

**‘Not knowing what is going on’
The experiences of people with
deafblindness—dual sensory
impairment in Australian hospitals—
a mixed methods study.**

by Annmaree Watharow

Thesis submitted in fulfilment of the requirements for
the degree of

Doctor of Philosophy

under the supervision of Dr Sue Joseph, Dr Sarah Wayland
and Dr Sarah Attfield

University of Technology Sydney
School of Public Health, Faculty of Health, and Faculty of
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Certificate of original authorship

I, Annmaree Therese Watharow declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature:

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Statement indicating the format of thesis

This is a hybrid thesis by research: with supervision from both the Faculty of Arts and Social Sciences at University of Technology, Sydney. My supervisors are Dr Sue Joseph (principal), Dr Sarah Attfield (alternate) and Dr Sarah Wayland, formerly of the Faculty of Health, University of Technology, Sydney. This cross-faculty collaboration has enabled a doctorate that embraces the storytelling of hospital experiences in a unique narrative space occupied by people with deafblindness—dual sensory impairment, and the health system, whose dominance in hegemony often silences these experiences. Uniquely, the research is conducted by a consumer-researcher with deafblindness.

List of papers/publications

- Watharow, A. 2017, *My path to PhD, and disability in the university*, UTS Futures, Sydney, viewed 13 December 2017, <<https://futures.uts.edu.au/blog/2017/12/13/path-phd-disability-university/>>.
- Watharow, A. 2018, 'The doctor can see you now', presented at *National Virtual Disability Conference* (online), Melbourne, 21 March 2018.
- Watharow, A. 2019a, 'The air that I breathe: surviving the loss of the communication senses through narrative writing', *Life Writing*, pp. 1–10, <https://doi.org/10.1080/14484528.2019.1570582>.
- Watharow, A. 2019b, 'The Doctor can see you better now: a cheap, effective and patient owned tool', *Deafblind International World Conference*, 12–16 August, Gold Coast, Australia.
- Watharow, A. 2019c, 'Rewriting the ontological self—following the loss of the communication senses', in B. Avieson, F. Giles & S. Joseph (eds.), *Still here: memoirs of trauma, illness and loss*, Routledge, New York, pp. 17–33.
- Watharow, A. 2019d, 'What happened to the fastest finger speller in the world?', *Deafblind International World Conference*, 12–16 August, Gold Coast, Australia.
- Watharow, A. 2020a, 'Consumers, communication and COVID-19', *NSW Ministry of Health: COVID-19 clinical communities of practice*, online, 27 May 2020.
- Watharow, A. 2020b, 'Out of adversity can come opportunity: some observations on the different narrative spaces occupied by deafblind patients', *Survive and Thrive: A Journal for Medical Humanities and Narrative as Medicine*, vol. 5, no. 1, article 8.
- Watharow, A. forthcoming, 'Owning my room: building a safe, accessible and productive space for student researchers with complex communication disabilities', in C. Burke & B. Byrne (eds.) *Social Research and Disability: Developing Inclusive Research for Disabled Researchers*, Routledge, New York, NY, chapter 1.

To the reader

*Midway on our life's journey, I found myself
In dark woods, the right road lost. To tell
About those woods is hard—so tangled and rough*
—Robert Pinsky (1994) *The Inferno of Dante: A New Verse Translation*
(Canto 1, p. 5).

Before you start on this journey into disability, deafblindness, dual sensory impairment and hospitals, I'd like to situate the work in its inceptions, innovations and points of difference—in its purposefulness—by way of my experience. In this origin story, both the thesis and its research, are problems that come with a drastic diagnosis. Key excerpts from my narrative include experience as an outpatient, orthopaedic and urology intern, hospital patient, and medical doctor specialising in mental health, before further impairment and a second devastating hospital stay. After this writing of the self, there are notes about the impact of disability on the conduct of doctoral research. These notes arise from my experience, but my aim is to ensure that academic research is more accessible for others. To conclude this Note to the Reader, there are notes on the writing, style, formatting and other choices made, to ensure that this thesis has broad-reaching accessibility.

I intended to use my story of lifelong disability, increasing impairments and decreasing competencies in this study: situating my voice and employing myself as data. When the voices and signs of the research participants generated rich, dense data that demanded expression, my memoir pieces were directed to other audiences (Watharow 2019a, 2019c, 2020b). What remains of myself as data is this prelude, which contextualises my position and experiences in brief, in order to privilege the research participants and their narratives.

These words are powerful; they can define, explain, wound, isolate and exclude. The absence of words, too, is disempowering, serving to control, to deny, to withhold, to perpetuate injustices. This thesis will encompass the presence and absence of words, signs, signals and vibrotactile elements to tell about people with deafblindness–dual sensory impairment (PWDBDSI) and what happens when they go to hospital. But the first words need to be about the researcher, and why this doctoral journey and thesis is singular, complex and Sisyphean.

The origin story

The un-creation of Annmaree Watharow had its embryogenesis at birth. In this beginning, there were only sounds that made no sense. There was also the belief of parents, the Irish general practitioner with his displayed jellybean jar and hidden drawer with injections, and my first kindergarten teacher. All are saying: she's just a daydreamer, she's lazy, this is why she doesn't speak. *Perhaps*, they think, *she is retarded*. At five years of age, an Ear, Nose and Throat surgeon casually removes my healthy tonsils and *en passant* gives my parents the unhealthy news: 'By the way, the kid is deaf.'

With hearing aids, the silence becomes a bubbling soup of dissonant sounds. Gradually, ever so gradually, heard and spoken language becomes (mostly) reliable phenomena. The hearing loss (why do we say *loss*, as though I've simply misplaced the decibels and, if I would just think really hard about it, I'd find them again?) is severe but manageable with increasingly efficient hearing aids (the early ones were large metal boxes that made the world a tinny-sounding place, which manufacturers could only improve on).

Like so many people with disabilities in the 1970–80s, I worked conscientiously to pass as able-bodied and normal. The pursuit of normal was important, a sign of my worthiness. I knew it was all my fault and, if I simply worked hard enough, I would be normal.

And I was successful.

I obtained my Year 12 Higher School Certificate and went on to study medicine. As long as I worked hard, and my hearing aids performed, I passed as normal. Early in my studies, I learned that disclosing my hearing impairment to people at university was harmful—one professor of surgery tried to have me thrown out of medicine and the university. At a meeting convened by the Dean of Medicine—after I spent a weekend in terror and weeping—he decreed I could stay, because he felt the community would benefit. I do need to mention here that I was not given any assistance with coursework, no accessibility provisions or accommodations. I had my head down and invisibility cloak on.

As I struggled through a medical degree in the hostile higher education space, some peculiar things started happening with my night vision. This was not my only problem—I became aware that my speech was imperfect; this *marked* me and unsettled attempts to pass as *normal*. At the hospital where I undertook my clinical attachments, I found a speech therapist married to a surgical trainee, who understood how important it was for me to have less word-mangling and *lithping*. Three times a week, she made time for me and I complied, practising those 's' sounds and complicated consonant blends.

In my final year of medical school, after increasingly bizarre experiences of falling into unseen bodies of water, running into people and 'seeing' shadows where none existed, I was diagnosed with Usher syndrome. I should have twigged so much earlier, but the fabric of my whole existence, held together with masking tape, was too fragile to admit more rents.

Medical students are deeply fascinated by the 'rare and interesting' patient species. I heard about the man with the 'amazing visual field defect you gotta see'. In clinical examination, visual fields are checked by a process called confrontation. In this process, the clinician (assumed to have 'normal' and full visual fields) compares their field of sight to that of the patient. So confronted, I now had evidence something more was wrong with me—my visual fields were worse than this well-documented patient. Unable to ignore this, I went to see the professor of ophthalmology. An afternoon of devastation. He told me that, as well as having hearing loss, I would go blind. Because I was so 'fascinating and rare', would I also please come back in two weeks for the registrar exams?

The esteemed professor left out so much. He didn't say that these losses would happen eventually. 'Eventually' was the one word that might have softened the scissoring. This diagnosis experience rent my hopes and expectations of the future, tearing the tightly taped repairs to my fabric apart. Unmade. Later, I would come to know that people with Usher syndrome all have diagnosis un-creation tales, but on this day, I was alone. I did what all good clinicians do when confronted with the unknown, rare and perplexing—I consulted MEDLINE and ordered some articles.

Vernon (1969). You were not my friend. You wrote of psychiatric hospitals, hallucinations, mental defects, horrors that await me. Apparently and eventually. Decades on, I have forgotten this devastation. For this thesis to have some historical 'flavour', I order an accessible copy of Vernon (1969). I don't register that I have read this before (although it is presently Arial 32 point).

I start reading.

My body has not forgotten. Flash backwards. The library shelves are in front of me. It is not 2018, but 1985. A sudden cold drenching. My body shuts down and I barely make it to the bathroom to retch (again) with such violence that, surely, I've torn my oesophagus. Buried somatic memories surface. It's another century, a different bathroom and I'm a much-changed person, but I relive the awful no-good horror in gastric ejection, gasping and adrenaline rush.

Back in the late 1980s and 1990s, failing sight forces me to give up the hours and rigours of paediatric fellowship exams. I move into general practice. With a background of adjusting to losses, I am also adjusting my career. I task my ophthalmologist to monitor my competence to practice, as well as my retinae.

You see, my retinal disease begins at the outside, with vision at night. The central field is spared for a time, a long time, I hope. Practising as a clinician becomes obsessively controlling my environment: good room lighting, placing my desk away from windows, quiet surrounds, soft furnishings to absorb extraneous noise and good spot lighting. I undertake a Masters of Psychological Medicine because my patients (60 percent of them) have mental health issues. Six lectures in undergraduate medicine in behavioural sciences and an incredibly patchy term in psychiatry is simply not enough to provide a support and treatment armamentarium. I move into mental health as a general practitioner (GP)–therapist. I love this role and this time in my life; I have largely internalised my difficulties.

Wreckage

Much sooner than I imagined, but later than originally predicted, the 'eventually' comes. My eyesight is dwindling to mere degrees in the centre; I am going blind. Recently, a vitreous detachment makes what little is left pea-soup green. I'm underwater in a clogged sea. Looking up from its bottomless depths. I know people are above, yet their forms are indecipherable and their sounds indistinct. Clarity is elusive, ephemeral. My hearing diminishes more and more and more. Paradoxically, I am deafer now that I am blind. With visual cues diminished and lip reading impossible, what I cannot see increases my confusion in

communication encounters. My connectivity to people, places and even things evanesces.

Yet again, 'eventually' finds me; this time with deficits worsening and new ones acquired. Hey! No one. Ever. Told. Me. That. My. Hearing. Could. Diminish. Too. It was all about my sight shrivelling. Apparently, this is possible, but not usual. So 'normal' is no longer achievable or safe. I am unmade. Again. I am/was/still might be a physician, but with the dual calamities of deafness and blindness, I can't be certain. There is a dearth of recorded lived experiences and reflections of scholars and healers grappling with the loss of their communication senses. Right now, my world is 'unmade'. My life is like a building site after an explosion: rubble and thick, stifling dust.

The time immediately after drastic diagnoses, injury or trauma is described in savage terms. Michele Crossley writes of 'narrative wreckage' and 'ontological assault' (2000, pp. 9,10). Amy Robillard tells of narrative collapse:

The word collapse was originally a physiological term referring to the breaking down or caving in of organs caused by a loss of support or intense external pressure. It's a falling in, a falling together. I'd always thought of it as a kind of falling apart (2014).

Paul Kalanithi, a neurosurgeon with terminal cancer, notes: 'Severe illness wasn't life-altering, it was life-shattering. It felt less like an epiphany—a piercing burst of light, illuminating What Really Matters—and more like someone had just firebombed the way forward' (2016, p. 119). I write of this life narrative breakage by deafblindness as 'drowning in sense-less-ness (multiple meanings and hyphenations intended)' in a recent essay on ontological loss (Watharow 2019c, p. 3). Our stories have stopped short—they are sundered, dis-emplotted by catastrophe.

Living with deafblindness is complex and messy. You feel grief at the loss of completeness; work is difficult and impossible to finesse; accidents are frequent; and further impairments loom, limp, or crash in and linger. You depend much on others, and have many situational vulnerabilities. Society is often a hostile space to dwell in and travel about. Despite all the adaptive changes I made throughout the years, my own career is over.

I can't go on. Ears and eyes are vulnerable to damage. I exist in a boundary space where there's naught but gloom. I haven't yet mastered the art of losing or memorialising my lost competencies, never to be found again.

Outpatients (1986)

In a darkened room in the Sydney Eye Hospital, I am having a fluorescein retinal angiogram. Not pleasant, it involves needles, nausea and some body fluids turning orange. Here, among old linoleum floors and blue hospital gowns, I break.

The professor is excited: 'Can you come to the Registrars' exams next week as a patient?'

I suppose so.

'Good, good. I'll see you then.'

I'm not given any referrals, support or counselling. I am not asked what I think, feel or what am I going to do. I am not asked if I have someone to drive me home. I don't; I caught the bus from uni. Even more astounding, I am not asked if I drive. I don't but others, similarly affected, do.

Internship (1987)

In the late 1980s, orthopaedic surgeons are known as a sexist bunch. This particular surgeon is repugnant as well. It is my second allocated term as an intern; I have lasted 35 minutes of protracted harassment. He knows, I can tell, and he despises me. Plus, I am a girl. He despises them, too (unless pretty, blonde and a theatre nurse). Twelve weeks of this is 12 weeks too many. I go to Medical Administration, informing them I cannot work for such a man. There are consequences, but I don't much care in the heat of burning anger. I am reassigned (this is to make me really suffer, apparently) to Urology, the trade mostly of men's plumbing.

The two surgeons are kind, delightful gentlemen; they have not had an intern allocated to their service for several years. I grow bold in their keenness, and tell them I have hearing loss and wear hearing aids, and that I find theatres difficult because masks prevent lip reading. They have a rule, they proceed to inform me—I have to perform half of all the operations. And they don't mind speaking loudly and turning off the theatre muzak.

But ... don't they realise I am a new intern, without cutting, slashing, dicing and sewing skills?

'You will learn,' I am told.

And I do, much to the great envy of all the other surgical interns, who spend endless hours holding up legs, leaning on retractors or swabbing little bleeding vessels.

Who knew excising a prostate was 'just like peeling a mandarin'? Who knew that removing testicles was 'so darned easy'?

I celebrate my first operation with a delicious Caramello Koala.

'Be careful where you bite that one,' my registrar hoots.

Ward 1 (2010)

I lie in bed in my hospital room, staring ceiling-ward with a right eye that sees no forms or beauty, and that has no function. The left eye is slowly deteriorating, the Mars-like denuded surface of its retina littered with globular deposits of rogue pigment, working their way inwards. The world grown smaller. I have developed a right retinal hole and the operation to repair it was as unsuccessful as it always was going to be, given its 10 percent success rate.

The Professorial Suite (2014)

I'm in London, in a desperate bid for an alternative diagnosis and future. A treatment, any treatment? The day is middling; I have a cup of mediocre tea and wander past the British Museum to Moorfields Eye Hospital.

The Professorial Suite is an odd space, with most of the room taken up by a few sheikhs and their many bodyguards. The ceilings are low. Large men, low ceilings, apprehension and reduced visual fields; I feel claustrophobic. The testing shows that one eye sees finger movements only. The other is shrunken and struggling. The professor tells me that a cure is not possible; deterioration is a certainty. This I already know; I have long known but have not acknowledged. I have not heard the words. He says, I should think about going back to university.

A throwaway line, an inconceivable idea? Or a *possible* re-creation story?

My consulting room (2015)

Mr H. has suffered an adverse event after leaving hospital, the result of staff not accommodating his accessibility needs. Mr H. has dual sensory impairment: he can't see or hear very well. He has misunderstood the diabetes education, misread the small-print instructions and given himself a near-lethal dose of insulin. After all, 3, 13 and 30 units of insulin sound similar, don't they?

Another month, another patient. One of my dear elderly ladies, Miss F., is brought to see me. She clutches a letter from the eye doctor, requesting a dementia workup, aged-care assessment and prescription for antipsychotics. She is 'seeing' things that aren't there, a little girl in a red coat who has lost her mother. *She may not be real*, Miss F. thinks, *but the little girl seems to need her mother desperately*. A detailed and distressing vision. These phenomena are not uncommon in people with low sight; they are called Charles Bonnet syndrome. For this reason, Miss F. isn't dementing, she doesn't need antipsychotics and she doesn't need a care home at this time. I call the specialist to remonstrate. Our mutual patient is losing her sight, not her marbles.

Finally, as I pack up my much-loved career, I see a former patient. Mr S. is brought in by his daughter, who is worried about his behaviour (or lack of it) after a recent hospitalisation with complications. The unfurling story reveals a personal trauma of epic proportions. Mr S. has severe hearing loss, due to old age and occupational noise exposure. He has vision loss from extensive macular degeneration. He sees little and doesn't hear much. He has hearing aids but doesn't like wearing them. I suspect he feels stigmatised and finds it difficult to manipulate the small controls. He can never find 'the damn things'. Despite all of this, he lives by himself; he is quirky and always wants to cook me his speciality, steak Diane.

Mr S's diminishing-self began with his admission to the local public hospital (one of great standing) presenting with abdominal pain. After some hours of nil by mouth, he is put onto clear fluids and then a light diet. Trouble is, no one seems to have told Mr S., in a way he could understand, that this was the plan. And then, no one pointed out his food and drink when it arrived. His meals were left untouched. Mr S. got sicker and sicker. And no one noticed. On the fourth day, he was semi-conscious and in renal failure from severe dehydration. Now, needing dialysis, he had the attention of the doctors and nurses.

I listen to the daughter and father, one distressed, the other depressed. I am outraged that this could happen. I am also terrified; this could happen to me. I have deafblindness. I am at risk of neglect and communication failures, too. Mr

S.'s bad outcome could be mine—but most shockingly, this is a story of preventable misadventure.

I am appalled. Aghast. I can see a future in which a neglectful, over-busy, task-oriented hospital is a place where I, too, come to harm.

Audiology clinic (2016)

Hearing loss is described according to severity, as follows:

- Mild hearing loss: hearing loss of 20–40 decibels;
- Moderate hearing loss: hearing loss of 41–60 decibels;
- Severe hearing loss: hearing loss of 61–80 decibels;
- Profound hearing loss or deafness: hearing loss of more than 81 decibels (Informed Health Online 2017).

A loss of 90 decibels is profoundly distressing. For 30 years, I have been saying that I am losing hearing as well as sight. Every specialist I see tells me 'That doesn't happen in Usher syndrome.' It will not be until 2019 that I obtain vindication. A doctor with Usher syndrome, who also was losing hearing, researched and found that hearing deterioration is the norm for one genetic subtype of Usher syndrome. Being right about my own condition is a hollow victory. There is no triumph of 'today, I am beleaguered by disease, but tomorrow good health will prevail'. The world is constructed for *them*, the sighted-hearing. Without sight, without sound, it is unconstructed, undone for me. I've lost the key to the door. My career is over. Caregiving must yield to being cared for.

Ward 2 (2016)

By anyone's standards, I am quite sick. Not yet needing Intensive Care, but not able to stay home. Oxygen is administered. I am told where the buzzer is and to 'just buzz us if you have any problems'. I ask for a safety pin to anchor the red-button buzzer to the sheets, because I won't be able to see it if it hangs down or falls.

'No, I am afraid we can't. That is an occupational health and safety issue.' I know I need to tell the nurses all about my sensory losses and how I need help with many things, but I can't speak a full sentence without shortness of breath. My husband, not allowed to stay, does all he can and tells everyone he sees.

The night is interminable, the morning not yet discernible. Suddenly, I struggle for breath, but I can't see or find the buzzer for the nurse. The oxygen saturation monitor on my finger shows plummeting blood oxygen levels, before it falls off. Air hunger is making me panicky, doom impending. I am saved by the patient in the bed opposite me, who buzzes and shouts. This wakes the girl next door, who also shouts and buzzes. A procession arrives that includes nurses, intern, registrar, intensivist and husband. I don't feel safe. Almost as bad, one doctor tells my husband my cognition has been affected; I don't answer any questions correctly.

'Did she have her hearing aids in?' my husband, Tony, replies with acerbity. He adds 'We have told everyone she has hearing and vision loss.'

2016 later

'Do a PhD,' my friend says. 'Use your experiences to prove the existence of laissez-faire care for people like yourself and the patients, then think about ways to transform the status quo.'

I apply.

I am accepted.

Now, the trial by combat begins.

Disability and the thesis: real-life impacts

Here I am, now at university. Much of my first year is spent in advocacy and working out systems of support, information management and funding.

My position as a PhD student is complicated by critical information gaps in institutional experience and academic knowledge. So my pursuit of the PhD is generating new knowledge, personal and research data on 10 areas in which my disability complicates my ability to initiate and progress in a research degree:

1. **Preparation limbo** There isn't support available for the application process, writing the research proposal, and documenting need and merit.
2. **Safe conduct** Universities are busy, cluttered places. I sought a safe space to work and keep expensive assistive equipment locked away, which was granted. To ensure my safe conduct, I needed to train accessibility assistants in safe guiding and environmental description.
3. **Access and communication** The position of Accessibility Assistant was created to provide a human bridge and problem-solving capacity whenever at the university. There are myriad documents that require converting into accessible formats, editing and reading aloud to me, when my limited residual vision can no longer cope. At one time, disability support staff suggested that one of the goals of support was so that I could move freely about the campus: that is, not needing paid support, when this in fact is not possible with my constellation of impairments.
4. **Digital spaces** The digital divide is real; much of the university's online content and platforms is not accessible to me.
5. **Pedagogy and supervisors** My supervisors have to undertake advocacy roles with support applications for extra funding, time and assistance, and pushing back against misperceptions about entitlement, fairness and parity.
6. **Unsafe spaces** The university experience is marred by micro-aggressions, acts of discrimination and some staff refusing to provide accommodations. These are distressing and reflect how parity and equity are not yet embedded at all levels in university.
7. **Knowledge-building about disability** Time is spent educating others about disability generally and deafblindness specifically, as well as finding new and creative means of doing things in accessible ways. For example, using Google docs for live transcription, customised to my font and contrast needs (Arial 38 point, and white text on black background).

8. **Methodological anxieties and tensions** The following chapters contain more on these but, in brief, I wondered how the narrative inquiry space would be impacted by the researcher's disability and the necessary entourage of human assistance to support, safeguard and act as safety net for the research itself.
9. **Vicissitudes of life** Doctoral students with disability have living realities like everyone else: mothers who are ageing with care requirements; children with diverse needs of their own; partners/friends who need support; and illnesses and accidents, over and above the impairment effects of the disability/ies.
10. **Time** This is a significant obstacle in my work. After timing a group of diverse activities with a fellow student, we establish that every act, from writing an abstract to locating and reading articles, takes between twice to seven times as long for me, with full human and technological assistance, as my sighted-hearing colleague. This demonstrates that, without such assistance, the research tasks are not achievable at all. Even with maximal support, funding and assistive devices, a student with deafblindness—dual sensory impairment (DBDSI) is still not on a par with their sighted-hearing counterparts. Time occupies a different dimension: time is taken, time is lost, time is protracted.

All of the above takes place while managing the impact and consequences of a degenerative condition. Residual senses dwindle. New adjustments need to be made both physically, for the research outputs, and psycho-emotionally, for the self. New dependencies are created and life can be hard. Now, at the end of the thesis, I can't read the computer screen, even on maximal font and minimal contrast settings. I need more sign language and tactile signals to navigate the world. This research is a *just in time* moment for me. Regaining my purpose, especially with how this study is informing some of the present pandemic response, has had/is having a reparative effect on me.

You can find a more complete account of my embarking on a PhD in my chapter, 'Owning my room: building a safe, accessible and productive space for student researchers with complex communication disabilities' in Ciaran Burke and Bronagh Byrne (eds), *Social research and disability: developing inclusive research for disabled researchers*, Routledge, London (forthcoming January 2021) chapter 1.

Notes on disability-related stylistic choices and considerations

Because I want this doctorate to be as accessible to as many people as possible, I made the following decisions:

- All tables are moved to the appendices, to be accessible for those who depend on screen readers and to all with low vision.
- Where tables are used in the main text, these are created as text-only lists (no bounding frames and solidus used in place of columns).
- The two models presented in this work have fully written descriptions located in the appendices.
- Because of the researcher's intense insider status, there are limitations in the research interviews themselves, but these are offset by minimising the

power dynamics, and the reciprocal trust and sharing between participants and researcher.

- There may be errors caused by the inability of existing assistive devices and support to overcome the 'insurmountable realities' (Vehmas and Watson 2014) of this disability for this researcher. Disadvantage is reduced, not eliminated. Every effort has been made to minimise these, with multiple hands and eyes overseeing the work. No one assisted in the creation, synthesis, analysis and critical reflections of this work, but many were needed for its execution.

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List of abbreviations

AA	accessibility assistants
AADB	American Association of the Deafblind
ABS	Australian Bureau of Statistics
ACR	academic consumer-researchers
ACT	Australian Capital Territory
ACSQHC	Australian Commission of Safety and Quality in Health Care
ADL	activity of daily living
AHEQS	Australian Hospital Experience Questionnaire Set
AHPEQS	Australian Hospital Patient Experience Question Set
AHPF	Australian Health Performance Framework
ASL	American Sign Language
ASLIA	Australian Sign Language Interpreters' Association
CALD	culturally and linguistically diverse
CDB	congenital deafblindness
CDBT	Critical Deafblind Theory
CDT	critical disability theory
CI	Cochlear Implantation
CODA	Child of Deaf Adult/s
CRPD	Convention on the Rights of People with Disabilities
DALY	Disability Adjusted Life Years
DB	deafblindness
DBDSI	deafblindness–dual sensory impairment
DSI	dual sensory impairment
ED	emergency department
GBD	Global Burden of Disease
GP	general practitioner
HBS	hostage bargaining syndrome
ICU	intensive care unit
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NEHS	National Eye Health Survey
NRS	National Relay Service
NSW	New South Wales
PEM	patient experience measure
PES	patient experience survey
PLWD	people living with disability
PWD	people with disabilities
PWDBDSI	people with deafblindness–dual sensory impairment
QoL	Quality of Life
RCACQS	Royal Commission into Aged Care Quality and Safety
RIDBC	Royal Institute of Deafblind Children

RP	retinitis pigmentosa
SACR	Student Academic Consumer Researcher
SCIE	Social Care Institute for Excellence
SOC	sense of coherence
UHC	universal health cover
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	Union of Physically Impaired Against Segregation
USA	United States of America
USH	Usher syndrome
WFDB	World Federation of the Deafblind
WHO	World Health Organization

Abstract

When patients with deafblindness–dual sensory impairment (DBDSI) go to hospital, their capacity to know what is happening to and about them is compromised.

This study examines, via a researcher who is an insider with deafblindness, the research question: What are the experiences in hospital of patients with DBDSI, with emphasis on what enables positive experiences and what disables individuals further.

This study's theoretical framework is underpinned by social relational theory and critical realism. These approaches view society (and the lives of people with DBDSI) as layered, complex and with power differentials that create challenges. The study proposes that research must be action-oriented for a more socially inclusive world. Standpoint methodology privileges the participants' voices as the expert-knowers of truth and situates the researcher (also an expert-knower and clinician) using these three lenses to refract throughout the doctorate.

The study uses a qualitative, narrative inquiry method to conduct semi-structured interviews with 18 participants, recruited from Australian impairment support groups and via snowball sampling. A small quantitative component, using an Australian patient-experience questionnaire, provides a barometer of hospital performance. Creative nonfiction techniques are used to illustrate the participant's journey, charting their hospital experience from beginning to end.

The research findings demonstrate a climate of poor experiences; there is a lack of accessibility to information and power exertions in the forms of negative touch, neglect, abuse and dehumanisation. These culminate in participants 'not knowing what is going on' and experiencing threats to security and safety.

The findings demonstrate that power exertions result in less care and communication. Less care and communication threaten and assault the ontological security of these patients, creating fear, uncertainty and distress.

Furthermore, the findings situate the expert-knowers—the participants—as being able to guide hospitals, professionals and patients from a position of inaction and indifference to one of knowing what is going: providing accessible formats on request; supplying interpreters as needed; harnessing patient capabilities; embracing technology; and developing and educating staff. These solutions will generate improved health, economic and wellbeing outcomes, resulting in a community where everyone has the potential to know what is going on.