes their experience as 'good' but what follows is a catalogue of disempowerment, delays getting interpreters, episodes of poor care and the humiliation of waiting so long for toileting assistance that they wet themselves. They cry.

So then, what does this 'good' really mean? It clearly doesn't correlate in this project with these participants, with a positive patient experience of good care and good communication. When pushed on this, the participant replied, 'I survived…but…I'd have to be really crook to go back.'

This is also an example of internal dissonance similarly to that described by Avery (2018) where a participant then avoids as far as possible, subsequent encounters with the system. Most participants indicated they would delay going back to hospital as long as they could with one participant vowing never to return to hospital:

'Not ever.'

So, *good* means I survived an awful experience. Smooth means anything but, the participant experiences really rough treatment but survives.

Okay means NOT okay. For many participants there was tacit acceptance of 'this is how things are,' as well as relief at surviving hospital experiences.

There is further dissonance in the absence from narratives of experiences of actual bodily disruption except when used to contextualise problems with communication and or care. Dissonance is also strikingly absent from the four narratives from participants who had worked in healthcare. Not only did they demonstrate a therapeutic emplotment, but they also characterised their experiences as 'inhumane' 'illegal' 'bad' and 'terrifying.'

Discussion

The experience of diverse storytelling styles and conventions outlined here is a contribution to the qualitative methodology arsenal of understanding different ways of being, doing and telling. Obtaining impairment histories and living realities information was a necessary prelude to conducting the

interviews and seeking variations to ethics approval, because "personal experience stories and life stories are interspersed with the individuals' personal and social encounters with their world in context" (Smith-Chandler & Swart, 2014, p. 428). These details helped us understand not only the accessibility and communication needs but what is being said, and why and how, engaging with current thinking as to the role of ethics approval processes that seek accessibility and inclusion (Then, et al., 2023). This information may be supplemented by the testimonial supports who add their voices, respectfully in this project, to the interviews. The collegiate aim is of making visible inequities and contributing to solutions.

Bernard (2013) argues for researchers to find "informants who are observant, reflective, and articulate—who know how to tell good stories" (p. 173). Few participants in this research tell a story with a beginning, middle and end in traditional narrative styles. Interestingly, the four who do have healthcare backgrounds give a traditional health history– style narrative with therapeutic emplotment of their hospital experiences. No one gives a 'hero'-style illness narrative as Woods (2011, 2012) discusses, where the patient overcomes all odds and emerges victorious. Frank's (2010, 2013) three illness typologies are not in evidence either. They are: (1) restitution narrative (where the illness is experienced and life returns to normal); (2) chaos narrative (where life is disrupted and out of control by the illness); and (3) quest narrative (where illness is experienced and life cannot return to the old normal, so a quest is made for a new normal and meaning). In fact, overwhelmingly the narratives are constructed of moments of disempowerment (majority) and rare episodes of communication success. The narratives uniformly are bereft of the clinical patient experience but drowning in the experience of disability. The participants often experience chaos because of their lack of access, power imbalances and not knowing what is going on; the experience of the illness is subsidiary. This chaos is reflected in the narrative style. The disempowerment is reflected in the strong verbs of forceful touch and the dehumanisation is evident in the metaphors and similes used.

Frank's story (2010) themes, presented above as illness typologies, relate directly to the experience of the illness itself, but not to how these participants experience the lack of accessibility, poor communication and care, and barriers to orientation and mobility.

Minichiello et al. (2008) comment that, while a participant often explicitly says what the researcher is looking for, words need examination and location in sentences; "sentences in this way are the most fundamental and indispensable units of any analysis of qualitative data" (p. 262). This not to be a universal truth. In this project, words were the commonest conduits of meaning: the strong verb to illustrate negative touch encounters, the emotional descriptions to demonstrate pain and distress. Then there are the associations of words such as 'mean' and 'unkind' with powerful perpetrators of harms against a minority of 'kind' professionals who actually do their jobs providing care and communication. There is diversity

within the diversity, where words may take many forms: spoken, written, visual signs and performance, tactile messages, gestures, vibration. These are the smallest unit of narrative content but, in this research, they are also the most powerful.

Visual and auditory metaphors (and similes) are valued generally in literature, and particularly in narrative medicine (Charon et al., 2017). In our interviews however, metaphors occupy an interesting and provocative place. They are largely and obviously absent as storytelling devices. The exception is the use of metaphor to describe dehumanisation and the 'less-than' status of people with disability. Narrative medicine principles and traditional qualitative methodology exhorts us to be alert to storytelling conventions and devices, and what their presence communicates—here, the paucity of metaphor generally and lack of conventional structures of storytelling signify were reflected upon. This may represent different ways of telling and our traditional methods must accommodate and acknowledge these epistemic insights.

Participants say what they mean unembellished, metaphor-poor, which some may misinterpret as lacking expressiveness. Efforts to present definitive typologies of illness narratives – such as in Frank (2010, 2013) or Woods (2011) – rely on sighted-hearingness and, privileges those with language proficiency and no need of communication assistance or testimonial support.

For people with deafblindness, their means of emphasising feelings and events are often different in mode and frequency to those of sighted-hearing narrators. The repertoire of emphasisers includes repetition, gestures and signs, touch, vibration, louder or lower vocalisations, expletives, or an interpreter flagging added weight. The repetition of disempowering events occurs frequently in narratives thus punctuating time and storylines as an event is repeatedly recalled.

The contradictions and tensions between what is said (the words) and what is experienced, looms large in the narratives. Where participants, people with disability generally, may be accustomed to discrimination and poorer levels of service and treatment, their words take on contradictory meanings. 'Good' may mean 'I survived', not 'I received quality care and communication.' This raises the question 'what does good actually mean' and has implications for both qualitative and quantitative methodologies. In particular, patient-experience evaluations need to consider carefully what an answer of 'good' might really mean from a patient living with disability so that the realities of the lived experiences are not dismissed in blind faith services and institutions are doing well. Of course, few patient experience surveys are fully accessible so people with communication disability are not seen, heard or understood in the first place. This article aims to provoke qualitative researchers to look at how research may exclude and silence. Epistemic and testimonial justice requires this strong conversation.

Being dual sensory impaired or deafblind involves experiencing poor service and attitudes for long periods of time. Complaining is a difficult and unreliable process that requires communication support to initiate and progress. Several participants display tacit acceptance of long waiting periods for information, poor staff attitudes and treatment, and unreliable support and care. This may partially explain the discord between describing an experience as positive or neutral, and the reality of what transpired.

These performative aspects of conducting and analysing research may be different to a sighted-hearing group of participants. This is why our qualitative methodologies need to evolve to be inclusive and embracing many ways of being, doing and telling.

Conclusion

Recommendations and Roadmap for Inclusive Research

At the core of this article is a case study example of what it may mean to engage in reflexive practice in designing, conducting, analysing, and understating a research project that seeks to include missing voices and stories to grow the research evidence base. It is important to note that the limitations of the study are grounded in a small sample size as well as challenges in a scant evidence base in proposing creative strategies to ensure inclusion of methods where communication is limited. Whilst the results cannot be generalised, given the sample size it is anticipated that the paper provides a prompt for future researchers to consider notions of ableism as well as approaches to enhanced research design that include people irrespective of their communication needs.

Below is a roadmap of summary of the findings of the reflexive practice undertaken during the study. They are presented as strategies to promote inclusivity to better understand what is being said, in qualitative (and indeed any) research projects.

Preparation Enhances Accessibility. What was prominent in reflecting on this case study was a reminder that all research involving people with disability, requires co-production from pre-project planning to knowledge translation and implementation. Within this frame of co-production, accessibility needs to be central not just for the approach to involving participants but understanding the needs of the research team especially if they have lived experience of disability.

As you move through the early stages of the project, especially when seeking human research ethics committee approval, allow time to gather impairment information and living realities details to understand accessibility and safety needs as well as position the life stories. This will then allow you to be alert to different ways of being, doing and telling for those with different modes of communication and storytelling.

Within these approaches, the financial impacts of research also need to be understood meaning that a budget both for accessibility inclusion (such as software, development of multiple formats for qualitative interviews not just online surveys,

amendments to documents), as well as the impact of data collection taking more time due to accessible needs to be included in all project management planning. In addition to the costs of resourcing the research team should also keep up to date as artificial intelligence (AI), accessibility technology and touch messaging systems continue to evolve rapidly. Noting that the evidence base explores over the last 5 years the inclusion of AI in decision making and participatory health care and management, using machine learning, for people with disability (Denecke et al., 2019). As yet this has not been a persistent inclusion in the literature relating to AI and data collection in qualitative research with people with disability. Meaning that communication methods and ways of telling will change too. Recognising the importance of these steps even in the early phase of grant writing or funding applications will allow for enhanced engagement with accessible and inclusive approaches.

Data Collection Requires Planning and Upskilling. In order to ensure safe storytelling spaces, the approach to capturing stories requires preparation to allow the team to employ multiple recording modes to capture diversity of storytelling styles and conventions e.g. audio, video, note taking, live transcription. Remember that if tactile communication is included, this may not be captured by any technical means meaning that the impetus is on the research team to take good field and interview notes to enhance data analysis and write up.

This case study explores minimally the role of interpreters, it is important to remember to use trusted-to-the-individual interpreters. This also means being ready to practice good communication etiquette e.g., understand the different cultural norms for turn taking and how to work with interpreters. When you are working with interpreters: it is important to be available to explore the difference between what is being asked and said, remember to contextualise and clarify; explain idiosyncrasies and revisit any ambiguities. Despite this reflection being obvious, don't play with the service animals unless invited and they are off harness.

Once you focus on understanding the role of the interpreters, ensure that you privilege the participant as principal narrator.

Data Analysis Reflections on Additional Communication Strategies and Positionality. Once interviews or focus groups are conducted, researchers set aside time to allow you to analyse the words, signs, gestures, sounds, vibrations, and touch messages in addition to sentences. Analysing with colleagues, or presenting this process at conferences, seminars or in academic publications allows the enhancing of qualitative research experiences so others can learn and refine. When publishing consider placing a position statement at the beginning of your article so that readers know standpoints of authors/project members.

It is important to grow expertise in disability-related qualitative research by creating opportunities for people with disability to be part of research, the results of your study in themselves, can also be used to inform social justice action to improve the lives of the participants and their communities. This case study serves as a reminder that having lived experience researchers in teams; allows for cultural immersion in communities and finally enhances the knowledge base for current and future generations.

This paper serves as a reminder for academics to reflect on ways in which epistemic injustices occur when people are not given opportunities to participate in research about them, accessibility supports they need or the understanding of the different ways they 'tell' stories. This research project was founded on the principle that only people with deafblindness are able to adequately tell their own stories, we know from a review of the evidence base that disability research is well represented in academic literature, however the strategies as to how to design a research project and then utilise novel approaches to data collection that address communication disability is required.

Offering participants choice and control over their narrative performance spaces and setting aside ideas of universalism in narrativity; for instance, that stories are told in a traditional linear mode with predictable, assessable elements, such as metaphors, as markers of richness. These are not the only ways of expressing experiences. Researchers must listen for nuances and newness in the altered narrative space of these participants with deafblindness to render their experiences legible and translate these into benefit for individuals, communities and society-at-large. Researchers and their qualitative methodologies must adapt and meet the challenges that capturing these epistemic insights requires.

Every project undertaken and every methodology used, involving people living with disability should be trustworthy, thoughtful, and inclusive. This article considers a little discussed aspect of qualitative methodology where ableism still prevails. Even with coproduction, cultural immersion, full accessibility provision, progress is still needed. A life lived/living with disability may represent different ways of being, doing and telling. So, if our knowledge building by research is to be epistemically insightful, engaging with different ways of telling: in performance and expression of narratives in our research.

The diverse ways to telling by these participants, gives evidence of the stratification and complexity of their reality. Researchers need to continue to examine and reflect, refine and adjust so that moving forwards we continue to add to the canon of lived experiences of disability and the qualitative methods utilised to capture these. What the authors have shown here is but a sliver of a whole.

Declaration of Conflicting Interests

ORCID iDs

Annmaree Watharow ● https://orcid.org/0009-0003-4194-9140
Sarah Wayland ● https://orcid.org/0000-0001-7040-6397

References

Alper, M. (2018). Inclusive sensory ethnography: Studying new media and neurodiversity in everyday life. *New Media and Society*, *20*(10), 3560–3579. https://doi.org/10.1177/1461444818755394

Avery, S. (2018). *Culture is inclusion: A narrative of Aboriginal and torres strait islander people with disability*. First Peoples Disability Network Australia.

Berger, R. J., & Lorenz, L. S. (2016). *Disability and qualitative inquiry: Methods for rethinking an ableist world*. Routledge.

Bernard, H. R. (2013). *Social research methods: Qualitative and quantitative methods*. Sage.

Berns, U. (2014). Performativity. In P. Huhn, J. Pier, W. Schmid, & J. Schonert (Eds.), *The living handbook of narratology* (pp. 1–27). Hamburg University.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Charon, R., DasGupta, S., & Hermann, N. (2017). *The principles and practice of narrative medicine*. Oxford University Press.

Denecke, K., Gabarron, E., Grainger, R., Konstantinidis, S. T., Lau, A., Rivera-Romero, O., Merolli, M., Miron-Shatz, T., & Merolli, M. (2019). Artificial intelligence for participatory health: Applications, impact, and future implications. *Yearbook of medical informatics*, *28*(1), 165–173. https://doi.org/10.1055/s-0039-1677902

Frank, A. W. (2010). *Letting stories breathe: A socio- narratology*. University of Chicago Press.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

Gjermestad, A., Skarsaune, S. N., & Bartlett, R. (2022). Advancing inclusive research with people with profound and multiple learning disabilities through a sensory-dialogical approach. *Journal of Intellectual Disabilities*, *27*(1), 40–53. https://doi.org/10.1177/17446295211062390

Hamilton, R. J., & Bowers, B. J. (2006). Internet recruitment and E-mail interviews in qualitative studies. *Qualitative Health Research*, *16*(6), 821–835. https://doi.org/10.1177/1049732306287599

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability and Society*, *15*(1), 25–47. https://doi.org/10.1080/09687590025757

Minichiello, V., Aroni, R., & Hays, T. N. (2008). In-*Depth interviewing: Principles, techniques, analysis*. Pearson Education.

Nind, M., & Strnadová, I. (2020). *Belonging for people with profound and multiple learning disabilities: Pushing the boundaries of inclusion*. Routledge.

Nordic Centre for Welfare and Social Issues. (2018). *The Nordic definition of deafblindness*. Nordic Centrefor Welfare and Social Issues.

Smith-Chandler, N., & Swart, E. (2014). In their own voices: Methodological considerations in narrative disability research. *Qualitative Health Research*, *24*(3), 420–430. https://doi.org/10.1177/1049732314523841

Teachman, G., McDonough, P., Macarthur, C., & Gibson, B. E. (2018). A critical dialogical methodology for conducting research with disabled youth who use augmentative and alternative communication. *Qualitative Inquiry*, *24*(1), 35–44. https://doi.org/10.1177/1077800417727763

Then, S. N., Chesterman, J., & Matsuyama, Y. (2023). Supporting the involvement of adults with cognitive disabilities in research: The need for reform. *Journal of Law and Medicine*, *30*(2), 459–471. https://eprints.qut.edu.au/242218/

Watharow, A. (2023). Chapter 3. In *Improving the experience of health care for people living with sensory disability; knowing what is going on*. Lived Places Publishing.

Watharow, A., Fagan, G., & Joseph, S. (2023). *Narrative medicine: Trauma and ethics*. Vernon Press.

Watharow, A., & Wayland, S. (2022). Making qualitative research inclusive: Methodological insights in disability research. *International Journal of Qualitative Methods*, *21*(21), 160940692210953. https://doi.org/10.1177/16094069221095316.

Woods, A. (2011). The limits of narrative: Provocations for the medical humanities. *Medical Humanities*, *37*(2), 73–78. https://doi.org/10.1136/medhum-2011-010045

Woods, A. (2012). Rethinking "Patient Testimony" in the medical humanities: the case of schizophrenia bulletin's first person accounts. *Journal of Literature and Science*, *6*(1), 38. https://doi.org/10.12929/jls.06.1.03

World Café (2017), 'The World Cafe Method', The World Café (website), viewed 28 February 2017. http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/

World Federation of the Deafblind (2018). *At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness*. World Federation of the Deafblind, viewed 25 September 2019. https://www.wfdb.eu/wp-content/uploads/2019/06/WFDB_complete_Final.pdf