UNIVERSITY
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‘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
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Arts and Social Sciences

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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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Signature removed prior to publication.

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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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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.

Introduction

The present COVID-19 pandemic has created a public health crisis unseen since the 1918–1920 influenza pandemic. In this country, the necessary changes to public and private life have created new difficulties for people with disabilities (PWD) generally and for people with deafblindness–dual sensory impairment (PWDBDSI) particularly. Lockdown, isolation, quarantining, social distancing, near-universal mask-wearing, and the rise and rise of telepractices are necessary to maintain public wellbeing at this time. For those who need health and social care, especially PWDBDSI, however, their lives have become more complex and difficult. This doctoral thesis examines one crucial aspect of caregiving—the quality of care given by hospitals (and hospital health professionals) to PWDBDSI. It centres PWDBDSI telling their stories about what happens to them when they go to hospital and are cared (or uncared) for, neglected and possibly abused by professional healthcare givers.

There is hybridity in this research journey; I am embedded in some of the life experience of the participants because I, too, have deafblindness, the co-occurring of sizeable hearing and vision loss that shapes my life, rendering it complex. My doctoral journey is not made alone. My accessibility needs are entwined in almost every task; each page I write must be reviewed for typos, ‘word salads’ and misbegotten punctuation marks. I cannot see these, nor can I hear the voices of virtual assistants. I cannot go to the library unguided, and I cannot converse on a phone without a relay service and voice interpreter. I cannot read an article without conversion into a mammoth-sized font.

But I *can do* this; that is, building new knowledge and creating greater understanding of what it is to be a patient with DBDSI. I have subjective experiential expertise in the realities and complexities of living with sensory impairment. I have objective expertise, too. I am/was a clinician, so have practical experience in health caregiving, looking after patients and their families. I have convened hundreds of chronic disease and disability management team meetings, and written numerous reports supporting PWD to obtain the care and services they need. I have been awed by how well the system can work, and made distraught by its failures. Now I am a researcher, learning at the same time as being immersed in my own, ongoing, relentless sensory degeneration.

At the heart of this thesis lie personal accounts of the patient-participants’ experience, of receiving various types of caretaking: caring, careful, careworn, careless, neglectful and abusive. Arthur Kleinman (2020), a clinician-professional caregiver and personal carer for his wife, writes about care and caregiving in his memoir: ‘Care is about accompanying someone through their experiences of alarm and injury. It is assisting, protecting, thinking ahead to prevent further difficulty … It is the human glue that holds together families, communities, and societies’ (Kleinman 2020, pp. 3–4).

It is imperative that we further understand rarely researched perspectives, which document the living impact of current climate of social and environmental barriers that characterise hospital systems, including: ignorance and dismissal, funding shortfalls, and time pressures. As Kleinman writes: ‘I believe we are living through a dangerous time when quality care is seriously threatened among families, in the health professions, in our hospitals and aged care homes, and in our society at large’ (2020, p. 4).

In this work, questions of quality care for PWDBDSI begin with definitions that foster inclusivity. The thesis is anchored by the Nordic definition of deafblindness, which describes deafblindness as an umbrella for all forms of co-occurring sight and hearing loss: ‘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 n.d.).

While this research begins with the Nordic definition, it rejects its overarching term of ‘deafblindness’, replacing it with the more encompassing terms ‘deafblindness–dual sensory impairment’ (DBDSI). In **Chapter 1**, I explain that including people who identify as *other than deafblind* is critical to participation. Before expanding on the specific patient experiences of this work’s research participants, this chapter provides understanding of the complexities, and tensions, of life with deafblindness (DB) and dual sensory impairment (DSI), because these complexities and tensions affect the contributors to this research. Only then we can examine what happens to them in hospital and theorise why this is the case.

Researchers and those affected by sensory loss use many phrases and metaphors to describe this state—the analogies below allow an aperture into individual lives and observed experiences of PWDBDSI:

- ‘It is a frightening world’ (Joseph, cited in Schneider 2006, p. 153)
- ‘Invisible’ (Ruth Silver 2012)
- ‘Deafblindness is typically among the most isolating of human conditions’ (Miner 1998, p. 48)
- ‘Being deafblind is like being deep underground, where there’s no light or sound. At first, I had difficulty breathing, but after a while I convinced myself that there was plenty of air. I was able to breathe again in that suffocating silent darkness’ (Yolanda de Rodriguez, cited in Tuckfield 1992)
- *Land of Silence and Darkness* (Werner Hertzog 1971)
- ‘We are the loneliest people on earth’ (participant, cited in Mathos, Lokar & Post 2011, p. 139)
- ‘drowning in sense-less-ness’ (Watharow 2019c, p. 3)
- ‘a caged bird’ (Billie Sinclair, cited in Tuckfield 1992)
- ‘the universe is a silent, dark world’ (World Federation of the Deafblind 2018, p. 43)

These observations are stark yet simplistic—slivers of a whole.

Because this thesis explores the lived experience of PWDBDSI in hospital, the strong relationship between patient experience and health outcomes (Sutherland et al. 2017) cannot be overstated. Unfortunately, very little is known about the experiences of patients with DBDSI; there are no academic studies in English that examine hospital experiences from the perspective of the patient with DBDSI.

With increasing age comes increasing sensory losses. With an ageing population comes greater single and dual sensory loss, alongside increased burdens of care. With the increasing survival of extremely low-birthweight infants, comes greater sensory losses and multiple disabilities. In the Global South, with preventable infectious diseases and birth complications come increased frequency of sensory loss, both single and dual. Thus, the population affected by single and combined sensory loss is increasing significantly. Recent Canadian data demonstrate that, since 2010, the number of older people with co-occurring sensory loss has continued to increase (Wittich 2019).

In the absence of any research demonstrating that patients with DBDSI have positive and parous experiences in hospitals, this research is timely; it is poised to fill lacunae and promote solutions. The research territory encompasses the Australian context of the question: What are the experiences in hospital of patients with deafblindness–dual sensory impairment? Secondary questions include:

- Are hospitals doing enough for patients who are deafblind or have a dual sensory impairment?
- How can patients proactively bolster their defences against negative hospital experiences?
- What changes are needed at the societal, hospital-institution and professional levels to improve experiences, and thus promote better health and wellbeing outcomes?

International readers can refer to a summary of the Australian healthcare system in **Appendix 1**.

The thesis falls into three natural, although unmarked sections. The first concerns itself with situating PWDBDSI into context: what we know from definition, data and debate. The second is preoccupied with the conduct of the research itself and the gathering of storied-data. The final section comprises the findings—what they are, what they mean, why these hospital experiences are happening and how to progress—never losing sight of the participants' lives, experiences and reflections. The participants offer hopes and dreams for the future; it is up to policymakers and hospitals—and every reader—to be moved to act.

The data collected from the narrative interviews (see **chapters 8–11**) offer the reader an opportunity to observe both the careful and the neglectful and/or abusive care that patients with sensory loss can experience. The thesis also highlights how narrative inquiry spaces differ for participants with DBDSI, and how words and experiences may create dissonance that clouds external assessments of experiences.

For patients with DBDSI, access to information intra-connects with power exertions by hospitals and their staff to create uncertainty and insecurity. These coalesce into PWDBDSI not knowing what is going on. These are not the one-on-one stories of traditional sighted-hearing researchers and participants. They are many and varied-on-many, explained in detail in **Chapter 8**.

This study found that the supports and aids needed for narrative inquiry are the same supports and aids needed for participants with DBDSI to know what is going on—to them, for them and around them—when in hospital spaces. Without such accommodations, negative experiences are likely. Negative experiences of denied access power the landscape of this work.

Chapter 1: Complexities establishes the foundation of who we are. Before knowledge-building begins about the hospital experiences of the dual sensory impaired, I explain (and explore) what it means to be such. The chapter navigates these multifaceted states of being, because the literature is full of contradictions, intricacies and absences. Being deafblind or dual sensory impaired is not simple. Receiving information in fragments changes lives and how they are lived. There is no homogeneity in condition. Differences abound in causation, remediation, communication modes, languages used, lived experiences and sociocultural adoptions. Identities are varied, sometimes fluid and sometimes in conflict. For a great many, the progression of existing deficits or acquisition of new impairments alters the geography of once-familiar terrains.

Away from the individual with heterogeneities, the larger landscape of disability thinking needs traversing. **Chapter 2: Ways of thinking** engages with the short history of disability activism—the Big Social Model, its proponents and dissidents. Along the way, I read Tom Shakespeare, who helps me reconcile the stark negativism that most social theorists have towards the medical model, with my experience as a clinician, which is: medicine does great and wonderful things to prevent, treat, cure, remediate, rehabilitate, research and predict impairment. Among these theories, there is room for hybridity.

These thoughts situate the research into a stratified reality of social relational-critical realism, where the medical model's contributions are augmented, not eschewed completely. The patient perspective is vital because the patient is the only one who can know what happens to them in hospital; in short, the patient is the expert-knower. **Chapter 3: Standpoint theory and positionality** embraces standpoint methodology to align the patient as expert-knower of the care they receive, not the caregiver nor the presiding institution. As well as positioning patient experience as principal source of truthful data, the chapter positions its researcher; it offers insight into my roles as a consumer, clinician and consumer-researcher, and my transition from learner to consumer-academic-researcher.

The literature is largely mute on hospital experiences of PWDBDSI. Generally, research about DB and DSI is a fledgling discipline. Of note is that research into this community remains done by researchers with an *outsider* perspective. **Chapter 4: Gathering and exploring the internal literature and liminal space** establishes that the existing academic literature is a thin knowledge platform. An expanded literature search to canvass the wider social care literature is necessary. The few topic-relevant materials are augmented by additional discoveries during the research process. The resultant 13 artefacts are mined for insights to position the research questions as urgent and relevant to communities of PWDBDSI.

The broader literature is strewn with accounts of threats to the health and wellbeing of those living with sensory losses, underscoring the great need to gain insights into what happens when health threats turn into hospital admissions. In **Chapter 5: Externalising the literature**, threats to health are examined in five broad categories: physical and public health threats, communication failures, psychological and cognitive threats, gender-based threats; and threats posed by social determinants of health and wellbeing.

Having established a knowledge platform for the research and demonstrated the existence of lacunae, **Chapter 6: Gathering the stories** outlines how the stories of care experiences were gathered. This chapter explores data collection, and identifies how the study was conducted using a social relational-critical realist framework, alongside standpoint methodology. Participants were engaged utilising a narrative inquiry method. Qualitative methods were supplemented with a small quantitative component, thus achieving research breadth as well as depth.

In essence, the participants were chosen because they met two pre-established inclusion criteria: they self-identify as having deafblindness or dual sensory impairment; and they are older than 18 years of age. Inclusivity is the objective; I am determined for no participant to be denied a voice. All communication needs and requests are met. The subtext is that, if I can provide accessibility, so too can hospitals, and other social institutions and groups.

Prior to designing interview guides and booking interviews, I immersed myself in the communities, via impairment support organisations. This enabled the participants and support networks to affirm the communities' concern about disparities in hospital care and created opportunities for them to contribute to the design and conduct of the research. Despite having my own experiences with deafblindness and as a clinician caring for patients with sensory loss, I would not have appreciated the spectrum of this community's heterogeneity without this immersion. Participants shared with others, so word-of-mouth resulted in the snowball recruitment of a further five participants.

The research interviews were completed over a year between April 2018 and March 2019, with the final transcription concluding in April 2019. Data collection modes included face-to-face in-depth narrative interviews with individual participants, telephone National Relay Service and email. Participants had control and choice over the best method/s for themselves.

Transcripts from individual in-depth interviews and field notes generated dense data which provide both a wide scope to answer the research questions posited as well as unexpected insights. **Chapter 6** explores how an inductive thematic method is utilised for data analysis. In the first analysis phase, the data was examined line by line within a comprehensive spreadsheet, and with accessibility assistants (AAs) acting as eyes and ears, to establish words, emotions and events of significance. One supervisor (SW) oversaw the first interview transcript thus examined, allowing for consensus of emerging themes.

In the second analysis phase, words, events and emotions were grouped into idea(s) clusters. In the third phase, these ideas were coalesced into subthemes. At the end of this three-phase analysis, the data evolved into three overarching themes that display strong connections to each other. These are illustrated in depth within **chapters 8–11** (findings) of this thesis.

Keeping the participants' stories central to the work is a binding promise I made to myself. **Chapter 7: The patient journey** keeps faith with the participants' voices and hands to present their stories. Their words and signs sit at the core of this research—and relating their narratives is its principal structural aim. This creative nonfiction chapter takes the reader on a journey, via a travelling trope of hospital experiences, from fearing a hospitalisation to the emergency room, from the ward to theatre, from recovery to the ward again and finally to discharge. There are glimpses of the experiences, the journeys there and back again. This chapter is the circulatory system: the heart, arteries and veins of the thesis.

One patient journey is described using a touchpoint framing, in which points of interaction, emotion and pain are designated, starting before the admission and ending with aftercare at home. This illuminates how every encounter with the health system and its staff is a potential point of pain, where improvements are needed.

As mentioned above, the findings of the research span four chapters. **Chapter 8: Performing narrative inquiry** illustrates the performative elements, corporeal and noncorporeal. This chapter shows what it means to be embedded in the research space, what changes to the narrative space are required, and how the participants' storytelling differs from that of traditional narrative.

Chapter 9: Living realities and border concerns situates the reader and research in the lives of participants. Their living realities are complex and they express many border concerns. One area of concern to many participants is aged care, which has deficiencies and difficulties that mirror those in hospitals. Essentially, the participants in aged care describe difficulties in three key areas. Aged care is an environment of deprivation; a space devoid of communication partners, plans and practices; and a place where PWDBDSI, both young and old, do not flourish.

'Not knowing what is going on', is the state that arises when people with sensory losses do not have access to information and/or are excluded from partnerships in care and decision-making. In **Chapter 10**, the results and findings begin to take shape. This chapter presents hospital experience data that describe categories of events, emotions and experiences of health system deficits and disparities. It discusses the overarching themes of accessibility, power and ontological security with the concepts and subthemes that constitute them, arising solely from the participants' stories but couched in the researcher's language. The subthemes and concepts are often found in more than one major theme—these cross-linkages strengthen the validity of the major themes. The participants' own words illustrate the themes and concepts. The dissonance between experience and words is again noted; a 'good' experience may be one that is survived, not one in which good care is provided. The 'not knowing what is going on' space compromises ontological security.

Chapter 11: The Report Card and the Wish List is bipartite. Part 1: 'The Report Card' quantitatively examines the quality of patient experience, using patient-experience measures designed in Australia in 2017. All but two questions of the patient-experience question set can be answered using the interview data. From this, a damning Report Card is produced that demonstrates widespread omissions of care. It is critical to have positive research framings that offer solutions via problem-solving and capacity-building. Part 2: 'The Wish List' brings salutogenic solutions as generated by the expert-knowers themselves. Solutions fall into key categories, according to who or what needs improvement.

Chapters 12 and **13** are discussion sections. **Chapter 12: Deaf, blind and mute** contains a dissection of power gradients of hospital staff and systems, denial of access by the hospital organism, and the insecurity and distress of the individual. A model is presented that encapsulates these disablers to good care.

Chapter 13: 'The health system should look after us' is a conversation between participants and the researcher about their hopes and dreams of better care experiences in hospitals. Hospitals and their staff need to comply with safeguarding frameworks, do their jobs and put the 'giving' and 'care' back into 'caregiving'. A model of good caregiving enablers and their attendant benefits to health and wellbeing is illustrated. These two chapters engage with the findings, which demonstrate an alarming decentring and neglect of patient care for PWDBDSI. These penultimate chapters examine and theorise on the relationship between power disparities and the negative impact on ontological security from 'not knowing what is going on'.

Being uninformed compromises patient wellbeing and confers the risk of poorer health outcomes. A lack of accessibility and respect pervades almost all hospital experiences that the participants reported. The role of support networks in mediating experiences is discussed, as is the muting of complaints by PWDBDSI about deficiencies in their care.

One pressing objective of this work is challenging the status quo of power and care disparities; the other is changing the status quo. 'The hospitals are meant to take care of us,' says one participant, 'but they don't.' 'It's a lucky dip,' another remarks.

A model evolves that promotes knowing what is going on, power parity and security. Access to information improves patient experiences, as well as health and wellbeing outcomes. **Chapter 13** aims to demonstrate how we can harness resources and capabilities to promote better care and communication for PWDBDSI. We can change from 'not knowing what is going on' to a more ontologically secure space, with power parity and access to information provided in the form best suited to the individual.

The implications for policy and practice are titanic. An attitudinal and organisational shift is needed, if hospitals are to heed the patient-participants' voices and comply with the *Convention on the Rights of People with Disabilities* (CRPD), federal and state legislation, and the NSW Department of Health's own policy guidelines for the care of patients with disabilities.

While the doctoral journey concludes in **Chapter 14: Where to from here?**, the work of providing care and communication to patients with DBDSI has barely begun. Whereas this work's key strength is privileging the participants' voices, it has multiple limitations. There are gaps in generalisability, owing to low or absent representation of key DBDSI communities: the older aged group, rural residents, babies, children and adolescents, Indigenous Australians, the homeless, the incarcerated, and veterans. These gaps have implications for future research directions and I acknowledge that any interest in the nascent field of DBDSI research is a welcome addition to the canon.

This thesis concludes by underscoring the critical need to put existing policies and these new recommendations into actual practice. The COVID-19 catastrophe this year produces an opportunity for putting research into action. The pandemic has exacerbated pre-COVID-19 disparities for PWDBDSI and created new ones. A conversation is beginning, however, with governments; support organisations; and PWD, their families and carers about how to mitigate these influences. It is hopeful that these discussions will lead to long-term changes and improve hospital experiences for patients with disabilities, including those with DBDSI. As one participant says, 'I reckon it's about bloody time.'

Chapter 1
Complexities

Introduction

Deafblindness is an unclear concept
— Möller and Danermark 2007, p. 44

This chapter illustrates how the contours and complexities of ‘deafblindness’ (DB) and ‘dual sensory impairment’ (DSI) are contentious and changing. Contested definitions and, as yet, incomplete global acceptance of this concept as a distinct disability, mark the changing boundaries of this research. This chapter begins with a discussion of terminology, because the nomenclature used matters.

My perspective is informed by both ends of the stethoscope, and by an inchoate but nonetheless developing body of research, which includes this study. I have been the GP for older patients, who have age-related hearing loss and diabetic retinopathy, or macular degeneration. Not one of them would ever present to a doctor, hospital, social worker or government office and say, ‘I have deafblindness’, or ‘I am deafblind’. I would not write that they are deafblind on their list of current medical conditions, but I would note ‘hearing loss’, ‘wears a hearing aid’ (if they do), or ‘has severe macular degeneration’ (if that were the case), for example.

Conversely, if I present to a hospital needing care, I use the term ‘deafblind’, because this is something staff are more likely to understand and respond appropriately to. I acknowledge that this is hope more than reality. Saying ‘I have vision and hearing loss’, or ‘dual sensory impairment’ seems too nebulous, because my deficits are severe. I need the gravitas of my impairments to be understood. I do not believe that the terms ‘dual sensory loss’ or ‘dual sensory impairment’ carry the same weight or wider sociocultural understanding as the term ‘deafblindness’ does. In practice, therefore, neither term nor phrase is all-inclusive—hence my decision to include both, thus coining both a new collective term and acronym in this work. Consequently, this thesis employs the term ‘person with deafblindness or dual sensory impairment’ with the acronym ‘PWDBDSI’, to denote any ‘person with deafblindness or dual sensory impairment’ of any age. This collective grouping is more inclusive than the umbrella expression ‘person with deafblindness’.

The use of umbrella terms, which arch over often widely diverse subpopulations is, in research domains, inconsistent, and in social and personal domains, problematic. Researchers seek uniformity and clarity, and many see ‘person with deafblindness’ as the suitable umbrella term (Wittich et al. 2013, World Federation of the Deafblind 2018). This usage often creates a divide, however, which leaves the older person with hearing and vision loss on the outer, both in my view and my own experience.

Full or partial loss of hearing and sight confers a multiplicative disabling effect, rather than an additive one; thus, the concept of a distinct disability becomes pertinent. Simcock calls this the ‘third’ (2017b, p. 814) sensory disability, while Dammeyer (2014) describes the effect of dual sensory loss on functioning in all aspects of life as ‘illustrated with the equation “1 + 1 = 3”’ (p. 555).

I can attest that DB and DSI constitute a unique and distinct disability. Because there are diversities of causation, presentation and remediation, each individual faces different barriers, requires personalised support and uses varying communication methods (World Federation of the Deafblind 2018). This presents manifold complexities for researchers, in addition to uncertainties regarding nomenclature, definitions, prevalence, causation and classification. Certainty is lacking because of inexact data and the presence of invisible populations. Identities, too, are fluid and mutable. There is strong evidence of an emerging Deafblind culture and also of developing understandings of intersectionality (Clark 2014; Roy 2019). Further changes to delineations are wrought by advances—in detection, diagnosis, treatment and remediations.

While there have been many changes in causation, as a result of improved preventative practices and immunisation uptakes, there is still work needed in the margins, such as efforts in the Global South to reduce rubella and birth complications as preventable causes of sensory loss. Increased social and legal safeguards and provisions have strengthened the standing for PWDBDSI, but here, too, there are large population clusters where these changes have yet to see fruition.

There are still individual invisible subpopulations who may not be seen, heard, provided with services or counted. Sensory impairment is common, yet the picture both internationally and within Australia is plagued by data gaps. These invisible populations include, but are not limited to the young DB, those ageing into or with DBDSI, the cognitively impaired, First Peoples of Australia, homeless people, veterans, prisoners, and rural and remote dwellers. Those in the Global South face multiple disadvantages as well as hiddenness. If members of invisible populations present to hospital, they have the risk of finding barriers to achieving optimal health outcomes from that encounter.

Perhaps the single greatest alteration in the contours of living with DBDSI in the 21st century derives from communication technology. The explosion in assistive technology and devices has improved the lives of many, connecting them both to the world and each other. A caveat: assistive technology can only derive communication benefits if an individual has such a device, knows how to use and navigate it, and it consistently works. These complexities, which are difficult to see, navigate and understand, are explored in this chapter.

Research complexities

Terminology

As mentioned, elucidating problems to do with nomenclature is key to this project and to the broader hospital experiences of PWDBDSI. Historically, the term 'deafblind' related to well-known individuals, who Enerstvedt (1996) refers to as 'the epoch of the stars' (Laura Bridgman, Helen Keller, Olga Skorokhodova, James Mitchell, Robert Smithdas and Ragnhild Kåta). These individuals were largely seen as isolated cases of success; others with deafblindness were institutionalised. In the 1950s, the denominations 'hard of hearing', 'deafness' and 'blindness' were used, with 'deafblindness' coming into increased currency later (Wittich et al. 2013). After the rubella epidemics of the 1960s, there was a rapid increase in the numbers of babies and children in the community requiring support and education. Parents no longer wished to consign their children to institutions. Local centres of education for the deaf, blind and deafblind were developed.

In the United States of America (USA), the term 'deaf-blind' was commonly used (and still is, by some) to indicate the joining together of two sensory impairments, but many researchers began to drop this hyphen in the 1990s (Lagati 1995). Bourquin comments: 'Deafblind is a term essentially identical with deaf-blind. Originating in Europe and now being adopted in the United States, it is sometimes preferred because it creates a single word that defines a unique circumstance of dual sensory loss' (2007, p. 24). Simcock reiterates this, noting that discarding the hyphen is 'a recognition of deafblindness as a third separate sensory impairment, alongside deafness and blindness' (2017b, p. 814).

The terms 'DB', 'Deafblind', 'deaf and blind', 'deaf-blind', 'dual sensory loss', 'dual sensory impairment (DSI)', 'DeafBlind', 'acquired deafblind', 'congenital deafblindness', 'combined vision and hearing impairment', 'multiple sensory impairment' and 'Usher syndrome' are often used interchangeably, inconsistently and indeterminately. Different researchers also prefer different denominations, adding to the challenge for creating common understanding, comparison and communication among researchers (Wittich et al. 2013).

Some researchers and organisations (Jaiswal et al. 2018; Roy, McVilly & Crisp 2018; Wittich et al. 2013; World Federation of the Deafblind 2018) use 'deafblind' as a comprehensive term to cover all variations and affected people. A number of researchers use an uppercase D and B, as in 'DeafBlind', to denote that each impairment is significant (Wolsley 2017). This is also seen in a few impairment support organisations, which use DeafBlind to demonstrate that, while both sensory losses are substantial, neither one can be predicated over the other (Schneider 2006). However, the predominate use of upper case/capital D terminology is when participants are from, and/or identify with, Deafblind culturally and linguistically diverse (CALD) communities.

Still other researchers and impairment support organisations use the terms 'deafblindness' and 'dual sensory impairment or loss' interchangeably

(Jaiswal et al. 2018; McDonnall et al. 2017; Wittich et al. 2013). Terms may be used to describe a particular subpopulation, such as ‘deafblindness’ for the younger population and ‘dual sensory impairment’ for the older. Sometimes, each is used as an umbrella term with respect to the other. The melange of meanings assigned to terms decreases the viability of comparisons, meta-analysis and meta-synthesis.

DSI can involve any two senses, although the term has evolved to refer specifically to combined impairment in hearing and vision (Blumsack 2009); it is often used to denote older people with acquired hearing and vision losses (Capella-McDonnall 2005; Heine & Browning 2002; Saunders & Echt 2007).

Wittich et al. (2013) surveyed researchers and rehabilitation professionals, and found:

> The large majority of articles using deafblind-related terminology were published in clinician-oriented journals, whereas authors of high-impact research journal articles (many outside the domain of sensory rehabilitation) were more likely to utilise terms such as dual sensory or combined impairment (p. 199).

There are also problems with terminology generalisations from the perspectives of consumers (who are not a homogenous mass), clinicians (who are not using the deafblind umbrella term for the older dual sensory impaired) and consumer-researchers (such as myself), who must navigate an unsettling variety of potential nomenclatures, while striving for precision. The population includes widely disparate groups, whose needs and identities are not necessarily served by the current umbrella terms. Studying a person with deafblindness from birth, the congenitally deafblind (CDB), is more difficult because this is a very small, dispersed and disparate population (Parker, Davidson & Banda 2007). It is important not to subsume this group into the larger group of older dual sensory impaired, because the age of onset of sensory loss confers different experiences, needs and vulnerabilities (Dammeyer 2014; Larsen & Damen 2014). Larsen and Damen’s message for researchers is to define your terminology and provide impairment information about any participants contributing to your study (2014).

A schism exists, where the largest group with sensory impairment are older people, who often say: ‘I don’t see or hear very well’, and do not identify, recognise or refer to themselves as ‘deafblind’, the most common overarching term in use (Dunsmore et al. 2020; Wittich et al. 2013; World Federation of the Deafblind 2018). Impairment may be seen as a ‘normal’ part of the ageing process and some older people may not know they have remediable impairments, thus rendering them invisible (Sense United Kingdom [UK] 2013; Shakespeare 2018). Further complexities arise out of the varied paths to deafblindness or dual sensory impairment. Some consumers may identify with the primary, or first-occurring impairment, coupled with the second; for example, deaf with vision loss, or blind with hearing loss.

Thus, one major limitation for researchers is that the literature has not reached consensus on how to designate this unique pluralistic population. By way of illustration, the papers used for this thesis are audited according to which term is used to describe the participants with hearing and vision loss. The full table can be viewed in **Appendix 2**.

Of the articles surveyed, 53 percent use ‘deafblind’ as the umbrella term to describe their research population, with 19 percent preferring ‘deaf-blind’ and 26 percent using ‘dual sensory loss or impairment’ as the umbrella term.

From the research readings (tabulated in **Appendix 3**), the following trends are clear: lowercase ‘deafblind’ is the most common descriptor and comprehensive term; and in the more recent research literature, there is a trend towards using ‘deafblind’ as an umbrella term for all groups of people with dual sensory loss (Jaiswal et al. 2018; Roy, McVilly & Crisp 2018; Wittich 2019; World Federation of the Deafblind 2018). Literature pertaining to older dual sensory impaired people use dual sensory impairment or loss more often. Both these findings are consistent with observations made in recent reviews (Jaiswal et al. 2018; Wittich et al. 2013).

Terminology in this research

In the heterogenous world of deafblindness and dual sensory impairment, there are many communities and outliers; there is not just one homogenous group, sheltering under the one extensive term. Further, simply using the term that the participant employs to describe themselves is a choice I am unwilling to obviate. One participant in Wittich et al. (2013) notes: ‘Labelling can be a sensitive subject, personally, I feel that it is whatever the individual feels comfortable with’ (p. 203). In my view, deafblindness (in any upper/lowercase or hyphenated form) cannot be used as a comprehensive term, because it does not—in its history, meaning and consumer usage—include people over 65 with acquired sensory losses, who make up the majority of individuals with dual sensory impairment. Without due acknowledgment, this group will remain ‘invisible’. Already, they are often unseen, uncounted and unsupported (House of Representatives Standing Committee on Health, Aged Care and Sport 2017; Sense UK 2013).

While there is a confronting reality that researchers exert power in how they use words to include and exclude, the intention of this research is not to evade but approach an inclusive position. Consequently, as mentioned in this chapter’s Introduction, my use of the term ‘person with deafblindness–dual sensory impairment’ for any person with co-occurring vision and hearing impairment’ (PWDBDSI), is adopted to conflate the two largest groups of people with combined sensory losses—people with deafblindness and those with dual sensory impairment. My intent is to remind the reader, visually and linguistically, that naming and identity are often linked, and that being too derivative of historical categorisation can exclude individuals.

Distinct disability and the Nordic definition

The idea that deafblindness is a complex, unique and distinct disability resonates with many legislators, policymakers and researchers (Bodsworth, Clare & Simblett 2011; Dammeyer 2010a, 2012, 2014; Dammeyer & Hendar 2013; Gullacksen et al. 2011; Langer 2009; Simcock 2017b; Wahlqvist 2015; World Federation of the Deafblind 2018). Being deafblind does not mean that you hear nothing and see nothing—most people who are deafblind or dual sensory impaired have some residual sight and/or hearing. It is the combination of sensory losses, however, that packs the big disabling punch.

In 1980, a Nordic collaboration—comprising a group of researchers, health professionals and government officials from Norway, Denmark, Iceland, Finland and Sweden—released their definition of deafblindness. This consists of two sentences that introduce the concept of a distinct disability for the first time: 'Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability' (Nordic Centre for Welfare and Social Issues n.d.). The Nordic collaboration reviewed its definition throughout the ensuing decades and organisational name changes, and in 2016, it released a plain English definition with extensive explanatory notes. The resulting definition addresses the distinct disability and complexities of living with deafblindness–dual sensory impairment. This 'new' Nordic definition (as opposed to the 1980 version) uses deafblindness as the umbrella term for both DB and DSI. The definition is as follows:

> 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 n.d.).

Dammeyer (2010) notes that the original (and subsequently, the new) Nordic definition is advantageous, because it does not privilege the medical evaluation; rather, it leverages the functional assessments of communication, mobility and access as having greater importance. The new Nordic definition addresses many of the intricacies of life with dual sensory impairments. In brief, the key complexities drawn from the explanatory notes are as follows:

1. Distinct and complex disability
2. Hard for each sense to compensate for the other
3. Time consuming
4. Energy draining
5. Information received in fragments
6. Activity limited
7. Participation reduced
8. Communication, access to information and mobility affected
9. Tactile sense critical as a conduit of information
10. Communication technology, assistive devices, interpreters and adaptations to the environment may be required
11. Despite the above, human assistance and support needed to provide access to information, mobility and safety

The Nordic countries have well-established supports and programs to assist PWDBDSI to live flourishing lives, which also have been linked to their acknowledgement of a distinct disability (World Federation of the Deafblind 2018). Specifically, deafblindness is mentioned as a distinct disability in the UN *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations 2006). This recognition in international law is bolstered by the term being adopted in other jurisdictions. Being named as having a distinct disability influences not only support and programs, but also how PWDBDSI perceive themselves (World Federation of the Deafblind 2018).

The idea of deafblindness as a distinct disability gained further traction through the major world deafblind impairment support organisations—including the Canadian Deafblind Association, Deafblind International, Helen Keller National Centre, Sense UK, American Association of the Deafblind, Nordic Collaboration, and World Federation of the Deafblind—employing this concept. More recently, countries such as India, Uganda and Peru have incorporated deafblindness as a distinct disability in their disability rights legislation, although some of these laws are still waiting enactment (World Federation of the Deafblind 2018).

While Australia does not have any legislated recognition of DBDSI as a distinct disability, it skirts around this issue with most impairment support organisations opting for definitions that are functional and that also acknowledge the complexity of two sensory impairments together. Separately, support for vision loss or hearing loss is inferior to support for deafblindness (Prain 2019).

PWDBDSI are a cohort needing safeguarding. When international law, the CRPD, recognises those with deafblindness as a unique disability group, signatory states thus ‘have an obligation to acknowledge and respond to the requirements of persons with deafblindness across legislation, policy, programmes and budgets’ (World Federation of the Deafblind 2018, p. 7). Failure to recognise this distinctiveness can result in data invisibility which, in turn, delays or denies development and provision of needed safeguards, services and funding.

An absence of cognisance also means that health professionals lack training and awareness of the complexities their patients face. Professionals may fail to provide services and support in an understanding and effective way, or services may not be developed because their patients’ complex needs are not recognised (World Federation of the Deafblind 2018). The absence of acknowledgment also results in impairment support organisations receiving less recognition and funding, and diminishes the support and advocacy they can provide to PWDBDSI. Additionally, these impairment support organisations do not receive a seat at the table in disability policy and planning (World Federation of the Deafblind 2018). Without the concept of their distinct disability accepted and enshrined at all levels in legislation, policy and practice, PWDBDSI will continue to be served poorly compared to both people with other disabilities and people without disability/ies.

Emerging culture(s)

A group is considered a cultural group when it has its own language, norms, traditions and values. An emerging CALD community, therefore, is evident in both local and international communities of Deafblind people (Clark 2014; Roy 2019). Deafblindness is a strong central identity for many, with a tactile language, norms and conventions (Clark 2014).

There is no research analysis of Deafblind culture and its emergence and manifestations in the Australian context, a finding confirmed by Roy, McVilly and Crisp (2018). However, there is clear anecdotal evidence from d/Deafblind support organisations, publications and individuals as well as recent empirical work on better research practices, which strongly recognises the existence of a distinct culture in Australia (Roy 2019).

Deafblind culture is comprised of tactile sign language and the primacy of touch. The use of uppercase ‘D’ in Deafblindness often denotes a cultural distinction—an indication that a person has adopted an identity with sign language and within a signing community (Arndt 2011b). There are reports of the DB being a ‘minority within a minority’; for instance, people who have been in the Deaf community, which is a visual language–using group, have been or felt ostracised after going blind, as described by DB college students in Arndt (2011a) and by DB adults in Stoffel (2012).

The Deafblind community has a unique social structure, incorporating guide dogs, support workers and interpreters. It has different social norms, such as long goodbyes because, historically, contact is difficult and members may experience long intervals between social events. There are other conventions, such as the etiquette of attracting someone’s attention or emphasising points by banging on a table to generate vibrations.

PWDBDSI may have a reduced worldview as a result of their decreased access to information, and the increased time they need to process this information, as a direct outcome of their sensory losses (Roy 2019). Imagine a jigsaw puzzle with many pieces which, no matter how you put it together, you remain several pieces short. Sometimes, those pieces do not matter, such as sections of the sky, but sometimes, the features of a person or significant details are missing. At times, a large number of pieces are absent, making comprehension of the whole elusive. This diminution of information, which compromises a full understanding of society and events, is echoed by MacDonald (1989). The culturally Deafblind do not view their absent or diminished sight and sound as a negative, burden, deficit or disability, however, ‘because according to the norms and values of their cultural group, they have normal, fulfilling, interactive lives without depending on sounds or spoken language to communicate’ (Arndt 2011b, p. 206).

Sensory impairment complexities

Single impairments

People with a single sensory impairment need to be considered and advised on prevention and remediation because they are a growing group in the community, one that is at risk of suffering a compounded communication disability if they acquire a second sensory impairment. Observing data on single impairments gives a broader understanding of how hearing and vision loss affects so many. The World Health Organization (WHO) estimates that, worldwide in 2005, there were 278 million people with impaired hearing and 314 million with impaired vision due to disease or uncorrected refractive errors (World Health Organization 2011).

In developing countries, up to 60 percent of hearing loss is treatable and up to 80 percent of vision loss is remediable (WHO 2011). WHO has a priority goal to decrease needless sensory impairments globally (WHO 2013). In Australia, 66 out of 100 Australians over 60 years of age have hearing loss (House of Representative Standing Committee on Health, Aged Care and Sport 2017). Most older Australians will be affected by hearing loss at some stage, rendering them vulnerable in healthcare settings, and at risk of social isolation and depressed mood. Dementia is another risk associated with hearing loss, though modifiable—the risk of dementia decreases with remediation (Mukadam et al. 2019). The Senate Inquiry recommends that hearing health in Australia should be prioritised as an urgent national priority (House of Representatives Standing Committee on Health, Aged Care and Sport 2017). In 2016, the National Eye Health Survey (NEHS) extrapolated from its data that there were 453,000 adult Australians (1.9 per 100 people) with bilateral vision impairment/blindness (Foreman et al. 2016). Thus, single impairments are common.

Co-occurring sensory impairment

People with DBDSI live complex and often marginalised lives. They face multiple barriers to both accessing support and being heard. This makes it difficult for them to articulate their needs and concerns, as well as making it problematic for PWDBDSI to be included in data collection: ‘if you are not heard or seen, you cannot be counted’ (World Federation of the Deafblind 2018).

Data on sensory impairment varies, depending on the population and how it is studied (Brennan 2003; Dammeyer 2014; Schneider 2006; Schneider et al. 2012). As noted in this chapter’s Introduction, research studies, reports and data collection also use different definitions and terms. This makes deriving reliable statistics and allowing comparisons between studies difficult. In addition, the DBDSI population is heterogeneous and geographically widespread. Further, not all studies discuss participant sensory deficit information explicitly. There is no large, population-based study that measures the prevalence of deafblindness and dual sensory impairment across all age groups. The *World Federation of the Deafblind Global Report 2018* (WFDB) is a collaboration that seeks to rectify this gap. This is the first attempt to gather data to estimate pan-national prevalence. Covering 97 million people across 22 nations (a mix of high-, middle-, and low-income countries), the report was completed in 2018. Significant findings are:

> Some 0.2–2 percent of the world's population live with deafblindness [deafblindness is used as an umbrella term for all dual sensory impairment]. Most PWDBDSI are over 65 years [as mentioned in the above section on terms], so the number of people with deafblindness increases with age. For the population over 75 years, 6 percent have co-occurring dual sensory loss. Deafblindness often coexists with other disabilities, because between 20 percent and 75 percent of people with deafblindness have additional disabilities (World Federation of the Deafblind 2018).

DBDSI Australian data

Prior to 2013, there was little Australian data on those with an impairment that affected both hearing and sight. In 2013, Senses Australia undertook a survey of state, territory and national data and determined that approximately 100,000 Australians are deafblind (Dyke 2013). This equates to 5 in 1000 Australians as having a dual sensory disability in 2013, with two-thirds of these people more than 75 years of age (Dyke 2013). As Australia's population continues to grow and age, these numbers could be doubled now in 2020. The experience in Canada, which has a similar health environment to ours in Australia, demonstrates a rising prevalence of affected older persons throughout half a decade (Wittich 2019).

Causation

Thus far, we have discussed how terminology impacts research and understandings, how deafblindness and dual sensory impairment have been defined for this work, and how CALD has evolved. In discussing the experiences of PWDBDSI, however, it is also important to factor in questions of causation, particularly because they inform life with DBDSI and communication experiences. There are two discrete causations relating to DBDSI that pertain solely to the age of onset of the sensory impairments: congenital and acquired.

Congenital deafblindness

Congenital deafblindness (CDB) occurs when sensory impairments are present at birth, or before language development (Dammeyer 2012). Acquired DBDSI relates to sensory losses that eventuate after the acquisition of language and/or a period of sightedness. Sometimes, there is a combination of both; in Usher syndrome (USH), for example, congenital deafness is combined with acquired vision impairment years or decades later (this is discussed in more detail shortly). The distinction between congenital and acquired DBDSI is important because the loss of vision and hearing before developing language (prelingual) confers greater difficulties and increased support needs (Dammeyer 2012; Larsen & Damen 2014).

For people who become deafblind early in life, the building blocks for acquiring oral language and visual cues for understanding the world are not present. In turn, this means that touch and any residual senses become the main channels for giving and receiving information. While a minority, those with CDB, are the most disadvantaged and dependent group. Larsen and Damen (2014) observe that a definition of deafblindness, which includes distinguishing between CDB and acquired DB, is preferred for research purposes because of these extremes.

The prevalence of CDB is approximately between 1:27,000 and 1:29,000 in a Danish population (Dammeyer 2010b). CDB comprises less than 1 percent of the total population of all individuals with DBDS (Schneider et al. 2012). From the Danish data cited by Dammeyer, the common causes of congenital deafblindness are:

> Rubella syndrome—28.3 percent
> CHARGE syndrome—20.0 percent (coloboma, heart defect, atresia choanae, growth retardation, genital abnormalities and ear abnormalities)
> Perinatal asphyxia—14.3 percent
> Down Syndrome—7.9 percent
> Prematurity—7.1 percent (Dammeyer 2012)

Acquired DBDSI

Acquired DB or DSI is the term used to describe hearing and vision losses that occur after acquiring language and/or a period of sightedness. The vast majority of people with DBDSI have an acquired causation. Using a prenatal to old age approach, List 1 demonstrates common causes and ages at which they occur.

List 1. Causation by age

Prenatal (during pregnancy)

- Infection e.g. rubella or cytomegalovirus
- An inherited condition or syndrome
- A chromosomal disorder during the foetus' early development
- Injury affecting the foetus

Perinatal (complications at birth)

- Premature birth
- Very low birthweight
- Neurological conditions as a result of a traumatic birth or lack of oxygen

Post-natal/ childhood

- Inherited conditions that present during developmental stages
- Autoimmune conditions
- Illness caused by virus or disease
- Injury to the eyes and ears
- Acquired brain injury

Young adult to older age

- Inherited conditions or syndromes that present later in the person's life
- Non-hereditary conditions and syndromes
- Autoimmune conditions

- Infection e.g. meningitis
- Consequences e.g. diabetes
- Injury to the eyes and ears
- Acquired brain injury
- The ageing process

In the older age group, causes of acquired sensory impairments include (see Chia et al. 2006; Dammeyer 2014; Foreman et al. 2016; House of Representatives Standing Committee on Health, Aged Care and Sport 2017; Jee et al. 2005; Tay et al. 2006):

Hearing loss

- Presbycusis (most common cause of hearing loss in older people)
- Occupational noise exposure
- Military noise exposure
- Recreational noise exposure
- Unknown aetiology

Vision loss

- Presbyopia
- Cataracts
- Glaucoma
- Age-related maculopathy (leading cause in older people)
- Diabetic retinopathy

Further to the above division into congenital and acquired causation, two other causations are mixed: congenital deafness with acquired vision loss and congenital blindness with acquired hearing loss. The commonest cause of the former is Usher syndrome (USH). For a contemporaneous and comprehensive classification of the older Canadian population, see Wittich and Simcock (2019).

Usher syndrome

Usher syndrome is the cause of approximately 50 percent of DBDSI in the under 65s age group (Dammeyer 2014; Wittich 2012). Sometimes written as Ushers syndrome and often abbreviated to USH (Mathur and Yang 2015; Wahlqvist 2015; Wahlqvist et al. 2016), this is what I have. USH is both congenital and acquired.

The syndrome is named for Charles Usher, a Scottish-born ophthalmologist, who worked principally in Aberdeen, Scotland, at the turn of the 20th century. Usher's lifelong research interest was in inherited eye disease. His name is associated with his finding the connection between deafness/hearing loss and vision loss caused by inherited forms of retinitis pigmentosa (RP), a progressive eye disorder. Usher (1914) found, in a cohort of 69 patients with RP, 11 'deaf mutes' and 19 additional patients with some degree of deafness. No deafness was noted in 20 cases. Nineteen cases had no records available regarding hearing. Accordingly, this means that, out of 49 patients with known hearing status, 30 had RP combined with hearing loss (Usher 1914, p. 135).

In brief, we now know that USH is an autosomal recessive condition, which can impact three major senses in the body: vision (progressive vision loss over time), hearing (loss varying in severity, usually present at birth, which may decline), and balance (vestibular areflexia present in some subtypes of USH only, and is not a universal feature). Sixteen loci are identified, which are either causative or modifier genes (Mathur & Yang 2015). While today, DNA testing is the only definitive way to determine diagnosis, type and subtype, traditionally, USH was divided into three groups with clusters of clinical associations and trajectories:

> **USH1**—congenital hearing loss, usually severe to profound, early onset of RP in the first decade and vestibular areflexia;
> **USH2**—moderate to severe hearing loss, normal balance, onset of RP within the second decade;
> **USH3**—progressive, unpredictable and variable hearing loss, balance dysfunction and RP (Mathur & Yang 2015, p. 407–8).

There are two caveats: the first, many people with USH have an atypical presentation and/or progression; second, some people who have a clinical USH diagnosis do not have it when DNA is tested: these are termed ‘masqueraders’.

Because the population is hard to quantify, prevalence of USH is variable; however, Mathur and Yang (2015) suggest an incidence of between 1:25,000 and 4:25,000 people. Sweden has a national USH database, with an incidence of USH at 1.4:100,000 people and with an equal male/female incidence (Wahlqvist 2015).

Remediation

There is no cure for USH. The mainstays of remediation are hearing aids, low-vision aids, and assistive devices and technology. Since the late 1980s, Cochlear Implantation (CI) has gained ascendancy as an effective remediation for severe to profound hearing loss in babies, children and adults. While Soper (2006) demonstrates benefits for most people with hearing loss, implantation is an invasive procedure that requires a general anaesthetic, surgery and includes the risk of adverse events (Gheorghe & Zamfir-Chiru-Anton 2015).

A recent meta-analysis of 42 studies of CI in adults showed unilateral cochlear implantation both ‘improved hearing and significantly improved quality of life’ (Gaylor et al. 2013, p. 265) in hearing-impaired adults. In some centres, most children with severe to profound hearing loss receive CIs, and most can hear speech and develop oral communication skills (Mathur & Yang 2015). Retinal prostheses and bionic eye technology have a long way to go to emulate these successes (Mathur & Yang 2015).

Specifically, examining USH subpopulations Wahlqvist (2015) found that USH3 participants with a CI reported better health and wellbeing scores than those without. At the time of research, those with USH3 and a CI ‘reported far fewer problems than the others, had better self-assessed health, few poor physical health days, few poor mental health days and few days of restricted capacity for work and ADL’ (Wahlqvist 2015, p. 60).

Notwithstanding small sample sizes in both studies, this effect merits further investigation because these findings suggest that implanted participants have fewer psychological disorders and distress. As Wahlqvist suggests, this may position CI more strongly as a remediator, given the high burden of psycho-emotional distress in the USH and wider DBDSI population.

There are deep divisions, however, among sectors of the hearing world and some of the Deaf and Deafblind communities about the ethics of CI (Clark 2014; Shariff 2015; Arndt 2011; Valente 2011), where views on salvaging hearing conflict with strongly held beliefs about cultural ethnocide. As seen above, there are tangible benefits of CI (using oralism as a benchmark, which is a position those in institutional power often adopt), but belonging to a clan also gives positive life outcomes. John Clark, a Deafblind American activist, writes that being Deafblind provides people with ‘a place of their own where everything is for them, where every social aspect and cultural feature empowers them, where deafness as an issue disappears, and where they are just people’ (Clark 2014, p. 454/2094). The ‘cochlear implant is not for deaf people’, explains Clark:

> The cochlear implant is for, and, promotes the interests of, hearing people. It was invented by a hearing man and the risky experiments and sometimes fatal operations were legalised by hearing people. The demand for it is driven by hearing parents. It financially benefits hearing teachers, hearing doctors, hearing speech therapists, and hearing businesses in the industry. It is only at the bottom of the industry that we find the token deaf person (2014, p. 419/2094).

Perhaps, it is time to push for multiculturalism. Gale (2011) agrees that bridging this divide would entail a bilingual approach with both signing, for culture and clarity, and a CI, for oralism.

The future: DNA testing and gene therapies

While remediation with cochlear implantation or hearing aids works for some, there is an active research community making progress in a range of possibilities. Early genetic testing for rare syndromes is a recent protocol development, enabling both detection of congenital deafness and blindness, as well as picking up those infants and children with USH, or other rare syndromes, much earlier than they would have otherwise (Sung et al. 2019). Early genetic testing effectively replaces the stressor of dealing with a late diagnosis of DBDSI or multiple disability with the anxiety of knowing what is to come for years, or even decades, beforehand. This is uncertain new territory and families in this position are at the vanguard; they need support to navigate it (Emily Shepherd 2019).

In research arenas, there are several therapies under investigation to halt progressivity, rescue or repair existing damage, or cure USH and other genetic-based sensory losses. Scientists can restore/rescue hearing and vestibular function in mice, by applying antisense oligonucleotides (Mathur & Yang 2015). While the journey from mice trials to human-established therapy is, by necessity, a long and fraught one, this is one of the few research directions for rescuing hearing loss. Most other research approaches centre around vision loss; those with promise include gene therapy with viral vectors and genome editing (Lamey 2019; Mathur & Yang 2015).

Invisible populations

By their nature, sensory impairments are often invisible; though impairments may be extensive, there may be no outward evidence of them. Within this invisible mantle lie hidden subpopulations at risk of, or with, sensory impairments that may not appear in the public awareness, research and data domains. These discrete groups are poorly understood; they have complex needs and may not be seen, counted or adequately supported. Multiple disadvantages are common in these groups, especially in the Global South, where developments in rights, safeguards, recognitions and support are either absent or in their infancy. Invisible populations of PWDBDSI are explored individually below.

Invisible second disability

Many with dual sensory impairment are only known as having one. In their research on students with sensory impairments in Sweden, Danermark and Möller (2008) noticed that not all people with impaired vision and impaired hearing are recognised as having both. Sometimes, the first sensory loss diagnosed draws the attention—rather than the combination of the two—resulting in implications for participation, activity and education (Danermark & Möller 2008). A similar effect is noted in Nigerian schools for the blind, where hearing loss is present in many but not detected (Aghaji et al. 2017). Sense UK found DSI was overwhelmingly under-diagnosed in UK residential aged care, both with known single impairment and no impairment (2013). Avery (2018) notes that this diagnostic overshadowing is common among First Peoples with disability. Avery recently remarked in a personal communication, ‘I use the word “co-occurring disability” and in my research I often saw the presence of two disabilities. The primary health system gives you a diagnosis but there would be another, or more’ (Avery 2019, pers. comm. 2 September). The incidence of a ‘co-occurring disability’ is significant because if your second disability is not acknowledged or diagnosed, then you cannot be properly supported.

The ‘young’ deafblind, under 65

This is a small population, who have high communication and support needs. Australian data on this group are difficult to ascertain, but estimates based on the 2011 Australian Bureau of Statistics (ABS) census suggests 33 percent of people with deafblindness are under 75 years old (Dyke 2013); this equates to just under 33,000 people. In 2011, Anderson, Harper and Lawson (citing Access Economics 2006) reported to the Disability Care and Support public inquiry that, Australia-wide, there were 7,000–9,000 people with deafblindness under 65 years old. While DBDSI is ‘rare’ for those under 65 (with ‘rare’ defined as affecting less than 1:2000 people (Rare Voices Australia n.d.), younger PWDBDSI have high support and resource needs. Of concern, and relevant to this study, is that many do not have access to assistive devices, technology and interpreters. In submissions to the House of Representatives Inquiry in 2017, three key problems with services for the PWDBDSI are highlighted:

1. Insufficient funds for communication equipment
2. Lack of training in how to use the equipment
3. Lack of support staff trained in working with DBDSI.

These problems suggest that younger deafblind patients are often communication disadvantaged in any situation, including when in hospital. This communication shortfall may improve as the National Disability Insurance Scheme (NDIS) is fully rolled out across Australia, providing funding for technology and assistive devices. The 2020 COVID-19 crisis prompted impairment support organisations, NGOs and other service providers to deliver telephone and online service provision. Many PWDBDSI were left isolated, because face-to-face and tactile language supports evaporated. The NDIS responded by allowing iPad purchases for accessing telepractices; however, uptake for many PWDBDSI was hampered by the catch-22 of little accessible information actually reaching individuals (Watharow 2020a).

Those deaf and DB people who use interpreters for Auslan and tactile sign languages are also at a communication disadvantage in hospitals, because of deficits in interpreter provision, training, availability and numbers (House of Representatives Standing Committee on Health, Aged Care and Sport 2017). This means they cannot be heard or understand what is happening to them.

One of the gaps in the present NDIS setup is how to give people with disabilities real choices in and control of their living arrangements. Failures of society and its services to provide appropriate housing and support means that younger PWDBDSI can be placed in residential aged care facilities, where there are no communication partners because the staff do not use tactile languages. The risk of abuse, neglect and isolation is high. In Australia, The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which commenced in April 2019 with its final report due 29 April 2022, is examining the experiences of younger PWDBDSI, who are hidden in residential aged care. This is beyond the scope of this work, but is indicative of the community concern about rates of violence, abuse, neglect and exploitation in all aspects of social life and the commitment to scrutiny.

Ageing with DBDSI

People with DBDSI age. This group includes the culturally Deafblind, congenitally deafblind, and those who have lived with DBDSI for some, or most, of their lives. In Australia, there are informal, yet disturbing, reports of people having difficulty accessing services, communication devices and interpreters within aged-care settings (House of Representatives Standing Committee on Health, Aged Care and Sport 2017). For those in residential aged care, there may be no staff members who can sign or use the manual alphabet, meaning those sign-language users with DB have no communication partners unless they are visited, or an interpreter is booked.

Simcock (2017a, 2017b) addresses a number of challenges that come with ageing with DB, including poorer access to information and services, restricted choices, changing communication needs and acquiring other impairments. Acquiring other impairments, or the worsening of existing impairments, often leads to changing communication needs. Hospitals may be where this occurs; for example, a tactile sign user may have a stroke and is then unable to use a two-handed signing method.

Ageing into DBDSI

People without disability grow old and a great many acquire a sensory impairment or two. Twenty years ago, Campbell et al. (1999) note that increasing numbers of older adults with sensory impairments means increasing numbers limited in their daily activities, which creates increasing need for services and, in turn, increasing demands placed on institutions that provide care. Yet, how can older PWDBDSI be supported in the first instance, if they are under-recognised, under-diagnosed, un-remediated and often unacknowledged as having support needs? Its prevalence is largely underestimated due to failure to detect, underreporting and nondisclosure.

Failure to diagnose is a crucial factor that leads to underreporting. Rates of sensory impairment among older people in residential care are significant, up to four times higher than among those in the general community (Brennan 2003; Sense UK 2013). Research reports that 35 percent of people in care homes were found to have undiagnosed dual sensory loss (Sense UK 2013). This situation is likely to be similar in Australia, with better screening, diagnosis and remediation recommended both in the community and aged-care facilities (House of Representatives Standing Committee on Health, Aged Care and Sport 2017).

Another contributing factor to the underreporting of sensory impairments in this group is using inaccessible formats and methods, with researchers finding self-reporting and/or proxy reporting to be ineffective (Berry, Kelley-Bock & Reid 2008; Brennan 2003; Brennan, Horowitz & Su 2005). In particular, if questionnaires and surveys are not provided in a wide variety of formats personalised to individual communication needs, this can lead to poor uptake (Bodsworth, Clare & Simblett 2011; Dammeyer 2014; Mathos, Lokar & Post 2011).

Most older people do not identify as ‘deafblind’, believing that hearing and vision loss are part of old age. Sensory impairment ‘may be concealed by the older person because of the stigmatization of these conditions’ (Brennan, Horowitz & Su 2005, p. 345). This is a factor in Australia: ‘many people still refuse to wear hearing aids because of the stigma attached’ (House of Representatives Standing Committee on Health, Aged Care and Sport 2017, p. 21). Wearing glasses does not seem to confer the same negative self-image as hearing aids.

The data are explicit however, in that the incidence of DBDSI rises with age, demonstrated by the exponential numbers of the over 65-year-olds who have both single and dual sensory loss (Brennan, Horowitz & Su 2005;

Desai et al. 2001; Foreman et al. 2016; House of Representatives Standing Committee on Health, Aged Care and Sport 2017). American researchers found that 21 percent of older adults had DSI, 37 percent had a single impairment and 43 percent had no sensory impairment (Brennan, Horowitz & Su 2005). Because their study was based on self-reporting and proxy reports, the authors suggest that this data underrepresents the affected population (Brennan, Horowitz & Su 2005). It is likely that many people, both in the community and aged-care facilities, are not diagnosed, thus remaining invisible.

The prevalence of acquired dual sensory impairments in older Australians is also underestimated. Schneider et al. (2012) posit that one in four Australians aged 80 and over, and living in the community, has a dual sensory impairment. An ongoing longitudinal study in Canada suggests that, in 2016, there were 570,000 men and 450,000 women with DSI, from a total population of 35.1 million (Statistics Canada 2016; Wittich 2019). This means 2.9 percent of the Canadian population have a dual sensory impairment. These DSI figures are the result of formal testing measures to determine impairment, not self-reporting. They demonstrate a doubling of PWDBDSI since 2011, principally due to the baby boomer generation ageing (Wittich 2019). Wittich (2019) surmises that men outnumber women with DSI because of hearing loss due to increased exposure to occupational and recreational noise. Men also make up the majority of veterans, homeless and prisoners—discussed separately below. Further, evidence suggests that the community and aged-care sector are ill-equipped for older citizens with DSI (Sense UK 2013; Wittich 2019).

Those with DSI face an increased risk of mortality, evidenced in many studies (Desai et al. 2001; Gopinath et al. 2013). Older people with DBDSI are not living lives of wellness either, with increased multiple disabilities, comorbidities (Desai et al. 2001) and social isolation (Heine & Browning 2014, 2015; Hersh 2013a; Jaiswal et al. 2018; Schneider et al. 2011; McDonnall et al. 2016).

Because many sensory impairments are remediable, priority should be placed on providing services for early detection and training care facility and hospital staff to reduce communication vulnerability and risk of hospital decline (Lin, Metter & O’Brien 2011). The paucity of dual sensory units—those that provide diagnosis, follow-up, support and remediation for both vision and hearing loss, both in Australia and overseas—is concerning. Such units enable better data collection, increased diagnosis of a second sensory impairment, and improved support services and staff training in managing this unique and complex disability. Research suggests that this approach garners strong support from those with sensory losses (Schneider et al. 2012).

First Peoples of Australia

The legacy of colonialism has left Australia’s First Peoples with ‘the largest socially determined life expectancy gap of any nation in the world’ (Gilroy & Donelly 2016, p. 15333/17224). Another unwelcome vestige is the higher rate of disability and poor health among First Peoples than non-Indigenous

Australians (Avery 2018). In addition, disability begins earlier in life, with higher rates of co-occurring disability (Avery 2019, pers. comm. 2 September). In short, the intersectionality of multiple disadvantages laminates further complexity on top of single and dual sensory impairment. Further, overt and covert racism complicates First Peoples' experience of disability. Health professionals and hospitals are often perpetrators, not protectors. Misattribution and misdiagnosis are common; for instance, unsteadiness due to disability is misattributed as drunkenness, with doctors failing to see medical conditions underlying the unsteadiness. First Peoples are also adversely impacted by the divide between rural/remote and urban areas, when accessing essential and support services (Avery 2018).

From the data available, while it is uncertain whether there has been full capture of First Peoples with single and dual sensory impairment, clearly, there is much to be concerned about. Of Aboriginal and Torres Strait Islander people, 42 percent have a sensory disability (Dyke 2013). Hearing loss profoundly impacts Aboriginal and Torres Strait Islander people; ear infections are commonplace and recurrent infections can cause permanent hearing loss with flow-on communication issues and educational difficulties (Dyke 2013). Misattribution begins early: many First Nations children with hearing loss are labelled 'bad black kids' at school (Avery 2019, pers. comm. 2 September). Self-reported ear/hearing problems for Indigenous children living in remote/very remote areas was 18 percent in 2001, and 11 percent in 2014–15. For Indigenous children in non-remote areas, those percentages were 11 percent and 8.4 percent, respectively (Australian Institute of Health and Welfare 2018d).

The 2017 report on hearing health (House of Representatives Standing Committee on Health, Aged Care and Sport 2017) and the 2016 NEHS (Foreman et al. 2016) also present worrying pictures of high rates of single sensory loss in Indigenous Australians. Spanning from 1992 to 2007, the Eye Health Survey in the Blue Mountains focused on an outer Sydney population, which contained no Indigenous residents (Chia et al. 2007; Jee et al. 2005; Tay et al. 2006). To rectify this omission, the NEHS purposively sampled Indigenous groups (Foreman et al. 2016). Bilateral vision impairment/blindness affects 4.57 percent of non-Indigenous adults over 50 years and 13.6 percent of Indigenous adults over 40 years (Australian Institute of Health and Welfare 2019b). This means that Indigenous Australians have three times the rate of vision impairment and blindness, and it presents earlier, than non-Indigenous Australians (Australian Institute of Health and Welfare 2018d, 2019b).

The literature review for this thesis did not identify data on the prevalence of DBDSI in Indigenous populations, though high rates of single sensory impairments indicate that the prevalence of DSI may also be considerable. The Clear View Report from Senses Australia (Dyke, 2013) states that 94 percent of vision loss in Indigenous Australians is preventable or treatable. The House of Representatives also notes that much of hearing loss among Indigenous people is preventable (House of Representatives Standing Committee on Health, Aged Care and Sport 2017); for these reasons, it is important to screen, treat and remediate Indigenous babies, children and adults. This means working with communities of First Peoples to access their expert knowledge for solutions that demonstrate respect and acknowledge First Peoples’ sovereignty and community resources.

There are clear data, service and support gaps for First Peoples with disability generally, and for sensory impairment, in particular. It can thus be expected that First Peoples will experience attitudinal, communication and access barriers in hospital and healthcare institutions.

The homeless

There appears to be no data available on the sensory impairments of this hard-to-reach population, who suffer multiple physical and psychosocial disadvantages. As a group, the homeless with DBDSI are invisible. For example, the 2018 government publication ‘Australia’s Health’ does not identify the homeless as a population group regarding health data (Australian Institute of Health and Welfare 2019a). Homelessness is associated with premature and accelerated ageing, which includes earlier onset sensory loss/es (Maxmen 2019).

While precise information is lacking, Australia’s homeless population is increasing, alongside rising housing costs. Australian census data from 2016 estimate that there are ‘116 000 homeless men, women and children, an increase from 2011 of 4.6%’ (Australian Institute of Health and Welfare 2019a, p. 3, citing Australian Bureau of Statistics 2018). Existing infrastructure is poorly equipped to identify, fund, support and ameliorate the needs of the homeless, especially those with acquired sensory impairments.

Intellectual disability

Fellinger et al. (2009) examined 253 people with intellectual disabilities in Scandinavia, finding that 21.4 percent had DSI. Prior to screening, only 3.6 percent were known to have sensory impairments (Fellinger et al. 2009). Therefore, 45 people with intellectual disability had significant loss of sight and hearing that had been undetected, unsupported and unremediated. Furthermore, diagnostic overshadowing may occur when new symptoms, behavioural changes or communication difficulties in a person with an intellectual disability (or other disability) is either ignored or misattributed to the primary disability (Blair 2019). This renders many people with an intellectual disability invisible.

Older adults with cognitive impairment/dementia

Sensory losses are common in the older population, coinciding with a rising incidence of cognitive impairment and as a potentially modifiable risk factor (Livingston et al. 2017; Mukadam et al. 2019; Rogers & Langa 2010). Diagnostic misattribution may occur when those with sensory loss/es are diagnosed with cognitive impairment when the problem is hearing and/or vision loss. Conversely, people with dementia and cognitive impairment have high rates of undetected sensory loss, as inferred from data on non-community-dwelling older people (Sense UK 2013). This is a further example of diagnostic overshadowing; as such, it is poorly studied and quantified (Wittich 2019; Blair 2019). More attention is needed, therefore, to detect and support older PWDBDSI, both with and without cognitive impairment.

Occupational and recreational noise exposure

Males have a higher rate of occupational-related hearing loss due to more men being in noisier workplaces, such as construction sites (House of Representatives Standing Committee on Health, Aged Care and Sport 2017; Wittich 2019). The increasing use of earbuds and headphones is another contributing factor; without public health awareness campaigns many will risk hearing damage (House of Representatives Standing Committee on Health, Aged Care and Sport 2017).

Veterans

Exposure to military noise leads to higher rates of hearing loss in veterans (Dammeyer 2014; House of Representatives Standing Committee on Health, Aged Care and Sport 2017). Here, the term 'veterans' describes current and former members, as well as any persons with experience, of the Australian Defence Forces (Australian Institute of Health and Welfare 2018b). Veterans represent 0.3 percent of the Australian population, most of whom are male (Australian Institute of Health and Welfare 2018b, citing ABS 2017). The Department of Veterans Affairs has contact with, and data on the health status of, only 20 percent of this population. The hearing and vision status of the remainder is thus largely unknown. There is a scarcity of data on DSI in this population, but it is thought to be more common than reported due to under-diagnosis (Smith, Bennett & Wilson 2008).

Prisoners

Little is known about the sensory impairments of incarcerated people. However, the prison population is both increasing and ageing; 92 percent are male, and First Peoples are over-represented (Australian Institute of Health and Welfare 2018c). Prisoners typically experience multiple disadvantages—they are more likely than the general population to have a disability, experience homelessness and be unemployed (Australian Institute of Health and Welfare 2018c). Several factors result in an ageing prison population: mandatory sentencing, longer sentences, older males sentenced for historic sex offences, fewer options for early release and a reduction in preventable deaths in custody (Australian Institute of Health and Welfare 2018c). Premature ageing also applies; a 50-year-old in the prison population equivalent to a 65-year-old in the general population (Trotter & Baidawi 2015). There is a data gap, however, with scant evidence on prevalence, type and course of sensory impairment in this literally hidden population.

Rural and remote dwellers

According to Dyke (2013), one-third of all PWDBDSI in Australia live in rural or remote areas. Avery (2018) also notes that First Peoples living in rural and remote communities are very poorly served by services for detection, diagnosis, treatment and remediation. Thus, geographical isolation may contribute to being unseen and unheard in data collection of and service delivery for PWDBDSI.

The ‘Global South’: an unknown space

Absent or poor data on sensory impairments, especially from developing nations, has long been a hindrance; this was the impetus for the WFDB global study (2018). The CRPD’s mandated improvements in social safeguarding and provisions (2006) have not reached all nations; therefore, many PWDBDSI continue to live with disadvantage, danger and distress. Marginalisation from the safeguarding of the CRPD is experienced widely in the Global South:

- In Nigeria, Deafblindness is not recognised as a distinct disability (Aghaji et al. 2017).
- In Thailand, little is known about DBDSI (Sukontharungsee, Bourquin & Poonpit 2006).
- In Nigeria, a second disability may be underestimated, such as non-detection of deafness in schools for the blind (Aghaji et al. 2017).
- In Africa, intersection of gender and disability is evidenced by high rates of sexual violence against women with DBDSI (Jensen & Marshall 2019).
- Women and girls with DBDSI have less access to reproductive healthcare than other women and girls with single disabilities, and even less than people without disability (Jensen & Marshall 2019).
- PWDBDSI are more likely to be kept isolated in their homes, unseen and not counted in national data (World Federation of the Deafblind 2018).
- A lack of language impedes many families, schools and services, although Uganda, for example, is developing a national tactile language, indicating change (Jensen & Marshall 2019).
- Advances in immunisations and obstetric care, which are taken for granted in developed countries, are still in their infancy in many developing countries (World Federation of the Deafblind 2018). In particular, prior to 2019, some countries still had no rubella vaccination program; in sub-Saharan Africa and parts of Asia, congenital rubella remains a threat (World Federation of the Deafblind 2018). Uganda, for instance, only began its first national rubella vaccination program in late 2019 (Jensen & Marshall 2019).
- The most appalling fact, however, is that most deafness, blindness and dual losses in children living in developing nations are preventable, yet remain untreated (Aghaji et al. 2017; World Health Organization 2011). In the developing world, DBDSI is still caused by infectious diseases and birth asphyxia, which are remediable by immunisation, obstetric care provision and advances in neonatology (World Federation of the Deafblind 2018).

Communication

> We are the loneliest people on the earth … we don’t find out information for months about world events much less about treatment options for depression. No one cares about us. It takes time to

> communicate with us as no one wants to take the time (Mathos, Lokar & Post 2011, p. 139).

PWDBDSI are frequently concealed from the gaze of researchers, data collectors, policymakers and service providers. They are isolated and invisible. Sensory impairments impact communication, access to information and mobility. Communication to access and exchange information is at the heart of almost every human endeavour and encounter. While there are many supportive communication methods and technologies available, these often pose difficulties for the impaired due to cost, availability and training support (House of Representatives Standing Committee on Health, Aged Care and Sport 2017). Not having access to communication isolates, depresses and confers risk.

The degree of sensory deficits varies widely across the DBDSI population, with a vast array of possible communication tools and languages used to aid daily life. There is not one single common communication method or language (Bodsworth, Clare & Simblett 2011); this has implications for PWDBDSI as well as families, services and researchers. A further legacy of the 21st century's cyber explosion is the development of a digital divide for people with disabilities generally and PWDBDSI specifically.

For most, DBDSI is not a static condition. An individual may need different communication language methods and technologies at different times of their lives, when progressivity supervenes, or innovation inspires. For example, an individual may move to tactile signing when no longer able to see a visual sign language. Innovations such as Facetime and Skype enable many sign-language users with residual vision to connect with each other without needing interpreters. Different circumstances may entail different communication methods; for example, using email for remote communication, tactile for PWDBDSI to PWDBDSI, and interpreters for PWDBDSI to sighted-hearing people.

While there are many innovative communication technologies available to PWDBDSI, barriers remain such as limited funds, training and trained support. A further caveat is that assistive technology is only helpful if it works. Breakdowns are frustrating and common (Möller 2005). A final stipulation: not all individuals with DBDSI can be assisted by technological devices and technologies at all times; for many, using human assistance such as communication-guides or interpreter-guides will remain essential (World Federation of the Deafblind 2018).

In the literature, it is well established that effective communication in hospital and healthcare settings confers benefit, and poor communication can confer risk (Slade et al. 2015). PWDBDSI are more likely to require hospitalisation or increased healthcare support as a result of their impairments and associated health threats, leaving them vulnerable to poorer outcomes. Given the vast heterogeneity of sensory deficits, communication methods, and assistive devices and technologies used by PWDBDSI, it is highly likely that there is a significant number who may be vulnerable in hospital settings, which will increase as the population ages.

Taking the time to communicate appropriately and effectively with PWDBDSI, however, makes a difference. This sentiment is echoed in the memoir *Words in my Hands: A Teacher, a Deaf-Blind Man, an Unforgettable Journey* (Chambers 2012). Bert, an older man with USH, says to his hand-over-hand sign-language teacher: ‘now with interpreters like you, I’m getting what I never had before. When you sign to me, I can hear the words in my head like you are talking to me’ (Chambers 2012, p. 2930/3094). List 2 details communication methods for PWDBDSI. They may utilise some, all or combinations of these methods, but are not limited to them.

List 2. Methods of communication for PWDBDSI

Oral

- Oral
- Voice interpreting
- Clear speech

Sign

- Auslan
- Hand-over-hands signing
- Restricted field/close vision signing
- Sign language from another country or culture
- Tactile signing
- Two-hand manual signing
- Video relay for Auslan

Touch

- Braille
- Finger spelling (tactile alphabet)
- Hand-over-hands signing
- Moon (system of embossed reading, simpler to feel than braille)
- Print on palm
- Social haptics
- Tactile signing
- Tadoma (hand over speaker’s mouth and throat, used by Helen Keller)
- Two-hand manual signing
- Vibrating devices
- Pro-tactile

Assistive devices

- Braille machine/computer/writer
- Cochlear implant
- Corrective glasses
- Handheld devices
- Hearing aids
- Note pad and pen
- Phone
- Roger pen
- Vibrating devices
- Large screens
- Magnifiers

Assistive technology

- Apps (for smartphones and tablets), e.g. Be My Eyes

- Internet relay chat
- iMessage/SMS
- Captioned phone services
- Captioning
- Teletexting
- Tele-interpreter
- Bluetooth
- Loop coil systems
- FM
- SMS relay with braille
- Video relay for Auslan users
- Relay service
- Speech to text

Human assistance

- Interpreter assistance
- Use of family, friends to interpret or act on their behalf
- Idiosyncratic or individual language used between families and PWDBDSI
- Sighted guide
- Interpreter-guide

Mobility and orientation aids (communicating with the environment)

- Sighted guide
- Guide/service dog
- MiniGuide (handheld ultrasonic device)
- Red-and-white striped cane (identifies a person as having combined sight and hearing impairment) (World Federation of the Deafblind 2018)

Other

- Lip reading
- Large print
- Non-symbolic communication (or prelingual communication) (Möller & Danermark 2007)
- Environmental audio description
- Combinations of methods depending on person, audience and situation

Conclusion

I am unable to reconcile the many longstanding divisions and distinctions in terminology that pre-date this doctorate. As a person with deafblindness, clinician and researcher, I choose to be as inclusive as possible. At its nub, this study asks the question: how does having co-occurring hearing loss and vision loss impact on hospital experiences? In this respect, people identifying as ‘Deafblind’, ‘deafblind’, ‘deaf-blind’, ‘dual sensory impaired’, ‘don’t hear very well and don’t see much’, and so on, are all at risk of communication failures and adverse outcomes.

This chapter explores the intricacies of denominations, definitions and data to reflect the complexities and illuminate the changing contours of the worlds of PWDBDSI. It also elucidates various causations of DBDSI and starts to render invisible DBDSI populations more visibly. This writing provides signposts to the landscape of PWDBDSI; it states who we are and where we can be found, and details the languages we speak. **Chapter 2**, which follows, examines what disability studies reveal about how we think about and research disability, and what has changed over time. Unsurprisingly, here too there are complexities and contentions—the term ‘disability’ can also be an unclear concept.

Chapter 2
Ways of thinking: the disabled body in society

Preamble

The previous **Chapter 1: Complexities** presents people with deafblindness–dual sensory impairment: what to call them, how to define them and what sub populations (hidden in plain sight and, more often, in exclusion) make up their numbers. This next section comprises three chapters. This chapter gazes over the current theories to inform how we think about PWD and how we explain their experiences. So much is written from researchers' sighted-hearing perspectives; it is time to cast a different lens over these models and theories. In addition to presenting five theories, this chapter examines the theoretical and methodological framework behind privileging the voices and signs of the research participants—known as standpoint theory.

Chapter 3 tackles the existing literature on the specific hospital experiences of PWDBDSI, to determine what we know, how we know it and who we know it about. Having established that there are subpopulations with diverse needs and experiences, how does the literature reflect and grapple with these subpopulations? More importantly, what is unknown and how sizeable is this lacuna? For this gap will justify the seeking of new knowledge via this doctoral study.

While the literature is largely silent on the actual experiences of PWDBDSI, there is a hefty body of research attesting to the health status and sequelae of having two co-occurring sensory losses, which is discussed in **Chapter 4**. These threats to health and wellbeing increase the likelihood of healthcare encounters and hospitalisations for PWDBDSI. These risks are *in addition* to the health threats that the sighted-hearing experience during their lives. Cataloguing the varied health threats demonstrates why it is vital to find out what happens when PWDBDSI are admitted to hospital.

Introduction

First, we explore how ways of thinking impact the living realities of PWD generally and PWDBDSI specifically. As a person with disabilities; as the sibling, daughter and friend to others with disabilities; as a doctor caring for people with complex lives and disabilities; and now as a researcher, my perspectives on what disability is and what life is like with two sensory impairments both collides with and falls away from the body of work that is disability theory. While I feel more kinship with some theories than others, all contribute to my current vantage point in determining the best theoretical framing for this doctoral research—examining what exactly happens when PWDBDSI are in hospital and how we explain it. After all, a theory or model is simply a system to explain what we find 'puzzling or disturbing' (Engel 1977, p. 130). Understanding disability is the subject of ongoing debate and interrogation by disability theorists.

Disability theories provide a space to explore the nature and experience of disability. Principally, current and past theories of disability are posited by sighted-hearing theorists; there is limited knowledge as to how adequately these theories capture the lives lived with fragmented information, communication complexities, mobility requirements and daily activity limitations. This chapter first explores these complexities within the disability theorising realms; the second part provides the theoretical and methodological framing. Privileging the voices, signs and touch signals of PWDBDSI is critical to this research.

Prior to the mid-20th century, disability (itself a troubled term with a history of pejorative usage) was viewed and understood either as evidence of moral culpability or as needing charitable benevolence. The 20th and 21st centuries have seen exponential growth and extensive debate about how to conceptualise and mediate disability.

In this doctorate, five contemporary models are considered. These are chosen to demonstrate how debates about disability straddle social, cultural and biological spheres. Each framing offers a partial explanation of life with disability. These are interrogated, with a particular emphasis on *if* and *how* theories, to explain lived experiences with dual sensory impairment. The five theories are:

1. The medical model (biomedical model and biopsychosocial extensions)
2. Disability as a social construct
3. Critical theories (critical disability theory [CDT], Crip theory, DeafCrit and DeafBlind critical theory)
4. Social justice and human rights framings
5. First Peoples' model of the 'culture of inclusion'

Each is considered individually below, examining their strengths, weaknesses and relevance to PWDBDSI within the context of their hospital experiences. The theory of disability underpinning this research is then discussed further. This research is anchored by the belief that PWDBDSI are the expert-knowers of what happens to them in hospital—this standpoint is both valid and truthful. Standpoint theory and methodology privileges this view through the voices, signs and tactile signals of the patient-participants. Finally, I turn the gaze upon my own standpoint/s.

The medical model

Sometimes called the biomedical model, the medical model was originally understood to be that 'disease is fully accounted for by deviations from the norm of measurable biological (somatic) variables' (Engel 1977, p. 130). This framing is much criticised (Berghs et al. 2016; Oliver 1998; Shakespeare & Watson 2001), which is partly understandable, considering that the social and human rights' framings arise from how medicine and healthcare professionals have constructed impairment and disability as individual concerns. Their view is of a personal tragedy, that impairment is some pathological aberration needing treatment and cure, wherever possible, and rehabilitation if a cure is not possible. In this model, correction and prevention of impairments is key (Berghs et al. 2016).

Engel notes that, before his 1977 version, the model 'leaves no room within its framework for the social, psychological, and behavioral dimensions of illness' (1977, p. 130). Engel's comments arose as a response to escalating tensions between psychiatry (which treats non-biologically measurable mental illness) and the traditional 'scientific' model of medicine (where pathology is measurable). He proposes that psychosocial elements need incorporation into the pathological model of disease and disability. This led to the construction of the biopsychosocial model.

Debate and dissension are widespread and longstanding. The medical model is paternalistic, reductive and places far too much emphasis on individual impairment/s, rather than society's contribution and responsibilities (Berghs et al. 2016). As a result, it is easy to forget how substantial its positive contributions are. The biomedical and biopsychosocial models of post-1977 medicine have given—and continue to invest in—screening, diagnosis, treatment, cure, prevention, rehabilitation and research of illness, injuries and impairments. As Shakespeare and Watson (2001) note: 'Why is it so wrong to maximise functioning and seek to reduce the impact of disease?' (p. 15).

The traditional medical model positions caregiving as central to the practice of healthcare (Kleinman 2020). However, over the past decades electronic/information technologies and cost-efficiency imperative have seen slippage of caregiving tenets; the 'human glue' Kleinman speaks of 'is being silenced and diminished in value' by modern medical institutional management and practices (2020, p. 4).

In terms of models that underpin policies, the medical models and various metrics of health and functioning are ubiquitous within the different institutional requirements for people with disabilities to produce certifications of their impairments and needs, such as to access the Australian NDIS, specialised educational services (Burnett 2007) and social support services including government payments. These processes, although necessary to allocate resources and meet needs, are disabling in themselves by reinforcing differences between bodies. Shildrick (2020) writes, 'to be perceived as differently embodied, however, is still to occupy a place defined as exceptional, rather than to simply be a part of a multiplicity of possibilities' (pp. 33/543). Vehmas and Watson (2014), however, point out that measuring disability and impairments is an unavoidable reality in times of limited resources, where there is a need to identify who the most disadvantaged are, what supports they need, and what works or does not work for them individually. To achieve these assessments and evaluations, metrics are necessary.

The medical model gives rise to metrics to quantify impairments, impacts and outcomes, resulting in measures such as Global Burden of Disease (GBD), Quality of Life (QoL) and Disability Adjusted Life Years (DALYs).

These are used extensively in policy, practice, insurance and economics, and many are found in the World Bank's *World Development Reports* and *Disease Control Priorities Reviews* (Berghs et al. 2016). These collective indices, while enabling evaluations, planning and welfare redistributions, do not reflect individual lived experiences; indeed, how can quality of life be measured without asking the person whose life it is? Ginsburg and Rapp (2012) note that there is rarely a conversation between metric experts and qualitative researchers in disability theorising.

Notwithstanding these reductive difficulties, the medical model shows that it can evolve from its beginnings in medicalising the disabled body and preferencing the able-bodied as a desired norm; first, by adding psychosocial and behaviour elements (Engel 1977, 1980); and second, with its classification systems. These systems appear largely through the work of the United Nations (UN) and WHO in the previous International Classification of Impairments, and Disability and Handicap (ICIDH), and the present-day International Classification of Functioning, Disability and Health (ICF). In the early versions of the ICIDH, the focus was on individual diseases, injuries and impairments, with little reference to how disability is impacted by social factors. The ICF is the attempt to recognise and respond to a key criticism of the medical model, in which able society disables people with impairments. The ICF regards disability as an interaction between biomedical and social factors:

> … in ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors.
> Among contextual factors are external environmental factors (for example, social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and so forth); and internal personal factors, which include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual (World Health Organization 2002, p. 10).

Thus, disability becomes an umbrella term for activity limitation and/or participation restriction. The ICF is primarily used as a framework in rehabilitation settings to assess what a person *can* do (i.e. activity) and what the individual *does* do (i.e. participation). While impairment is personal, contextual and environmental factors also contribute. Because it bridges impairment with personal, social and environmental contextual factors, the ICF framing is also known as a 'bio-psycho-social' approach (Berghs et al. 2016). Its signature strengths are its wide acceptance as a classification scheme, invocation of uniform terminologies in research and public health, and creation of international standards (Berghs et al. 2016; Stephens & Danermark 2005).

Another advantage of the ICF is the authors' neutral stance, with respect to the personal identities adopted by PWD: 'people have the right to be called what they choose' (World Health Organization 2007, p. 250). Thus, people with sensory impairments can choose to call themselves deaf/Deaf, blind, deafblind, Deafblind, dual sensory impaired or a 'bit hard of hearing and not seeing too well', without any reference to decibels of hearing lost or degrees of vision present. This is an explicit acknowledgement that disability is not a homogeneous identity defined by medical, or other, assessments.

Disability groups critique the ICF as 'predicated on statistical norms and values that are still fundamentally disablist' (Berghs et al. 2016, p. 31). So, while seeking to encompass social and biomedical factors, the ICF still contributes to the construction of disability as deviant from 'normal'. In addition, the tight linking of impairments to health neglects the many situations where a person has an impairment, such as hearing or vision loss, but is in good health; or instances where a person with hearing impairment who declines to wear hearing aids. Most PWD want to be seen as normal, but different (Shakespeare & Watson 2001). More importantly, many people with impairments do not consider themselves as having one. The Deaf communities do not see impairment or disability in hearing loss and Deafness (Solomon 2012). Deaf people and the d/Deafblind often have a different concept of wellness from that of hearing people (Clark 2014; Griggs 1998). In respect to deaf people, Stephens and Danermark (2005) comment that, in addition to failing to understand wellness and different concepts of disability, the ICF also fails to navigate the 'impacts of disability on a person', adding that there is 'no subjective aspect to function and impairments' allowed in the ICF classifications (p. 65). For PWDBDSI, there are key deficiencies in what the ICF applies to this population. Möller (2003) notes that there is time lost in almost every activity due to sensory losses, and that this has an impact on QoL, which is not accounted for in the ICF.

With respect to this research and its participants, the medical model underpins the hospital system, where the interactions studied take place. Hospitals are spaces where patients generally, and PWD specifically, experience power imbalances (Rowland et al. 2017). The medical model does not allow for examination of these experiences in the same way that it scrutinises and evaluates its treatment programs. It is important for emancipatory research to avoid framings that disempower, disadvantage or disable people.

The medical model, even as it has metamorphosed into the ICF's focus on health and participation, still falls well short of capturing both the breadth and nuances of individual lived experiences. The medical model fails to come to grips with the social disadvantages that PWD and PWDBDSI experience, which arrest or inhibit flourishing in important areas of social life (Berghs et al. 2016; Priestley 2003; Shakespeare 2014).

Disability as a social construct

Socially framed models arose out of disability activism in the 1970s and 1980s. The Union of Physically Impaired Against Segregation (UPIAS) declares:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way

> we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc (Union of the Physically Impaired Against Segregation and The Disability Alliance 1976, pp. 3–4).

Here, disability is presented as something society confers on top of impairment effects. This signals a move away from the individual with an impairment, needing medical intervention, remediation and compliance, to society and its institutions needing to remove environmental and attitudinal barriers. This positions disabled people as an oppressed social group. Social modelists, particularly the British, use the terminology *disabled people* to highlight that people are disabled by society, not by their bodies.

The 'Big Idea' was thus born, repudiating the medical model and replacing it with a materialist ideology that declares society constructs disability. If there are no social, environmental or attitudinal barriers, there will be no 'disability'. This new way of understanding disability gained traction with the strong social model, also known as the big social model or British social model (Shakespeare 2014; Shakespeare & Watson 2001). Here, the term 'strong social model' is used for clarity and uniformity. A key proponent of this model, Oliver argues:

> It is not the individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of the disabled people are fully taken into account in its social organisation (1998, p. 32).

The strong social model's 'accessible and rhetorically potent' ideas (Shakespeare & Watson 1996) were pivotal in galvanising the disability movements' process of raising awareness, removing environmental barriers, and reforming legislation for the rights and safeguards for disabled people. Disability is thus *solved* by breaking down barriers (Shakespeare 2018; Shakespeare & Watson 2001). This reinvigorated disability politics (Scambler 2018) and was a source of pride and identity to many in the disability rights' communities (Pinder 1997).

The strong social model views disability as a single solid identity, which can be harnessed for social and political action. It provides the momentum for legislative change to increase safeguards for disabled people and penalties for discriminatory practices, as well as standards and requirements for new buildings to have ramps, accessible walkways, lifts, toilets for wheelchair users, and so forth. Social welfare provisions are expanded to promote independent living and support, based on what is needed. Viewing disabled people as a collective is a powerful and productive agent of change; early social theorists were committed to legislative safeguarding, social support and barrier removal (Vehmas & Watson 2014). The strong social model is not individual, however, nor is it impairment-specific. This homogenous approach to disability is not sustainable because disability is, in fact, heterogeneous. How we conceptualise disability must include understanding the vast differences contained therein.

Shakespeare and Watson (2001) note that disability ‘is a multiplicity, a plurality’ (p. 19), stating that ‘[a]ll these differences have salient impacts at both the individual and psychological level, and at the social and structural level’ (p. 15). Priestley (2003), too, notes that disability is not a singular static phenomenon; it varies throughout a person’s life and a model of disability needs to account for these changes and complexities: ‘the weaknesses of the existing disability literature has been a tendency to focus on a fairly narrow range of issues, those affecting adults of working age’ (Priestley 2003, p. 3). He believes it is only by taking a life-course approach—through birth, childhood, youth, adulthood, older age, dying and death—that disability can be understood in its breadth and depth. For many with degenerative forms of DBDSI, a life-course approach is appropriate, because their disability shifts and changes over time, creating a need for different supports. The life course approach sits more comfortably with the position I vouchsafed earlier of the descriptor PWDBDSI. Disability is not just the province of babies, children and working age adults: but of older people too. Older citizens will likely enter the state of disability at some time, perhaps many times. The experience and social phenomena may differ but those ageing into disability deserve consideration, accounting and support services too.

Another critical weakness of the strong social model is that it excludes embodiment (Crow 1996; Pinder 1997; Shakespeare 2014; Shakespeare & Watson 2001; Thomas 1999b). This means individual experience is sidelined, because the focus is solely on broader social environmental change. Thus, the social model is lacking what Shildrick (2020) calls ‘the extraordinary significance of human corporal reality’ (p. 33, 543). It became necessary to reclaim the body because, no matter what social and environmental changes are made, some impairments remain to cause distress, limitation and suffering (Crow 1996; Shakespeare 2014).

Particularly relevant to PWDBDSI, impairments can be so severe as to be unmitigable by removing barriers. Vehmas and Watson (2014) call these the ‘insurmountable realities’ (p. 27) of some impairments. Disability as a social construct and impairment as an individual concern, therefore, are fuzzy, sometimes irreconcilable, concepts.

Contentions arise when examining the base concepts of impairment and disability. For Mike Oliver, a British advocate of the strong social model, impairment is ‘an attribute of the individual body or mind, and disability, a relationship between a person with impairment and society. A binary division is established between the biological and the social’ (1998, p. 30). Shakespeare and Watson (2001) demonstrate the futility of this dualistic view, stating: ‘The unsustainable distinction between impairment (bodily difference) and disability (social creation) can be demonstrated by asking “where does impairment end and disability start?”’ (p. 18).

Another significant weakness of the strong social model is that it dismisses and rejects the medical model, naming society as directly responsible for disability. The rationale is flawed, inferring that when barriers are removed there is no role for medicine, because there is no disability. This ignores the obvious, that medical activities are essential for disabled people to manage health, wellbeing and impairments—such as prevention, diagnosis, treatment, supports, rehabilitation, pharmacotherapy and research (Shakespeare 2014). Some aspects of traditional medical paternalism, with its focus on cure at all costs, should be repudiated, but a good medical model is necessary for the long-term health and wellbeing of all.

A further divisive view espoused by the strong social model is that organisations and charities are redundant, because the model does not take an impairment-specific approach to disabled people (Oliver 2004). Yet, most impairment-specific organisations provide necessary medical, social and advocacy support. For PWDBDSI in Australia, key impairment support organisations provide a range of services, including coordination and planning support for the NDIS. Because those with DBDSI are a complex group, with limitations in almost every daily activity, a materialist approach cannot explore and explain these limitations (Möller 2003). This is a group for whom a barrier-free utopia is not possible—the complexities of their impairments, psychosocial relational difficulties, and environmental and attitudinal barriers may make employment and full participation difficult to achieve, no matter what accommodations are made. There are arguments within the social model for not just reclaiming the body, but also recognising the psychosocial relations and impairment effects that compound life for individuals with disabilities (Thomas 2003, 2012).

Critical realism: a relational discourse

Shakespeare (2014) writes: ‘People are disabled by society *and* by their bodies and minds’ (p. 5). Social relational theory is an attempt to embrace, more fully, the complexities and diversities of disabilities by viewing experiences as laminated, multifactorial and contextual. Shakespeare (2014) sees social relational theory as falling under the aegis of critical realism metatheory.

Critical realism is a philosophy of science, providing a compass for researchers seeking to elucidate knowledge and social ‘truths’ (Bhaskar 1978, cited in Burnett 2007). Critical realists view individuals and society as both independent of and interdependent on each other (Burnett 2007). In line with the principal tenet of social relational theory, reality is stratified, differentiated, ever-changing and nonhomogeneous (Danermark et al. 2005; Shakespeare 2014; Söder 1989).

A strength of critical realism is that the theory is not disability-specific, but that disability is included as part of the layers of human experience. Disability is thus defined as ‘a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision’ (Shakespeare 2014, pp. 25–26).

As part of this laminated and changeable reality, disability is not a rigid or static entity, nor is it the same for all. Accordingly, disability is seen on a spectrum, within which there can be movement in either direction (Shakespeare 2014). As reality changes, perspectives shift and events occur—and how disability is experienced can change. Individual experience matters. Perhaps a pertinent way to illustrate this is with Shakespeare's story. In 2008, he suffered a spinal cord injury on top of lifelong short stature, writing:

> Acquiring an impairment in addition to my congenital impairment was very difficult. I had experienced pain and limitations throughout my adult life, but now was dependent and restricted. I experienced my increased disability as resulting more from my own lack of functioning than as a result of inaccessible environments, although of course I have experienced my share of those … I remain convinced that the relational discourse of disability … is the best way of understanding the complex and multidimensional experience of disablement (Shakespeare 2014, p. 6).

This is an important point because much early disability theory and practice treated disability and impairments either as fixed entities or dualistic (disabled or able), not as 'uncertain, fluid and liquid rather than solid' (Scambler 2018, p. 53, 208).

Critical realism also observes that examining social relations via research can help elucidate the causal mechanism for positive and negative experiences (Burnett 2007). Studying disability and impairment, and life with these, is crucial to effect change. As Bhaskar (1989) writes: 'the world cannot be rationally changed unless it is adequately interpreted' (cited in Burnett 2007, p.5).

Lived experiences matter; thus, ethnography is a valid research methodology within critical realism (Danermark et al. 2005; Shakespeare 2014). Knowledge from lived experiences can inform us about what change is required—where, when and for whom. If we take no account of experiences, or embodiment, then we continue to disempower PWD generally and those with DBDSI particularly. As the slogan states, 'nothing about us without us' (Charlton 1998).

A further pivotal premise of critical realism is dismissing the notion of 'neutral' or objective research. Bhaskar (1989) writes:

> Human sciences are necessarily non-neutral; that they are intrinsically critical (both of beliefs and their objects) and self-critical; that accounts of social reality are not only value-impregnated but value-impregnating, not only practically-imbued but practically-imbuing; and that in particular they both causally motivate and logically entail evaluative and practical judgements *ceteris paribus* (cited in Burnett 2007, p. 409).

As a consumer-researcher or lived-experience researcher in this project, this is pertinent, confirming that the so-called 'scientific observer' state is not possible or reasonable. This research aims to make judgements on whether hospitals treat PWDBDSI equitably: 'if we are to describe disability, disablism and oppression properly, we have to explicate the moral and political wrongs related to these phenomena' (Vehmas & Watson 2014).

Critical theories

Critical theories arise out of the European Marxist tradition, known as the Frankfurt School. According to Frankfurt School theorists, a critical theory is differentiated from traditional theory because it seeks to emancipate and liberate humans from the many dimensions of prevailing social domination—such as slavery, gendered oppression, racism and disability—to create a 'world which satisfies the needs and powers' of human beings (Horkheimer 1972, cited in Bohman 2005, p. 246). Shildrick (2020) writes that critical theories are: 'one of the fields in which new ideas have evolved most rapidly, suggesting the kind of changes in ways of thinking that can have significant material effects on the everyday reality of people with disabilities' (p. 32).

Critical disability theory

During the past two decades, critical theorising regarding disability gained momentum, because many believed a shakeup was needed when thinking about the 'disability problem' (Vehmas & Watson 2014, p. 639). Work from researchers in the late 1990s, including British disability theorist Mairian Corker, draws on the North American civil rights movements and feminist theory, where much research is also located. According to Davis (2010), Corker's central aim was to:

> … analyse and make more explicit the diverse and complex identities of disabled people. She was particularly critical of the male dominated technical rational approach to disability studies that perpetuated gender stereotypes and overemphasised binary opposites (such as structure/agency, reason/emotion, presence/absence, universalism/relativism (Davis 2010, p. 187).

What we are seeing is how disability identity has unfolded, with first the medical model that situates disability in individual impairment, then a collective identity that empowers legal and social reform, followed by dissatisfaction with the disembodiment that this entails. Critical realism and social relational theories brought the body back into a striated reality with multiple, mutable identities. Critical theories now place identities at the centre of discourse. Language is an important theme in CDT, with the reclamation of traditionally used derogatory terms (e.g. 'crip') and disability embraced as normative diversity. Therefore, CDT does not use people-first terminology, as in 'people with disability', preferring identity-first nomenclature as in 'disabled people' (Shildrick 2020). This reclamation is to demonstrate that disability is just part of the many differences experienced in human lives. By working together and valuing disabled people's diverse identities, and their intersections, we can begin to address the power disparities at the core of disability oppression (Corker 1998; Davis 2010). Society's failure to reduce or eliminate disadvantage for PWD is seen as power based—with more power for the able-bodied and less for the disabled. Furthermore, critical theorists believe that critical responses to research are mandatory, otherwise powerful institutions will continue to oppress.

CDT highlights intersectionality and other factors that create disability alongside impairment, such as gender, age, race, ethnicity and socioeconomic class (Berghs et al. 2016). CDT embraces parallels within a family of critical theories such as feminist theory and critical race theory, and identity theories such as Queer theory and Crip theory. Thus, CDT is well situated to understand the intersectionality and multidimensionality of disability, while simultaneously seeking to deconstruct difference, breaking the binary of disabled and able-bodied (Vehmas & Watson 2014).

The endpoint for CDT is transformative political change. CDT sees both the necessity of political engagement to obtain insights and eschews the neutral observer status of traditional research. As Harding (2004) writes: ‘The more value-neutral a conceptual framework appears, the more likely it is to advance the hegemonic interests of dominant groups, and the less likely it is to be able to detect important actualities of social relations’ (p. 6).

Tension exists for some disability theorists who are uneasy about applying critical theories of oppressed groups, such as feminist theory or critical race theory, to disability. Ginsburg and Rapp (2012) write:

> Disability is a different form of difference unlike the deeply embodied categories of race and gender, from which one can only enter or exit rarely and with enormous and conscious effort … disability can happen in a heartbeat, turning one’s vantage point around and implicating others (p. 173).

Shakespeare (2014), too, holds that disability is different to other oppressions in that removing all social and political constraints does not ameliorate all disabilities; he emphasises that disabilities are not just a matter of cultural perspective. Some impairments will continue to cause difficulties, distress and even early demise, despite barrier removal, because the biology is strong and persistent (Shakespeare 2014). The reason that many with DBDSI experience such insurmountable realities is a core characteristic of the population, because of one sense unable to compensate for the other—creating access, communication and mobility difficulties.

For this work, a principle, perhaps terminal, weakness of identity-based disability theory is that it does not account for those whom disability is **not** an identity, those who eschew a disability identity existing compulsorily with impairment and the great many who are ageing into disability who know not about disability identities and intersectionality. We must not keep older person in a liminal space apart, and this is why the combination of deafblindness with dual sensory impairment (DBDSI) in this thesis is both overdue and necessitous.

Additionally, Vehmas and Watson (2014) believe that CDT does not engage enough with the ‘key ethical and political issues faced by disabled people’ (p. 638). This is because it is too concerned with deconstructing socially produced binaries that exist for one (normal, able) to dominate the other (abnormal, disabled) (Goodley, Hughes & Davis 2012; Vehmas & Watson 2014). Again, this neglects the question of the impairment's biological realities, which remain even if political power is equalised.

Notwithstanding these concerns, a significant strength of CDT is privileging the voices of disabled people; this is seen in standpoint theory, which arose out of critical feminist theories. Standpoint theory is used extensively in disability research as a framework for supporting qualitative methodologies that seek to gain closer understandings of the experiences of disadvantaged peoples. Standpoint theory argues that exploring the views of the least empowered gives insights into institutions and systems that wield greater power. This is relevant to my doctoral research because, while most hospital patients are disempowered, PWDBDSI in hospital are among the least powerful. I write more on the patient perspective and powerlessness in **Chapter 3: Standpoint theory and positionality**.

Identity-specific critical theories

Critical theories include identity-specific theories such as Crip, which focuses on disability, cultural and sexual identities in historical, literary and cultural contexts (McRuer 2006). There is minimal empirical health-related research, however, which disadvantages Crip theory as a framework for the research proposed here.

Critical theorising has generated other identity/impairment-specific theories potentially relevant to this study—DeafCrit and critical Deafblind theory—but these do not embrace disability as central to identity.

DeafCrit

DeafCrit theory arose as a response to marginalisation by an ableist/audist mainstream society (Shariff 2015). DeafCrit aligns with critical race theories, but not with critical disability studies or any theoretical framing that confers disability status or impairment on d/Deaf people and their cultures. Not only disavowing deficit disability models, DeafCrit views mainstream medical intervention, education and oral society as perpetrating ethnocide and linguicide (Valente 2011). This is a contentious framing for this research, because some Deafblind people have experienced exclusion from once-beloved Deaf communities and institutions when vision loss precluded their using a visual-based sign language to communicate (Arndt 2011; Shariff 2015; Solomon 2012; Wolsey 2017).

Critical Deafblind theory

Critical Deafblind theory (CDBT) is a nascent theory, first seeded with Keating and Hadden stating that vision-centric and/or sound-centric discourses are limited in understanding the lived realities of people with dual sensory loss and d/Deafblindness (2010). In Shariff's 2015 dissertation on the lives of DeafBlind leaders, he was unable to use a framework (CDT or DeafCrit) that the participants themselves rejected as oppressive. Shariff proposes a '"new critical DeafBlind theory" lens based upon the identified values and literature of people who are Deafblind' (2015, p. 60). Tenets held by CDBT include:

1. Specific and vehement denial of deficit-based models of understanding DeafBlindness as a disability
2. Repudiation of Deaf culture's oppression
3. Interrogation of 'ableism as centered in the nondisabled, visual-centric and audio-centric epistemologies' (Shariff 2015, p. 61)
4. New terminology for oppression and discrimination of the DeafBlind by those who are sighted-hearing or sighted: vidaudism. Shariff writes that vidaudism is 'derived from the combination of the syllables from Latin "vid" (to see) and Greek "aud" (to hear), in combination with the suffix "ism" (an oppressive and especially discriminatory attitude or belief)' (2015, p. 62).
5. Vidaudism, like racism, consists of the following dimensions: micro/macro institutional forms, conscious and unconscious elements, and a cumulative impact on the individual and group (Shariff 2015, p. 63)
6. 'Tactile state-of-being' (Shariff 2015, p.61) and experiences of those who live with dual sensory loss are valued. Society must respect tactile and sign languages, and acknowledge the DeafBlind identity as legitimate.
7. Capabilities and autonomy of its members and communities promoted
8. Emancipatory research orientations and practices demanded, with community co-creation to avoid further oppression
9. Research conducted with members of the DeafBlind culture from 'their own sensory world perspective with the cultural rules that governed their behaviour and language use' (Shariff 2015, p. 63)
10. An overarching commitment to social justice for people who are DeafBlind. Society must treat all DeafBlind members as equal to non-DeafBlind. Central to this commitment is 'an interrogation and elimination of intervention based on condescending views of the DeafBlind ways of being' (Shariff 2015, p. 65).

CDBT offers an interesting framing for understanding vidaudism. Vidaudism sees the internalisation of messages of superiority, from both sighted-hearing groups and the Deaf communities' visual ways of being and doing. This is especially pertinent during the COVID-19 pandemic, where PWDBDSI are falling through policy and service cracks because they cannot access telephone and telepractices of the socially distant new normal. A tactile-centric way of being is not compatible with the virtual world, and vulnerable PWDBDSI may be deprived of services and support because of this need for face-to-face or tactile communication.

The central premise of CDBT, that a sighted-hearing society cannot speak for the experiences of those who are not, is sound—the very act of knowledge-gathering is sense dependent and communication enmeshed. This research, in which a deafblind researcher is conducting with deafblind/dual sensory impaired participants, is thus a potentially truer reckoning of how things really are. The challenge of conducting ethically sensitive research with d/Deafblind participants strongly aligns with the aims of this research.

By offering a somewhat pedantic perspective of one sliver of people in the USA with d/Deafblindness, CDBT has inalienable cultural roots, which excludes many with dual sensory loss—for PWDBDSI, this can be disabling in itself. PWDBDSI may travel between many identities of sensory impairment throughout their lives, and many come to sensory loss late in life. Not all are culturally immersed: heterogeneity of abilities, communication and identities is the norm. Further, belonging to a signing community is often a decision made by parents on behalf of their babies and children with hearing losses, on whether or not to sign (Solomon 2012). Additionally, the theory fails to embrace multicultural approaches, such as teaching babies signing for culture and clarity together with using cochlear implants or hearing aids for oralism. These other identities and histories are not included in this theory; therefore, it is not apposite for this research.

CDBT is also an anti-medical model; this is in line with many in the Deaf and d/Deafblind communities who view remediation, such as hearing aids and cochlear implants, and newborn hearing screening and other preventative practices, negatively (Clark 2014; Valente 2011). These extreme views are held by some, but it is my view that medicine is important to any model of disability to promote wellness, decrease suffering and provide treatment choices (not proscriptions). It is a human right to respect culture, as well as have choices in and control over remediation decision-making.

Social justice and human rights framings of disability

The International Year of the Disabled marked disability as a global issue in 1981; subsequently, there has been a multi-jurisdictional movement to enshrine legal safeguards and rights for PWD. The USA has the *Americans with Disabilities Act*, the UK has the *Disability Discrimination Act and Equality Act*, Canada has the *Accessible Canada Act* and Australia has the *National Disability Discrimination Act*.

The UK, EU and Nordic countries have all enacted rights-based safeguards specifically for PWDBDSI—recognition that dual sensory impairment is a distinct and significant disability that confers substantive disadvantage.

In the 2000s, the idea that inequality and disability are connected gained traction in both the Global North and South (Berghs et al. 2016; Swartz & Bantjes 2016), culminating in 2006 with the *UN Convention on the Rights of People with Disability* and the production of a CRPD. I concentrate on the CRPD as the major disability framework in the human rights and social justice arenas; its key aim is providing legal safeguards and removing barriers that cause or contribute to disadvantage, discrimination and disability (Berghs et al. 2016). The CRPD contains more than 50 articles and an optional protocol. It endeavours to provide legal remedies, as well as encouragement, to signatory nations to ensure the provision of social environments and structures that allow people with disabilities to flourish. Australia became a signatory on 16 August 2008.

The CRPD engages with the problematics of defining disability, recognising 'that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (*UN Convention on the Rights of Persons with Disabilities* 2006). Note that human rights models prefer person-first terminology, as in PWD (Berghs et al. 2016; Grech & Soldatic 2016).

The focus on human rights and social justice continues to grow, both internationally and nationally, in public health and development particularly (Berghs et al. 2016; Grech 2016). Yet, despite its promise and growth, a common criticism is that enforcement is difficult: 'Most analyses of the impact of the CRPD identify non-enforcement as a problem. Evidence suggests that the CRPD has very little national "bite" in terms of defined sanctions' (Berghs et al. 2016, p. 35). Currently, no country is fully compliant with all provisions, thus the convention is an incomplete phenomenon (Series 2020). Further complicating matters, nations and territories are no longer the causal agents of inequities; there are new non-geographical disabling, yet slippery, structures, which prove difficult to scrutinise and bring to account. These are 'powerful predator states and transnational private powers, including foreign investors and creditors, international currency speculators, and transnational corporations' (Fraser 2008, p. 454/4652). It is difficult to detect human rights abuses and bring to justice companies and structures that occupy these liminal and ambiguous legal positions.

For the purposes of this research, the framings of human rights overlap with others, such as civil rights and social theories, to varying degrees. Berghs et al. suggest that researchers apply a human rights lens when conducting their studies, to ensure the key requirements of accessibility, equality of opportunity, intersectionality, non-discrimination, participation and inclusion are met as stepping stones to human dignity and respect (2016, p. 98). This research honours these core premises by ensuring that accessibility needs are met and participants are included in research coproduction, regardless of their identities or cultural and linguistic backgrounds.

Human rights framings, in the form of the CRPD, have done much to promote the visibility of disability in global discourse and development (Goodley & Swartz 2016). The CRPD has little muscle to seek justice for PWD, however, which is a major weakness. Further, much of human rights and social justice is concerned with 'big picture' fights, not the individual experience of disability. Even if all rights are secured, insurmountable realities may still remain for individuals due to impairment effects (Vehmas & Watson 2014). Additionally, none of the theories outlined thus far has specific engagement with First Peoples history, culture and experience.

First Peoples' standpoint on inclusion and difference

Recent work condemns the dominant disability discourse for its 'whiteness' (Stienstra 2020, p. 453). Indigenous experiences of disability are rarely explored in disability studies. The First Peoples' standpoint on inclusion and disability seeks to break down or eliminate the colonial-constructed divide between us (white, able-bodied—a privileged position) and other (black, disabled—a disadvantageous position), and return to a pre-colonial state of cultural inclusion of difference.

Disability among Aboriginal and Torres Strait Islander peoples is a complex experience, historically overlooked and poorly understood. Their experiences differ from non-Indigenous people in many respects. Aboriginal and Torres Strait Islander Australians experience disability at almost twice the rate of other Australians (Avery 2018; Commonwealth of Australia 2017). Their history and experiences can also confer disability and intergenerational disadvantage (Avery 2018; Gilroy & Donnelly 2016). Colonial and postcolonial events had, and still have, a protracted disempowering influence on the lives of First Peoples.

First, Aboriginal and Torres Strait Islander peoples walk in 'two worlds': the world and the non-Indigenous world (Avery 2018, p. 190). This confers complexities not covered by traditional theories of disability—the data itself is incomplete; geographical spread is wide; disadvantage is both intergenerational and multiple; they experience intersectionality and entrenched racism—all are deep and divisive. Disability among Aboriginal and Torres Strait Islander peoples is associated with a lower life expectancy than non-Indigenous peoples (Avery 2018).

The impact of multiple disabilities is also profound. Among Aboriginal and Torres Strait Islander people with severe disability, co-occurring disabilities present, on average, at 2.5 disability types per person (Avery 2018). First Peoples' experiences of disability are complex, multilayered and largely hidden.

Historically, First Peoples accepted disability as a normal difference of humanity; therefore, pre-colonial culture was inclusive. Avery (2018) describes evidence of footprints left by a one-legged Aboriginal hunter, single but in concert with the bi-pedal prints left by companions. Tellingly, there is no word for 'disability' in any Aboriginal or Torres Strait Islander language (Avery 2018). As Avery explains, 'this finding is a contemporary expression of a culture of inclusion that has survived despite other disruptive influences upon community functioning' (2018, p. 182):

> A First Peoples' cultural model presents a philosophically different approach based on the premise that there is 'no word for disability', hence negativity is not observed. In this respect, the Utopian endpoint of the medical and social models of disability—cure and accommodate—is the starting point of an Indigenous cultural model of inclusion. By contrast, the First Peoples' model is the only model that seeks to improve the human condition through positive affirmation, as distinct to merely negating the adverse impact of difference (2018, p. 191).

The central tenet of the 'culture is inclusion' model is fostering participation and inclusion in society; within Aboriginal and Torres Strait Islander communities, parity in participation is the norm. This is distinct from the disparity found in their interactions with social systems, attitudes and structures outside of these communities (Avery 2018).

The First People's cultural model also asserts that disability exists on a continuum and that those with more severe forms of single and multiple disability experience greater disadvantage (Avery 2018). Similar to Shakespeare's (2014) view, this is a social relational concept that disputes the collective, fixed entity view of disability.

This model is compatible with medical and social models; this is an important point because some theories of disability repudiate the medical model despite its central role in detection, treatment, research, prevention and remediation of disabling impairments. Additionally, the model is affirmative, taking the end point of other models (inclusion) as its starting point.

Finally, Avery's work repositions First Peoples as expert-knowers and realigns the First Peoples as seekers, keepers and owners of this knowledge, signalling an affirmative move away from being 'objects' of study and recipients of services. The model is not perfect, however; Avery notes that some Deaf men experience a lack of inclusion in community events (Avery 2018). I wonder if, perhaps, this represents new complexities of colonial and postcolonial damage, rather than historical exclusions?

The First Peoples' model represents a millennium-old approach of inclusion and participation of all people in a community. While aspirational, it is challenging to actualise. The model represents a significant advance in disability theorising by moving away from able-bodied/disabled constructs, towards an acceptance of difference in human expressions and experience.

Relating theories to the doctoral study

The multifarious theories canvassed above—from the medical and socially constructed models, to the critical theories, social justice and human rights' framings, and the First Peoples' 'culture is inclusion' model—are not as problematic as at first appearance. The models cover shifts in thinking, and exhibit evidence of ongoing critical review and debate, as theorists seek to understand the truth of life with disability. It is questionable whether any one theory can encapsulate all things for all people with disabilities generally, and those with deafblindness or sensory impairments specifically. Mike Oliver guardian of the strong social model, writes (in exasperation, perhaps after duelling ideas with various critics):

> Models are merely ways to help us better understand the world, or those bits of it under scrutiny. If we expect models to explain rather than aid understanding, they are bound to be found wanting … we cannot assume that models in general and the social model in particular, can explain disability in totality (Oliver 1996, cited in Pinder 1997, p. 40).

Idealistically, for this researcher and for this research question, I take strands of all the theories that support lives lived with disability: a strong medical model, for its promotion of biopsychosocial health and wellbeing; the social model, for the social changes and barrier removal needed to ease some or all difficulties; social relational/critical realism, for its understanding of reality, identities and disability as layered, shifting and complex; and critical theories, for arguing that the standpoints we take matter, and that elucidation and reparation of power disparities is crucial for ending oppression. In the Global North and, especially, South, human rights for people with disabilities bear promoting and safeguarding so that all may flourish; we should aspire to a society where difference is merely the variety of being human and participation parity is the norm for all. A world where disability needs and has no words.

The chosen theory

For the purposes of this research, I must choose a path that best represents my own experiences of disability, and those of my research participants. In this context, a social relational-critical realist stance acknowledges the multiplicity of identities and experiences, as well as the diverse array of social structures that exert, pull and place obstacles in our paths to participation. In so doing, this stance also acknowledges that, for some PWDBDSI, barrier removal and full inclusion is not possible.

The literature identifies that some people in society have more power than others. In terms of the hospital setting, or structure, this research seeks to understand how much *agency* does a patient with DBDSI have when confined by the healthcare/hospital structure? Social relational theory, as applied to PWDBDSI, posits that they have less agency because their sensory impairments lead to decreased mobility and limited access to information, diminished means of communication, and that their impairments impact on social engagement. As a result, this research must take the standpoint, the view as it were, from the participants' perspective. So, while social relational-critical realism informs our thinking on disability and its complexities, as well as how reality is stratified, shifting and changeable, the search for enablers of positive change and examination of power structures—scholar activism—is the goal of this research; thus, the standpoint methodology is the theoretical framework best suited to privilege the voices and signs of the participants.

Chapter 3

Standpoint theory and positionality: honouring patient-participant perspectives while mediating my consumer-researcher identities

Introduction

This work is designed—and positioned—to advantage the research's participant-patients in telling their stories through ethnographic interviews. This thesis positions my experiences—writing from the following viewpoints:

1. person with disabilities
2. student consumer-researcher
3. patient
4. clinician
5. activist

While the outlooks from the patient-participants' (and my own particular) perspectives are multifarious, nonetheless, it is important to chronicle and examine them. Standpoint theorists, critical realists and disability scholars argue that even the most extensive scientific observations do not have the same veracity as the lived experience of oppressed groups/persons/patients (Burnett 2007; Charon et al. 2017; Harding 2004; Shakespeare 2014). I conduct this research through the lens of standpoint theory, positioning the participants as creators of knowledge, and considering the dearth of literature from the viewpoints of those with a lived experience of DB or DSI.

First, I outline the conceptual basis of using standpoint theory as the methodology for this research. Standpoint theory also directs the choice of ethnography as the vehicle for eliciting the testimony of PWDBDSI, asking the essential question: 'What is your story of being in hospital?' This research is predicated on PWDBDSI as 'expert-knowers' (Barnes & Mercer 1997, p. 7). I am both an expert-knower and consumer-researcher, examining one area of our/their lived experiences. I also interrogate my positionality, with its multiple lenses and personal perspectives—a significant part of this chapter thus surveys the researcher's standpoints and their potential impacts on the research. Accessing this multiplicity of viewpoints requires an understanding of the underpinning theory.

This research is structured to privilege the voices and perspectives of patients with DBDSI. There can be no record of these patients' experiences and no analysis by this researcher without considering accessibility and narrative space requirements.

Why standpoint theory?

There is richness found in examining the standpoints of PWDBDSI—although they are much discussed in deafblind communities, their stories have not been officially told. It is fundamental that we provide the means of eliciting narratives to ensure we can hear/see/feel a story from another's position. Reliance on proxies (partners, families, workers, clinicians or other observers) is not the same, nor as truthful (Harding 2004). There is empowerment in telling your own tale in your preferred way (Harding 2004).

Standpoint theory originated in both Marxist thought and early feminist theories (Borland 2020; Harding 2004; Paradies 2018). First coined by Harding, the term is simultaneously an explanatory theory, method and theory of method (Harding 2004, p. 1). At its core, standpoint theory empowers oppressed groups by allowing them to voice how the social order works from the perspective of the oppressed/subject-as-knower (Harding 2004).

As the central tenets of standpoint theory attest, first, all knowledge is situated socially and second, power relations shape this knowledge (Paradies 2018); therefore, there can be no neutral or objective position (Rowland et al. 2017). Researchers need to challenge and delimit restrictive research practices, rather than operating from a position of 'neutrality'. As Paradies (2018) writes, 'researchers, scholars and other experts no longer have a mandate to stand above and dictate truth and reality to others' (p. 125). Rather, researchers must stand with their participants as co-creators of knowledge. Harding (2004) refers to this as letting subjects become 'the-authors-of-knowledge' (p. 4).

Oppressed or marginalised groups are situated socially in ways that allow them to raise questions not readily apparent to the non-marginalised. Power relations shape knowledge; therefore, research that intersects with power relations, should begin with the perspectives of the oppressed or marginalised (Paradies 2018, p. 120).

Society is stratified by numerous influences—such as gender, race, class and ability—where 'one's social positions shape what one can know' (Borland 2020, para. 1). For example, PWDBDSI occupy a social situation both in and out of hospital that is critically unexamined. This is confirmed by the lacunae found in the literature review. These individuals have less power (due to decreased access to information, communication and mobility restrictions); therefore, they are uniquely positioned to describe patterns of care, attitudes and behaviours that may be less visible to those working in and managing hospitals. Harding (1991) calls this effect 'strong objectivity' (p. 138), which means: 'people at the bottom of social hierarchies have a unique standpoint that is a better starting point for scholarship … recognising the standpoint of "knowledge-producers" makes people more aware of the power inherent in positions of scientific authority' (Borland 2020, para. 2).

In addition, these insights are 'less partial and less distorted' (Harding 1991, p. 121) than those produced by people in social positions of power, or their institutions. Conversely, those powerful people and institutions construct the prevailing discourse, which passes for truth (Paradies 2018). Rolin (2009) defines power as the ability of an individual or group to constrain the choices available to another individual or group (p. 219).

This research seeks to uncover hidden power disparities in social relations between patients with DBDSI and hospital-institutions, but there are also aspects of power that pose 'a challenge to this uncovering of the hidden' (Rolin 2009, p. 219). Power relations can contaminate and distort social scientific evidence. For example, if power is exerted by failing to provide accessible quality assurance, performance review and patient-satisfaction forms, this distorts results because the voices of those with sensory impairments are removed from the area of study. Distortion can also occur through participant intimidation, such as patients feeling apprehensive about receiving adverse treatment if they complain. Fear and shame may also lead to suppression, depriving participants of the means to communicate their social experiences (Rolin 2009). PWDBDSI may lack the dominant language and/or oralism to voice their experience, while staff and researchers may lack the skills to receive information; for example, the power exerted by failing to provide interpreters.

Sometimes, there are hermeneutic injustices where participants have no name for, or understandings of, an experience, thus rendering them powerless to change or protest about their situation (Rolin 2009). This is relevant to PWD, who frequently experience discrimination, harassment and microaggressions without being able to label the incidents for what they are, while also internalising their negative impact. Avery (2018) describes this effect on Indigenous Australians with disabilities and the 'double disadvantage' of racism, while Shariff (2015) writes about vidaudism, where the sighted-hearing prevailing norm oppresses those with co-occurring hearing and vision loss, similarly to racism.

Trust-building is important in work imbued with standpoint theory to reduce the researchers' own distortions and contamination. To ameliorate this, Rolin (2009) contends, the research area should demonstrate a commitment to long-lasting social change. Nakata (1998), who uses standpoint theory to frame his work with Indigenous peoples, reminds researchers that the only way to produce meaningful knowledge about, and improve the situation of, a group is by immersing in their culture and community. This is where consumer-researchers have an advantage, being somewhat closer to their participants' standpoints than the researcher on the sidelines. As well as being a methodological theory that does not perpetuate oppression, standpoint theory instructs that power relations are considered as part of the research process. That is, the research itself needs to situate these power relations as a discrete object of inquiry, asking what kind of obstacles they may present to both social change and knowledge-building. This is examined critically in the discussion chapters.

Standpoint theory is not just concerned with examining power relations between the oppressed and their oppressors, but also those between the researcher and subjects of inquiry. Researchers exert power by making decisions about the subject matter and how it is studied, but this power is not entirely one-sided. There are complexities, and the role of power in the interactive nature of research is often under-recognised. Participants, the subject-knowers, determine 'what experiences are significant to tell about and what degree of detail to tell about them' (Rolin 2009, p. 223). A caveat here is that the communication needs of individual research participants may be significant; thus, if researchers do not meet these needs, the choice to speak, and of what, is obliterated. As Rolin (2009) notes, ‘informants as well as social scientists may have to struggle against the workings of power relations in order to reveal how such relations constrain an individual’s or a group’s abilities to act’ (p. 223). In this work, the hospital-as-institution exerts power at many levels, on many groups and individuals, which may reduce the voice of the patient with sensory impairments, consciously or unconsciously. Thus, little may be heard or valued from the PWDBDSI’s standpoint. For example, using the dominant structures’ framework to collect knowledge constrains those with less power. Thus, information collected in a hospital that evaluates diagnoses and treatments does not reflect the PWD’s experience, for this has not been sought. Many PWD, including Indigenous peoples and PWDBDSI, mistrust healthcare systems after poor experiences (Avery 2018; National Disability Services NSW 2014; Shariff 2015). The realities of negative encounters further strengthen standpoint theory as the chosen methodology. The research methodology must be independent of health systems and institutions.

The present research is situated within a climate of community concern about access to and experiences within the healthcare sectors. The 2018 WFDB global report notes the absence of information and makes a commitment to ’conduct additional research on the issues facing persons with deafblindness, including health status and access to healthcare, social participation and wellbeing’ (World Federation of the Deafblind 2018, p. 17). The current study, therefore, is situated within the community, not outside it, and considers the community’s concerns above those of academia or hospital-institutions.

Research is the process of generating evidence, and the unsought voices of PWDBDSI require discovery. This is this doctorate’s intention—to elicit hospital experience(s), examine the power relations, and consider solutions and redress. Standpoint theory instructs researchers to enjoin knowledge production ‘with a process of empowerment’ (Rolin 2009, p. 220); in doing so, they can bring about change, resulting in a more just society. Paradies (2018) calls this process ‘scholar activism’ (p. 119). The emancipatory research principles of standpoint methodology are also central in critical realism (Burnett 2007; Danermark et al. 2005; Shakespeare 2014).

It must be acknowledged that standpoint theory faces significant contentions. The theory is weakest in its division between oppressed and oppressor—this could be considered dualistic and does not explicitly recognise the many identities that individuals occupy. Both sides may be homogenised, creating a reductive oppressed and oppressor stereotype (obverse sides of the same coin) and ignoring the complexity of lived experience and multiplicity of identities. As Paradies (2018) explains, ‘by adopting a multi-dimensional approach to identity and social location, intersectionality fractures the implicit dualism of standpoint theory’ (p. 120). As Harding (2004) suggests, by recognising that we all have multiple identities and inhabit multiple locations, we can then mediate any arising tensions. Further questions develop from exactly what influences the knowledge gained from standpoint research projects: the participants' experiences? The participants' social location? Or indeed, the disability discourses underpinning these projects? Harding (2004) welcomes debate and dissensions arising from privileging the marginalised view, writing: 'know that this reality is our best knowledge, that it too is socially constructed but also that it is empirically accurate' (p.12).

The question to answer now, when considering any unsteady theoretical grounds, is: does standpoint theory 'produce a reliable account of some part of reality?' (Harding 2004, p. 11). As a methodology, standpoint theory is validated and valuable for researching disability (Gilroy & Donnelly 2016), studying Indigenous Australians (Ardill 2013; Nakata 1998, 2007) and gathering patient perspectives (Rowland et al. 2017). My particular body of research supports using standpoint theory with participants with DBDSI, for what may be the first time. I contend that PWDBDSI are in a unique position when in hospital, and thus hold situated, expert knowledge of healthcare systems, attitudes and hospitals.

The patient standpoint

This expert-knower patient perspective is, as Rowland et al. (2017) state 'a particular kind of situated knowledge, specifically an embodied knowledge of vulnerability' (p. 76). Additionally, this notion of vulnerability brings into play power paradigms central to standpoint theory. The patient perspective is considered essentially powerless and vulnerable, with a power divide between recipients of medical care and providers of that care. The participants in this research, however, are not simply patients with a particular patient position and perspective, we are also PWD with situational vulnerabilities that confer added risk in hospital environments. Asking the following yields necessary information: What happened? How did you feel? What were the enablers of good communication and care? And, what were the disablers? Situated knowledge, therefore, can transform poor care in health institutions via standpoint methodology. Because the PWDBDSI perspective is largely absent from the research literature, addressing this imbalance is a significant function of this doctorate.

At times, I use 'patient perspective' as if there is only one single viewpoint, but as Rowland et al. (2017) point out, patients have many identities and perspectives that act on and inform their experience. Researchers and policy papers often use the tropes 'patient', 'patient perspective' or 'patient point of view' without interrogating them (Rowland et al. 2017)—this is also significant. It positions the patient's perspective as a singular phenomenon, with only one dimension. Rowland et al. write:

> We quickly discovered it was difficult to contain participants to singular categories of involvement and/or illness experience. Participants with chronic illness also spoke about their patient experiences in emergency departments. Participants with their own patient experience also talked about their roles as caregivers for parents and children (2017, p. 81).

This demonstrates the complexity and multiplicity of 'the patient perspective', which I expect to be further complicated by the communication disabilities of my research participants. Rowland et al. use standpoint discourse to examine patient perspectives in patient engagement programs; one of their participants said this about his patient experiences:

> You could write a paper about communication in a hospital setting … But, you know, until I knew how it felt to not be communicated (with) on that level, I don't think I could have understood it in the same way [pause]. It is sort of an out of body experience (Rowland et al. 2017, p. 8).

This account illustrates the embodiment and disembodiment of vulnerability. Being a patient in hospital is different to inhabiting one's normal life. The patient perspective thus serves 'as a reminder of our shared physicality and shared vulnerability, bringing attention to the indignities and the fears and the vulnerabilities and the time warp' (Rowland et al. 2017, p. 83). All these observations are tilted towards sighted-hearing perspectives; however, the lens of this research is on those with absent or limited dual senses, and yields knowledge from new standpoints.

There is likely a fundamental discord between what doctors and nurses think about the care they provide, and the care a patient with sensory impairments experiences. This reflects a power disadvantage, which is more than that of simply being a patient, which is also disempowering. This research uses standpoint framing to seek, elicit and value the voices, signs and touch signals of patient-participants with DBDSI. I then use standpoint values to examine those experiences, critique the power relations, and offer real and sustainable solutions to PWDBDSI, so they may participate in their own care, share in clinical decision-making, and have better health and wellbeing outcomes.

My particular standpoint/s

As established, the standpoint of this research is to position the participants' experiences front and centre as expert-knowers (Barnes & Mercer 1997, p. 7), and as holders of a more truthful, less distorted view of the realities of being a patient with sensory impairment in hospital. I now turn to consider my own position in this process, because I adopt many changing identities and states of being. As stated in the Introduction, I am both an expert-knower and consumer-researcher, as well as a clinician and activist. Many student researchers describe occupying several identities during a doctoral research project and how these may change over time. Fisher (2011) describes this as 'changing states' (p. 103) as she evolved from student to researcher, and Pini (2004) describes inhabiting several identities during her research, which were fluid and continually shifting. She tells how one of her identities, the 'country girl' (p. 173), encouraged her research participants to respond positively towards her (Pini 2004).

I inhabit more roles, which seem extricable only with difficulty. I am a consumer with deafblindness, learner researcher and clinician—this last is a tightly embedded role that, if lost, threatens destruction of the self. And how do these roles, complicated by being female and relatively privileged, impact on the research and standpoints? Probably, the positions of gender and race do not balance out, because they are mediated by the existence of significant disability. Simultaneously, it seems that I began practising what I now know as 'scholar activism' (Paradies 2018, p. 119). My concerns for what happens when people with sensory impairment go to hospital arise from anecdotal and personal experiences—both as a patient and carer of patients. This research is just one method of proving the need for wider awareness of, and practice changes to, how PWDBDSI are treated in hospitals.

Consumer-researcher standpoint

The consumer-/expert-researcher position is a poorly studied phenomenon outside the field of mental health, where most papers are generated. There is debate in disability studies as to whether the only avenue to understanding disability is the necessity (or otherwise) of researchers being consumers with disability (Shakespeare 2014). Griffiths, Jorm and Christensen (2004) write about the role of 'academic consumer-researchers' (ACR) (p. 191). By using the acronym Student ACR (SACR), I follow their usage, extrapolating from their observations to create the 'student academic consumer-researcher' that describes my particular situation. ACRs, they propose, act as a bridge between researchers and participants to level the traditional power imbalance between the two. At the time of writing, any literature on consumer-researchers is primarily mental health–focused; there are no articles to guide how a dual sensory impaired student might conduct qualitative interviews with consumers who are deafblind or dual sensory impaired.

What specifically is a consumer-researcher?

For the purposes of this research, a consumer is a person living with DBDSI—that is, an expert-knower. For my research to build knowledge that contributes to better healthcare and communication experiences, it must address consumers' concerns and experiences (that is, PWDBDSI). The student researcher with disabilities brings unique consumer perspectives to the research table, as well as the need for practical accommodations. Professor Kay Jamison describes how she acts as an ACR: 'I have tried, as best I could, to use my own experiences of the disease to inform my research, teaching, clinical practice and advocacy work' (Jamison, cited in Griffiths, Jorm & Christensen 2004, p. 192). My SACR self is someone who is studying and working towards proficiency in using lived experiences of DBDSI in research, teaching, clinical work and advocacy.

My standpoint is on shifting ground, for mine is a degenerative condition; as I adjust to one set of degrees of vision and/or decibels of hearing lost, another loss seems fast upon me. From the start of this doctoral journey to the final write-up and review, more losses have supervened: loss of clarity, contrast and acuity of the little sense remaining. These pose both personal and practical challenges to my research; the participants understand the fragility of adjustment to loss/es and the at-times hostility of 'normal' society with its many sensory hurdles.

While being a consumer-researcher provides a location for trust-building and reciprocity through mutual experiences and cultural understandings, it doesn't imply a perfect dovetailing of like minds, bodies and lives. As explicated in **Chapter 1**, people with sensory losses experience vast heterogeneity in all aspects of living realities. I must remain attuned to these differences and avoid assumptions. This further reinforces why this research cannot use singular umbrellas of 'deafblindness' or 'dual sensory impairment' to reduce the population.

This research is situated in community concern as well as personal experience. Consumers participating in my research are positive at information sessions and support group meetings, and eager to be included. They are clearly influenced by my status as a sight- and hearing-impaired person, 'like us', and because I proposed to address a central anxiety in their lives. This engendered trust, which grew throughout the 18 months I spent immersing in the support group meetings and contact with others. These men and women also spoke to their friends and family, and gave my email address to facilitate requests for inclusion in interviews.

Learning to be a SACR means navigating the support needs of everyone in the conversation. There are rewards evident in the process of organising for inclusivity itself; that is, to maximise participation in a research project that revolves around a central preoccupying concern of the participants and the wider PWDBDSI group.

Student academic consumer-researcher: tensions, barriers and benefits

In my case, the seemingly distinct positions of being a person with deafblindness and student researcher are inextricably entwined with accessibility—the research cannot progress without adjustments and accommodations to the disabilities of researcher and expert-knower participant alike. The hard reality of being deafblind is dependence on others for nearly all tasks (Möller 2003). The need for accessibility and communication support underpins all positions and identities. For a deafblind SACR, this means bringing to the research space a number of 'others'. In my case, this is any permutation of accessibility assistant/s, voice interpreter, sighted guide and live transcriber, depending on a situation's requirements. There is co-dependency and mutuality, because I am the employer of accessibility assistants as well as a service recipient. I have to trust my support staff—their note-taking and tactile signalling—just as there must be trust between participant and interpreter, then interpreter and myself, that stories are rendered authentically. The most important position is that of the recipient of the participant narrators' stories. I am entrusted to take these and use them well, to work for change and ensure they would 'not be left on a shelf to gather dust' (Sally, research participant). This is my central standpoint: to be supportive of my community first. If an issue arises in the research involving the participants, their welfare and wishes override all others, including any notional research 'rigour' and 'objectivity'.

Being a student researcher with DBDSI is uncharted territory. There is a dearth of published research on the university and postgraduate experiences of people with dual sensory impairments (Arndt 2011a; Chanock, Stevens & Freeman 2010, 2011; Wolsey 2017). Being situated as a doctoral student with disabilities confers extra complexities and difficulties. Universities can be hostile spaces for PWD generally (Goode 2007; Mutanga 2017), and those with deafblindness specifically (Arndt 2011a; Wolsey 2017). Some complexities include the paradox of invisibility co-occurring with extra-visibility, the practical needs of additional funding and support, the educator's role in the specific disability and the emotional load this entails. Finally, students/candidates with dual sensory impairments face a protraction of time—but what is this exactly and what does it mean? These are explored briefly now.

(1) Invisibility

When students' needs are unmet, students become invisible. Invisibility occurred on many occasions when group discussions used whiteboards, technology failed, assistants were sick or unavailable, and when academics declined to use accessibility technology. Then, I too became invisible. Some days, you must decide which fights are worth having, and which are not.

(2) Visibility

Goode (2007) discusses the notion of 'extra visibility', where students have to actively campaign so their needs are met. I also found that needing an 'entourage', talking too loudly, bumping into things and needing accessible material increased my visibility—whether wanted or not.

(3) Practical needs and funding for these

Goode (2007) mentions:

> … the multitude of processes that students with disabilities undergo: bureaucracy, waiting for accommodations, equipment and conversions. [Many students] faced huge obstacles in their first semester because of slowness of the bureaucratic process beyond the university and the length of time they had to wait for reasonable adjustments to be put in place. Waiting for the support they were entitled to, whether brailling, laptop, computer software, note takers or mobility related, had a huge impact on some students' ability to study effectively (p. 45).

Universities have to provide funding and personnel, which is enshrined in Australian disability anti-discrimination laws and international charters such as the CRPD. Major communication technology developments mean that staff need to be up-to-date and versed in the latest iterations. The present research was only able to proceed because of the University of Technology Sydney's funding model, which gives me choices and control.

(4) The educator role

While I came to university to become a knowledge-builder in my chosen subject area, it quickly became apparent that I had work to do building others' knowledge of disabilities. As well as being a student and supervisee, the educator identity is highly visible and hardworking within the university. Lack of embedded policy and support at all levels of tertiary institutions means that disabled students are knowledge-building about their disability while studying. This can be a significant additional burden for students. 'In addition to managing their classes and social lives, they had to educate others about deaf-blindness' (Arndt 2011a, p. 1).

Goode (2007) discusses the 'emotional work' of being at university with disability/ies. This labour is twofold:

1. Managing your own disability and course study loads, university life and everyday activities.
2. Educating others about the disability, its effects, technology used and accommodations needed.

(5) The need for more time to fulfil role obligations as a student researcher

Many have noted that student activities 'take longer' if you are a student with sensory losses. One blind student noted: 'for obvious reasons it takes me longer to write an essay than most people' (Goode 2007, p. 46). Stoffel himself, in *Deaf-blind Reality: Living the Life*, estimates that it takes him five times longer to read than an able-bodied student (Stoffel 2012). In an effort to delineate exactly what taking more time means for me specifically, I timed activities that were components of a course I undertook in 2018, *12 Weeks to Publication Course1*. I collaborated with a fellow PhD student, who is sighted-hearing. At baseline, without accessibility assistance, I was unable to complete any of the tasks. With full assistance I was able to complete tasks but took longer. (See List 3).

List 3. Time taken for selected *12 weeks to publication* activities

Activities (estimated hours // time actually taken)

- Find and read a model article (90 minutes // 3 hours)
- Draft an abstract (60 minutes // 2 hours [plus more to edit])
- Revise abstract according to review (30 minutes // 30 minutes [plus more to edit])
- Read Chapter 3 'The Argument' (60 minutes // 7 hours)
- Peer review each other's work (30 minutes // 30 minutes [time limited as allocated by facilitator])
- Draft a query letter (30 minutes // 30 minutes [plus more to edit])
- Read chapter (60 minutes // 3 hours)
- Evaluate current citations (60 minutes // 2 hours)
- Identify, find and read related literature (8 hours // 36+ hours)
- Evaluate related literature (60+ minutes // 2 hours)
- Week 5 activities (reading and writing) (2 hours // 6 hours)
- Read Chapter 6 (30 minutes // 1 hour)

These findings demonstrate that more time and patience are needed when research students with sensory disabilities are writing abstracts, reviews, reports, articles, posters, papers and dissertations. They need even more time (from two to six times longer), however, for reading tasks that accompany or precede writing tasks. I felt it was important to attempt to quantify the time spent, because otherwise, there is a lot of 'it takes longer' without any understanding of what this means. Those supporting and/or supervising student researchers need to establish reasonable and achievable timeframes and deadlines. This timekeeping mini-study reflects how the researcher role engages with the student role in unexpected ways. Challenging the vagueness of ‘it takes longer’, I sought to replace this with some specificity.

I am not alone in wresting with time. In Sweden, Möller (2003) found that people living with deafblindness ‘lost time’ (p. 4) in almost every single activity. In addition to taking longer to read, write and participate in university life and learning, my supervisors and teachers must spend more time in engaging with me. Möller (2003) concurs, writing that professionals often spend twice as long with deafblind people and book double appointment slots.

Plural realities

Clinician

I bring more than my dual identities of a person with disabilities and student researcher to the research space. I am also a clinician with more than two decades’ experience in medical practice. I spent a long time in ‘denial’, which allowed me to ‘normalise’ myself and pass through my working life (for a period) unmolested by the stigma and judgements of others. There came a time, however, when ‘staying in the closet’ was no longer safe nor possible. This role welded into being by permeating how I see and solve the problems of others, and the social responsibilities I take on. The diminution of my medical role was, and is, felt keenly. So, I came to this space as a student (again), who needed to learn new skills to achieve my research goals while, at the same time, navigating the often-hostile terrain of accessibility issues. In addition, I had to work out how to ‘become’ a safe, respectful and emancipatory researcher with these added personae.

When the clinician role is added, further complexities are introduced to the student and consumer-researcher standpoint. Fisher (2011) writes of the challenges of being both a clinician and student researcher. My own journey is more complex, owing to increased identities that need locating (clinician), accommodating (disabled self), and learning (academic researcher). My research question is precipitated by my clinician experiences, as well as my lived realities of being a hospital patient with DBDSI. No identity or position is fixed or immutable—they glide or bump along a spectrum. Being a clinician is a complex position for me. Being a doctor defines you. As Dr Eric J. Cassell writes:

> By middle age, the roles may be so firmly set that disease can lead to the virtual destruction of a person by making the performance of his or her roles impossible … a doctor who cannot doctor … he or she is diminished by the loss of function (1982, p. 642).

This is at once both correct and incorrect. The readjustment towards a new normal does allow for me to continue as a doctor, though it may be different—ancillary perhaps, rather than central. Time (much time) is needed for such a transformation. Sometimes, as in my case, the clinician role can kindle the researcher role.

From her standpoint as a clinician-turned-doctoral student, Fisher (2011) has salient advice to other clinician-student researchers: build a research space with others who can discuss the research, theories and difficulties. She advises wide reading; she found, as I have, that clinical training and work do not prepare you for considering social concerns in a sociological and conceptual way. Thus, broadening my reading with social and disability theories proved critical in the early stages of my student researcher journey. This reading, to broaden horizons and challenge ways of thinking, is important; the clinician is taught through medical model framings—that patients have problems in their bodies, social circumstances may complicate wellness, find solutions. Clinicians often find complex situations difficult and may avoid patients with these, disliking the disempowerment (Ofri 2013). To ameliorate this, Fisher (2011) suggests finding a mentor who challenges your belief systems and assumptions. My second supervisor, Dr Sarah Wayland, is this person; she is instrumental in moving me further along the social relational theory evolutionary scale to see disability beyond the effects of individual impairments, in a stratified reality. Fisher (2011) further advises that a research project should stem from clinical work and evoke passion and curiosity. This doctorate arises from my own and other patients' negative hospital and communication experiences. This then positions me as a clinician, expert-researcher and expert-knower (Barnes & Mercer 1997). Maintaining reflexivity is suggested as a tool for self-awareness, identifying and challenging assumptions, and dealing with emotional responses to the interviews and research.

I kept a journal that contains all the threads of my doctoral process: administrative, accessibility related and research issues. It is not practical to have a deafblind person navigate several diaries, because the likelihood of mis-entering information is high. This had the advantage of providing a timeline of how issues unfold and resolve, how accessibility assistants are allocated and managed, how and when self-advocacy is needed, who I consulted and for what advice, when I felt overwhelmed with the enormity of the tasks ahead, and the critical management of funds to support my access needs. In this way, journaling was seminal in enabling me to document difficult experiences, role conflicts and position shifts, as well as to put thick lines through goals achieved. Known as 'the black book', this is the chronicle of my journey for all the selves undertaking this doctoral research.

Conflict is expected between selves if, and when, the clinician position shifts into primary focus. If a participant discloses an intercurrent, potentially serious medical or abusive episode, by law a medical practitioner is not allowed to be a bystander. In reality, the participants were members of my community, too. I was determined to act in the participants best interests even if contrary to the research. This position was affirmed by Scott Avery, a First Peoples with disability researcher and fellow doctoral candidate, who advises: 'Your first responsibility is to your tribe, so no conflict there!' (Avery 2019, pers. comm., 3 September).

Scholar activist

Another tenet of standpoint theory is the role of scholar activist—stating that it is not enough to produce research outcomes, social change must be the endeavour. Thus, researchers may not adopt a neutral, non-participatory role.

The way to honour participants' stories, Rolin (2009) contends, is to demonstrate a commitment to the long haul of social change in the research area. Nakata (1998), who uses standpoint theory in working with Indigenous peoples, reminds researchers that, you can only produce meaningful knowledge about a group to improve their situation, by immersing yourself in their culture and community. Social anthropologists have long advocated cultural immersion (Bernard 2013). There is mutual benefit here; it was advantageous both for me and many participants that my team and I learned sign language and social haptics. Participants saw it as valuable, respectful and inclusive. When immersing and engaging with a wide range of participants with diverse impairments and histories, it is important to confirm that the research's concerns and focus match the community's concerns. As a researcher, deciding to pursue a personal or institutional-driven research topic without community co-creation runs counter to standpoint theory principles.

My concerns surrounding my patients' and my own damaging hospital experiences, along with anecdotal accounts heard in the communities, made me consider how PWDBDSI could be self-empowered during a hospitalisation. I devised the idea of wristbands that PWDBDSI can wear (if desired) when in hospital. These serve to identify and remind staff, in all locations and wards, that there is a patient who needs time and accommodations for effective communication. At a meeting with the Clinical Excellence Commission from the Ministry of Health in April 2017, I was advised 'We are not aware of this as a specific problem, you had best prove it first' (Watharow 2017, pers. comm. April). I was not prepared to wait three or four years before producing these for the communities wanting them, however, because I felt that the sooner individuals had a cheap and simple identifier, the better. This meant, alongside my doctoral research, I was running a philanthropic and person-empowering project to supply free wristbands to people with any sensory impairments in Australia.

Parallel results came through—that the bands are helpful and that the problems PWDBDSI experience in hospital are profound, distressing to participants and denied by authorities. My scholar activist role meant new lessons in raising funds as well as awareness; I used the GoFundMe platform to provide thousands of bands to people both pre-COVID-19 and during the pandemic. Potential bias arose when impairment support organisations started giving out bands before I had begun interviews, meaning that some research participants had previously used the bands and were keen to share their experiences. I reconciled this potential bias with the knowledge that, if the bands help improve experiences, then they are important to the community, which supersedes research neutrality.

A further lesson of scholarly activism is the importance of disseminating information; the results of this research is critical to mobilising a force for change. This requires long-haul support from accessibility assistants and others, because this consumer is dependent on such support for communication.

Intersectionality

What are the intersections of gender, age, race and class in all these roles? Being female in medical school in the 1980s, our tutors and lecturers were often of the old school; one surgeon proclaimed, 'I don't hold with girls holding scalpels'. Luckily, I knew I would not be any good at it—lacking the vision and hearing to function in operating theatres—but there was a pervasive current of girls unsettling clinical practice norms and changing the medical workforce, as women began to make up more than 50 percent of intakes. I had been long aware, too, of how women are perceived as hysterical and exaggerating attention-seekers, with all the case studies on 'difficult patients' (aka 'heartsink patients' [Launer 2018, p. 1433/3003], because the doctor's heart sinks when seeing the patient's name on the daily appointment list). Medical research and teaching traditionally portrays females as smaller versions of males; the slew of recent research and reviews highlights the colossal extent of this and the harm it is has done (Dusenbery 2018; Dwass 2019; McGregor 2020; Norman 2018; Perez 2019). If you work in general practice, you learn what medical school failed to acknowledge—that women and girls suffer more, are offered less pain relief and often face negligible belief from families, employers and society as to the validity of their symptoms and suffering.

Like most of my female colleagues, I had more female patients than did male doctors. We understood each other. Then, too, women and girls with deafblindness experience more difficulties, barriers and violence than males with deafblindness. I have had, and still do have, experiences where my gender influences how I am perceived and treated, yet still I say that the extreme nature of my vision and hearing loss makes extricating gender influences tenuous and slippery. There are also socioeconomic effects—for all the net gains of my professional standing and expectations of income, the losses of being unable to achieve my career goals, evaporation of my clinician role over time, and increased expenditure on disability support throughout decades means that net losses prevail.

While my standpoints are many and varied, and intersectional influences uncertain, just being able to undertake doctoral studies is a privilege. The education I have had and gained has opened tertiary institution doors to doctoral studies. Fifty years elapsed between the first college degree awarded to a deafblind person, Helen Keller, and the next, Robert Smithdas. Smithdas became the first person with deafblindness to obtain a master's degree. A doctorate was conferred to Adeline Becht in 1982, in clinical and counselling psychology ('Deaf, Blind, and Now Ph.D' 1982), followed by several more since then. Stoffel (2011) briefly describes his doctoral journey in his collection of lived stories of PWDBDSI. Dr Nicole Lo-A-Njoe-Kort (2019) describes how the doctors' disagreement about her declining hearing ('it simply does not happen in Usher syndrome') led her to undertake a PhD in just that. She proved her point—there is a subgroup of Usher, type 2, who suffer degeneration of hearing as well as vision over time. We are small in number, but we have the will in common to make things better for PWDBDSI.

Chapter 4
Gathering and exploring the internal literature and liminal space

Preamble
The overview of the literature spans two chapters: **Chapter 4** demonstrates and responds to the paucity of scholarly literature on the specific research question. It utilises an alternative literature search and appraisal strategy, embracing and valuing the wide variety of non-academic material, as well as peer-reviewed research. This inclusive search seeks the current state of knowledge surrounding what happens when PWDBDSI go to hospital—what we know, how we know it and what we do not know. There is an internal examination of patient and carer testimonies, professional practice materials, organisational and policy documents, and research papers. What emerges is a liminal space, fraught with unknowns.

Chapter 5 then examines the literature external to the research questions, but which describes how the lives and impairments of PWDBDSI pose threats to their health and wellbeing. These threats increase the risk of hospital and healthcare encounters for PWDBDSI.

Introduction

It is reasonable to surmise, from lived experience and anecdotal reports, that PWDBDSI have a situational vulnerability when hospitalised. DB and DSI are complex conditions, exhibiting vast heterogeneity within the commonality of reduced or absent sight and hearing. These confer difficulties in accessing information, communication and mobility. The world and its institutions can be hostile terrain with attitudinal, social and physical barriers. In the wider DBDSI literature, researchers are beginning to explore the population's vulnerabilities, challenging ideas of a constant state of risk. Simcock (2017b) posits two arms of the 'complex concept' (p. 813) of vulnerability—on one hand, PWDBDSI with significant accessibility, mobility and communication needs are at risk of harm from neglect, while on the other hand, their human rights are adversely impacted by overprotective practices (Simcock 2017b). It is not yet known, however, how work is proceeding specifically within the context of hospitalisation of PWDBDSI.

This literature review assesses the status of available knowledge on the specific situational vulnerability of hospital experiences, preferably from the perspectives of PWDBDSI themselves. What are the disabling factors and what are enabling ones? The present research extends its positive framing to the literature, looking at salutogenesis and ways of improving in the future.

A comprehensive scoping search of the existent literature was performed in 2017 to establish its breadth and depth regarding the research questions. In 2019, a follow-up search was undertaken to identify any subsequent publications that could shape the outcomes of this study. I chose the start date of 1990 for all searches—which coincided with my own nascent career as a medical practitioner—in the hope of capturing material about hospital experiences contemporaneous with my own.

Search strategy

April 2017 – December 2017

The initial scoping review of databases used the keywords ‘deafblind’, ‘deaf-blind’, ‘deaf and blind’, ‘dual sensory impairment’, ‘dual sensory loss’, ‘healthcare’, ‘hospital’ and ‘adult’. Databases reviewed included PUBMED, MEDLINE, Psych Info, Proquest, Health and Society, INFORMIT, Social Science, EBSCO and Trove. RefWorks, a bibliographic software program, was utilised to track references because of its accessibility features.

One article specific to the research question was identified—Fernández-Valderas, Macías-Seda and Gil-García (2017)—which was written in Spanish. In their review of public health and disability research Berghs et al. (2016) write that, to be truly inclusive, literature from other countries should be included in searches, translated and considered. Accordingly, a translator from the Faculty of Arts and Social Sciences at UTS translated the article from Spanish into English. An email was sent the lead author, requesting a copy of the questionnaire used in their research, to both contextualise the article and potentially inform this research.

Because of the poor yield of empirical research, the inclusion criteria was extended to include user- and/or carer-testimony, practitioner knowledge, organisational knowledge, policy/community knowledge and research knowledge, as per the Social Care Institute for Excellence (SCIE) guidelines (Pawson et al. 2003). Pawson et al. (2003) write:

> … all these sources have a vital role to play in building up the social care evidence base, there being no hierarchy implied in the above list … it is important not to neglect sources of knowledge that are tacit, that currently lack prestige and seem less compelling (p. viii).

April 2017 – December 2019

After widening the search net to include internet-based search engines such as Google and Google Scholar, I began seeking grey literature from national deafblind organisation websites, including the Royal Institute of Deafblind Children (RIDBC), the Deaf Society NSW, Senses Australia, Able Australia and Better Hearing Australia, as well as international organisations including Sense UK, DeafBlind UK, Deafblind International, the Nordic Staff Training Centre for Deafblind Services (NUD), The World Federation of the Deafblind (WFDB), the American Association of the Deafblind (AADB) and the Helen Keller National Centre (Long Island, USA). Hand searching of government reports and government-sanctioned reports, support organisation materials, publications, and newsletters ensured that information providing insight into the hospital experiences of DBDSI adults was included.

Physically, the Renwick Library, RIDBC and the North Rocks branch of the RIDBC were searched throughout three days in April 2017, using a VisioBook reader and with the help of an accessibility assistant. I was unable to do a hand search of the library at Vision Australia's headquarters in Kooyong, because materials were not available; they were in the process of moving premises. One day in June 2017 was spent hand searching the small library holdings of the Deaf Society NSW at Parramatta, NSW. On another day in July 2017, I visited the Helen Keller National Centre, Long Island, USA, where I undertook a search and conducted interviews with key informants. These searches yielded book reviews (in impairment support organisation newsletters) for Audrey Revell’s memoir, which shared her daughter Janis’s life with DB. Also located in newsletters were publisher media releases and reviews of Dianne Chambers’ memoir of being an interpreter-teacher for Bert, an 84-year-old man with Usher syndrome. Stoffel’s (2012) collection of lived experiences of PWDBDSI was located in the RIDBC library search, as well as in newsletters from USA impairment support organisations. The Usher Coalition (a US-based Usher syndrome support and research organisation) posted reviews of *Walk in my shoes* (DeWitt 2016); however, this collection of personal stories from 27 people with Usher syndrome did not detail or reflect on hospitalisations, and so was excluded.

Several reports by Sense UK were found relevant and included: Sense UK (2013), Ellis, Keenan and Hodges (2015) and White (2014); some were excluded because they did not engage with hospital experiences, though they addressed healthcare access and communication issues. For example, the report by Ellis and Hodges (2013) examines the opinions of people with Usher syndrome, their experiences of diagnosis and subsequent life adjustments. There are many healthcare and diagnosis issues for this group, but these experiences tended to occur outside hospital.

To explore available memoir/autoethnographic/illness-disability narrative material, I searched the following to locate books or articles:

1. Amazon
2. iBooks
3. *The New York Times*
4. *The Guardian*
5. *The Times* (London)
6. Google.

In addition, Ellis and Hodges (2013) note, that prior to 2013, there was very little study or examples of lived-experience accounts from people with Usher syndrome or DB. Since then, the acquisition, accessibility and use of technology has grown, and PWD now document their experiences in books, blogs, articles, online discussion forums, Facebook and so on (Ellis & Hodges 2013). The present study adds lived experiences chronicled in books by patients with DBDSI; their parents/carers; or professionals providing therapy, observations and/or care to a PWDBDSI. Other personal lived-experience accounts were excluded because they did not contain hospital experiences, such as Silver's *Invisible* (2012) and Clark's *Where I stand* (2014). Similarly, Girma's *Haben: The Deafblind woman who conquered Harvard Law* (2019) was excluded; while documenting the complexities of life, higher education, work and advocacy for a young American woman with DB, it contains no chronicled hospital experiences. Much of the excluded lived-experience material on sensory impairments grapples with diagnostic delays and difficulties that occur outside hospital.

Ongoing research process

More material was located during the research process, through both wide reading and attending conferences. From a topic-relevance perspective, this resulted in two papers on cochlear implantation that contain commentary from patients themselves on the experiences of hospital for this surgical procedure; these are included. Two items by the same author had the same subject with similar, though not identical, content. One, intended for nurses about patients with DBDSI was retained; the other for community optometrists was not. While quantitative, a further study by Huddle et al. (2016) was included; it is a reference in another article on the community cost of DSI. This item speaks directly to the burden and cost of hospitalisations of PWDBDSI.

Attendance at the Usher Syndrome Connections Family conference in July 2017 enabled me to meet with Rebecca Alexander, a writer and therapist with Usher syndrome, and obtain her memoir, *Not fade away*. Alexander comments that while she includes substantial material on her prolonged hospitalisation, she edited it to be less harrowing for the reader (Alexander 2017, pers. comm., 19 July).

After attending the Deafblind International World Conference in 2019, I located a contemporaneous and relevant conference paper from Japan, detailing hospital experiences of Japanese adults and children with DB. Because this session was live transcribed, the presentation is also included in the review.

Subsequent search of literature post-data collection

In 2019, a repeat search of the literature, using the same strategy allowed for a recanvas of the same databases. This yielded two further articles: Nagai, Minami and Otomo (2015), which is in Japanese and not available as a full text—this has been requested from the authors for translation but has not been received to date (July 2020); and White (2014), which was previously located in the hand search of the RIDBC Renwick Library.

Database searches in 2017, 2019 (EBSCO, ProQuest, PubMed, Scopus).
Exclusion criteria applied: 1990–2017; 1990–2019; NOT child, children, youth, education, behaviour

n = 1546

Material located in research process 2017–2020

Wider social care literature (grey) conducted in 2017–2020 of material 1990–2020.
Identified through other sources (hand searches, online organisations, news media)
Exclusion criteria applied

Duplicates removed and exclusion criteria applied

Abstract (n = 2)

n = 5

n = 7

Literature after screening by reading abstract (n = 1)

Records excluded as unable to access (n = 1)

Items:
- Fernández-Valderas, Marcías-Seda & Gil-García (2017)

Items:
- Alexander & Alper (2014)
- Huddle et al. (2016)
- Mascia & Silver (1996)
- Soper (2006)
- Takahashi (2019)

Items:
- Ellis, Keenan & Hodges (2015)
- Chambers (2012)
- Revell (2006)
- Sense UK (2016)
- Stoffel (2012)
- Todd (2001)
- White (2014)

Items included in the review, 2020, n = 13
- Research knowledge, n = 6 (Ellis, Keenan & Hodges 2015; Fernández-Valderas, Marcías-Seda & Gil-García 2017; Huddle et al. 2016; Mascia & Silver 1996; Soper 2006; Takahashi 2019)
- User and carer knowledge, n = 4 (Alexander & Alper 2014; Chambers 2012; Revell 2006; Stoffel 2012)
- Policy/community knowledge, n = 2 (Sense UK 2016; White 2014)
- Practitioner knowledge, n = 1 (Todd 2001)
- Organisational knowledge, n = 0

Figure 1. Literature search flowchart

Inclusion/Exclusion

The inclusion criteria focuses on adults (over 18) with any combination or severity of dual sensory loss, whether congenital or acquired. Both peer- and non-peer-reviewed material were accepted as per the methodological focus of the expanded scoping review. The searches were nominally conducted from 1990 onwards.

The exclusion criteria focuses on removing literature about paediatrics, education and behavioural management, as well as literature with no relationship to hospital or healthcare. In all domains, much of the material pertains to single sensory impairment only, for example, *The point of vanishing: a memoir of two years in solitude* by Howard Axelrod (2015); and *Notes on blindness: a journey through the dark* by John Hull (2017). These were excluded in keeping with the distinct disability framing of DBDSI, along with all literature on single sensory impairment.

Material was also excluded if it considered disability as a homogenous category. An example is the NSW State Government report *Patient perspectives: exploring experiences of hospital care for people with disability* (October 2017). DSI was not one of the disability categories and its lengthy questionnaire form was not provided readily in accessible formats, so it is likely that patients with DSI were underrepresented in the report, if at all. Thus, it is not included in this review due to its lack of specificity and unclear representation of patients with DBDSI.

Search results

After the application of exclusion criteria, 13 source materials remained. These items contain lived experiences, observations of or substantive references to PWDBDSI in hospital. One quantitative article was included, Huddle et al. (2016), because it discusses hospitals and patients with DSI, and the associated costs and burdens.

The varied literature derives from the UK, USA, Japan and Spain; most originate from the UK and USA. No studies were located that examine hospital experiences of PWDBDSI in Australia specifically.

The searches reveal a small but growing international community, where technology and globalisation connect professionals, academics, researchers, students, organisations and consumers. However, hospital inpatient experiences remain understudied and poorly understood. Literature from impairment support organisations (e.g. newsletters and blog postings) abound with anecdotal accounts of difficult experiences but have not resulted in formal empirical studies of inpatient hospital narratives. Few personal narratives exist in any form. This demonstrates a substantial gap in the literature, which this research seeks to begin to fill.

Data extraction and analysis

With a similar population in a similar search situation, Simcock (2017b) sought for more relaxed appraisal criteria, preferencing relevance to the research question over the assessments of ‘quality’ and ‘rigour’ favoured by traditional guidelines for literature searches and appraisal. As Pawson et al. (2003) note:

> By placing all potential sources of knowledge side by side at the entry point to the social care literature, this approach sends a powerful message that all are of potential value. It does not privilege one type of evidence above another, but nor does it preclude the possibility of making quality judgements about particular pieces of evidence within each source (p. 26).

The literature included for analysis is diverse, with differing or absent definitions of DBDSI, and varying causation and age of onset, languages spoken and communication methods. The general lack of participant impairment information impeded meta-analysis.

Following Pawson et al. (2003), the source material classification system of the SCIE is utilised to categorise the 13 items included from the literature review. This system was chosen because it embraces the diversity of knowledge in a non-hierarchical way and offers a way forward to examine the limited material available to glean insights. The categories of Pawson et al. (2003) are defined below, and the flow chart (visual description provided in **Appendix 4**) provides the type and number of source materials in each. Social care knowledge is divided into five types:

1. **Organisational knowledge** Gained from management and governance of social care (n = 0).
2. **Practitioner knowledge** Gained from the conduct of social care (n = 2) (Chambers 2012; Todd 2001). Note, one source is a memoir by an interpreter-teacher about her student, so it falls into two source categories because it is also carer-testimony.
3. **Research knowledge** Gathered systematically with predetermined design (n = 6) (Ellis, Keenan & Hodges 2015; Fernández-Valderas, Macías-Seda & Gil-García 2017; Huddle et al. 2016; Mascia & Silver 1996; Soper 2006; Takahashi 2019).
4. **Policy community knowledge** Gained from wider policy environment (n = 2) (Sense UK 2016; White 2014).
5. **User and carer knowledge** Gained from experience of service use and reflection thereupon (n = 4) (Alexander & Alper 2014; Chambers 2012; Revell 2006; Stoffel 2012).

The purpose of the material is also assessed for this appraisal, using the following SCIE classification. I acknowledge that this fails to accord a value and category to user and carer accounts found in memoir, creative nonfiction and other lived-experience narrative types. These are, by necessity, included in the 'tacit wisdom' category. Material is divided into seven purposes:

- **Purpose 1** Assesses client needs, problems
- **Purpose 2** examines program and organisational improvement
- **Purpose 3** Emancipatory research that empowers users
- **Purpose 4** Research that relates to compliance, benchmarking, auditing and regulation
- **Purpose 5** Program research and evaluation; what works, how, when, where, who for and why
- **Purpose 6** Offers tacit wisdom or practical insights
- **Purpose 7** Tests social theory for building knowledge
(abridged from Pawson et al. 2003)

Each item's purpose was ascertained, along with the source type, location, description, purpose, population, impairment information (where provided) and limitations information, which are summarised in the table in **Appendix 3**. These appraisal criteria are similar to those utilised by Simcock (2017b) and advocated by Pawson et al. (2003).

Interrogating the literature gathered

This section first looks broadly at the included literature, before examining the lived experience and its impacts on the PWDBDSI, then how the health system responds to people with sensory disability. These factors are explored in the thematic analyses.

Broad observations about the literature

In the material gathered for analysis, there is no consensus on definitions or common terms observed. Limited information regarding participants is available; many items do not identify aetiology or age of onset of sensory loss. The user and carer testimonies are exceptions to this; these have rich, detailed accounts of lives and hospital experiences. Sample sizes are small, with single case studies and memoirs predominating (n=5). Parker, Davidson and Banda (2007) note that single case studies are a valid (and necessary) methodology in this population, because of the geographical spread and rarity of some subtypes of DBDSI. Bodsworth, Clare and Simblett (2011) note that the diverse communication methods used among the population and subpopulations further hinders recruitment. Possibly, communication support needs contribute to the scarcity of personal memoir material. The exception to the small sample sizes in this literature review is the sole quantitative study, with 291 recruits (Huddle et al. 2016); however, this contains no lived experience. There are few peer-reviewed articles (n = 3) and no meta-analyses (n = 0) or systematic reviews (n = 0). Initially, systematic reviews were found, covering vulnerability (Simcock 2017b), participation (Jaiswal et al. 2018) and DB (Dammeyer 2014). None address hospital experiences, however, and while they inform other sections of the doctorate (including health threats), they are not part of this review.

Generally, the canvassing and appraisal of the literature demonstrate the strong role of support organisations, particularly in the grey literature, where impairment support groups have commissioned reports into areas of concern and relevance to PWDBDSI, for example, Sense UK, whose reports include *Equal access to healthcare: the importance of accessible healthcare service for people who are deafblind* (Sense UK 2016); *The experiences of people with rare syndromes and sensory impairments in hospitals and clinics* (Ellis, Keenan & Hodges 2015); and *What does good care look like for a deafblind person* (White 2014).

Included are three personal testimonies, which cover three different perspectives: a person with Usher syndrome (Alexander & Alper 2014); a professional sign-language teacher's memoir and practice insights from her time with Bert, an older man with Usher syndrome (Chambers 2012); and the recollections of a mother-carer about her daughter with DB (Revell 2006).

Scott Stoffel's edited book of lived experiences, *Deafblind Reality* (2012), includes a chapter devoted to experiences in hospitals and healthcare settings, ominously titled 'Bad Medicine'. There are seven contributors, predominantly from the USA, with one each from the UK and New Zealand.

One important feature of the material gathered is that most of the lived-experience contributors have congenital DB, rare syndromes or Usher syndrome (Alexander & Alper 2014; Chambers 2012; Ellis, Keenan & Hodges 2015; Fernández-Valderas, Macías-Seda & Gil-García 2017; Revell 2006). The survey respondents in Huddle et al. (2016) were older Americans with dual sensory loss. This review, therefore, contains no qualitative studies or narrative recollections of the older age group's lived experience. In some items, participant information is unclear, such as Takahashi (2019), but it is likely that the lived experiences of the over 65s is largely absent from this material.

Thematic analysis

Notwithstanding the limited scholarly material on the lived experiences of hospital by PWDBDSI, the 13 items that offer some or partial relevance to the topic at hand are mined for insights and common themes. Reading, rereading and analysis of the literature allows for the discernment of some recurring themes within each source. Such cyclical analysis is an iterative and recursive process (Leech & Onwuegbuzie 2008a). In other words, researchers can repeatedly examine the qualitative literature, and so be open to unexpected findings. The themes generated by this interrogation of the topic-specific literature are considered individually below.

Difficult spaces

Sense UK (2016) found that hospitals are 'very challenging to navigate for people who are deafblind' (p. 24). 'Help me more,' says a respondent with DB in Takahashi (2019); this is a common exhortation in the lived-experience literature, as well as within impairment support material. Hospitals are seen as hostile spaces, which need more help and understanding for information access about their condition/s, communication support in encounters with staff in all the varied hospital spaces, and orientation to hospital and room geography for safer mobility (Alexander & Alper 2014; Ellis, Keenan & Hodges 2015; Fernández-Valderas, Macías-Seda & Gil-García 2017; Revell 2006; Sense UK 2016; Stoffel 2012; Takahashi 2019).

Physical spaces are problematic, with Sense UK (2016); Fernández-Valderas, Macías-Seda and Gil-García (2017); Stoffel (2012); White (2014) and Takahashi (2019) all describing barriers to orientation and mobility. Physical barriers are not the only hurdles for patients with sensory losses. In Stoffel (2012), a contributor, Carol, writes:

> When I pressed the button to go to the loo [toilet], nobody responded. Oh, I was all worked up. I just kept saying under my breath, 'Where the bloody hell is the nurse?' But nobody would come and help this blind patient. After a while, I was so desperate for a wee. So in the end, I had to grope for my cane, eventually found it, and felt for the sides of beds. Oh, I was so embarrassed, as I could feel everybody was staring at me. One woman just shouted, 'It's up there!' I thought to myself, 'How the hell do I know what you mean?' She was probably pointing; that's real useful for a blind person. Then she just shouted, 'Hey, love, you're going the wrong way.' Then she shouted, 'No! Left a bit! No! More!' I was getting more and more frustrated. But I finally found the toilet without banging my head on the door. I just slammed

> the door and would've thought a nurse would have ran to me, but no. So, anyway, when I came out of toilet, I tried to remember the way back to my bed, tapping other people's beds with my cane. Suddenly, it was silent. Oh, it felt terrible, but I eventually got there. But I can't believe there wasn't a single nurse there that could spare a minute to help me (Carol O'Connor, cited in Stoffel 2012, pp. 110–111).

The above demonstrates the risk of harm and dehumanising effect of neglecting the special needs of patients with DBDSI, when accommodations are not made, barriers to accessibly are present and helpful staff are absent.

Participants in Takahashi (2019) wish for a hospital with staff 'who understand DB' and who promote communication by 'speaking slowly, clearly and loudly'. Notably, the cochlear implantation articles demonstrate that a specialist procedure for a sensory impaired patient can be beneficial when performed in an informed and accommodating environment (Mascia & Silver 1996; Soper 2006).

However, informed consent remains contentious, with almost all hospitals represented across the literature failing to provide forms in accessible-to-the-individual-patient formats. Alexander and Alper (2014) write of the tragi-comic experience of CI marketing materials, with a 10-page inaccessible questionnaire: 'to add insult to injury, the questionnaire was in very small print. Awesome' (pp. 254, 309).

Throughout various healthcare spaces, not providing material in accessible formats is a grievance for PWDBDSI, because so much is in written format. In Sense UK's 2016 report, *Equal access to healthcare*, one participant notes: 'At the moment someone has to read letters [from the hospital] out to me. This is not OK as it should be private and confidential' (p. 14). In Ellis, Keenan and Hodges (2015), the participants report similar experiences. The case study of Stephen, in White (2014), highlights the benefits of large-print medication instructions, which he could follow and understand: 'Stephen felt well informed about his health and empowered to manage his aftercare independently and effectively' (p. 7).

An important finding from the literature is that there seems to be little progress over time; hospitals are suspended in bubbles insulated from the need of the PWDBDSI around them, and the legal, moral and policy frameworks are impenetrable. Barriers to accessing information, communication and mobility remain in the UK, as evidenced from Todd (2001) to Sense UK (2016). The research from Spain, the USA and Japan support the view that excluding patients with DBDSI in healthcare and hospitals may be a global issue. These countries have safeguards in place and are signatories to conventions, yet compliance and enforcement is either lax or non-existent.

In Ellis, Keenan and Hodges (2015), the difficult spaces of outpatient hospitals are identified as follows: making appointments, getting referrals, contacting the clinic, travelling to the clinic, being at the hospital or clinic, and during the consultation and afterwards. Ellis, Keenan and Hodges

(2015) record undertaking some accompanied hospital clinic visits to note what transpires with patients in situ, rather than relying solely on patient and carer recollections. This allowed the study:

> … to gain as real a sense as possible of the patient experience, of the individual difficulties faced by some participants during their hospital visits, and of their needs as sensory impaired people within the hospital environment, and how these were addressed (Ellis, Keenan & Hodges 2015, p. 51).

While they weren't intimate inpatient experiences, they do demonstrate partial, real-time yet short-term interactions with hospital environments, staff and accessibility.

Problems and solutions

While there are no appreciative inquiry-type questions in Takahashi (2019), he clearly states that his research's purpose is 'for [the healthcare system in Japan] … to hear this problem'. Likewise, Stoffel's (2012) contributors offer their lived experiences for readers to understand their problems, but there is no analysis or salutogenesis. Stoffel (2012) foregrounds his 'Bad Medicine' chapter-catalogue of disasters, writing: 'The lack of communication can be damaging, both mentally and physically, yet few people seem to understand' (p. 103).

This lack of understanding by healthcare staff lies at the heart of most articles; many are a bid, explicit or implicit, for healthcare or hospital staff to empathise. As one respondent asked in Takahashi (2019), 'Can the staff at this hospital understand deafblindness?'

Most of the sourced material demonstrates the professional, institutional and societal failures to understand the position and needs of PWDBDSI. Todd (2001) comments that the 2004 Sense UK report, *Who cares? Access to healthcare for Deafblind people*, about healthcare experiences in the UK, notes a principal difference between outpatient and inpatient experiences. While patients usually attended outpatient clinics with an interpreter or support person (for example, a worker, family or friend), as an inpatient, nursing staff needed to know how to communicate with the patient's particular set of impairments and communication methods, because support people are not always available. Stoffel (2012) notes that even family support is not always reliable: '... some doctors—and even family members—fail to take the time to communicate medical issues with deaf-blind patients' (p. 103). Commonly, it seems, there is a lack of forethought in booking and providing interpreter support when needed by PWDBDSI. Sense UK (2016) notes: 'Poor or inadequate communication, such as an interpreter not being provided, can lead to missed opportunities for care, misunderstanding of needs, inappropriate pressure on family members, loss of privacy and more' (p. 4). White (2014) reinforces that all health services and hospitals should book interpreters proactively for deafblind people.

Impact of staff knowledge

While no material specifically addresses staff attitudes, the general ignorance of staff about DBDSI is widely described, which further demonstrates how difficult hospital and clinic spaces are for PWDBDSI (Alexander & Alper 2014; Chambers 2012; Fernández-Valderas, Macías-Seda & Gil-García 2017; Revell 2006; Sense UK 2016; Takahashi 2019; Todd 2001). The clear exceptions to this are the two papers on CI (Mascia & Silver 1996; Soper 2006); this surgery takes place in units where staff are familiar with DBDSI. These papers demonstrate the general long-term benefits of CI for improving communication, understanding, wellbeing and social participation (Mascia & Silver 1996; Soper 2006). Alexander (Alexander & Alper 2014) affirms this position, realising that her CI is the way for her to maintain social engagement and communication. The example of Stephen in White (2014) also illustrates that positive experiences are possible with education and embedded positive practices. Stephen takes care to record his communication needs, orientation to the ward and his bay, accommodations in theatre and recovery, and handover of his communication needs at every shift; he also goes home with large-print instruction sheets, which are accessible to him (White 2014).

Fernández-Valderas, Macías-Seda and Gil-García (2017) is a solutions-focused work, which asks appreciative inquiry-style questions in a semi-structured interview form. For example, question 4 reads: ‘Can you think of something to improve the situation?’ Participants’ responses include asking for more interpreter support, better signage and for staff to try to understand people with DB.

Practitioner papers, memoirs and research commissioned by impairment support organisations both illustrate problems and focus on solutions. The common chorus is for more help and understanding. The 2016 Sense UK report notes that, when talking to deafblind people about their experiences:

> … [it is] apparent that small adjustments to practice or a wider understanding of their needs would make all the difference. Most of the challenges that deafblind people face are about a lack of awareness of their needs and how best to meet them (p. 9).

The report goes on to summarise the UK’s National Health Service *Accessible information standard* for healthcare services and staff, as follows.

1. Identify the communication and information needs of those who use their service.
2. Record the communication and information needs they have identified clearly and consistently on the individual’s record. They should record someone’s needs, not why they have those needs; that is, ‘requires BSL interpreter’ (British sign language) not ‘person is d/Deaf’.
3. Have a consistent flagging system so that if a member of staff opens an individual’s record, they can immediately check whether the person has a communication or information need.
4. Share the identified information and communication needs of individuals when appropriate. For example, a GP referring a patient to the hospital should include whether the person needs a

deafblind manual interpreter in the referral letter, so that the hospital can arrange one for their upcoming appointment.

5. Meet the identified communication and information needs. For example, send an appointment letter in braille or book an interpreter for an appointment (Sense UK 2016, p. 28).

Distress

Providing good care to PWDBDSI means understanding that there is no one-size-fits-all communication method and that many PWDBDSI do not understand the whys and wherefores of their healthcare (Todd 2001). This can cause distress over and above the anxiety of their concomitant illness experience. An informant to the 2016 Sense UK report notes:

> Hearing and sighted people are passive recipients of information all the time, but deafblind people are not and we have to rely on others to decide if information is important or not … The key thing is that I do not know what information is out there … I do not know what I have missed out on (p. 14).

The lack of understanding and rising psycho-emotional distress is strongly wed to the information deficit: ‘I felt strong anxiety during hospitalisation because I couldn’t get any information’ says one of Takahashi’s participants (2019). The emotional aspects of hospital experiences are also found in the user/carer testimonies; Sense UK (2016) describes that some patients are so distressed by previous experiences and communication failures that they delay or do not seek help for later health issues. Revell (2006) tells the story about the (mis)treatment of her daughter, Janis, during a psychiatric admission, painting a disturbing picture of the treatment of PWDBDSI in psychiatric hospitals. Similarly, Stoffel (2012), Sense UK (2016), and Ellis, Keenan and Hodges (2015) all discuss the emotional fallout of treatment and loss of trust in health systems and professionals. Stoffel’s contributors detail an array of psychological and physical traumas associated with being ill in hospital, as Patricia describes:

> The worst aspect was the doctors’ lack of concern for me as a person and their total rejection when they found they could do nothing for me. It seemed like they just wanted to get rid of me the moment it was clear something hadn’t worked. They never made any effort to console me or consider how the failure affected me psychologically. It was just, ‘Well, this didn’t work. Good-bye.’ I felt I had been conned and never really trusted a doctor ever again. I lost hope for the future (2012, p. 116).

Conversely, the research from Spain (Fernández-Valderas, Macías-Seda & Gil-García 2017) specifically asks the question: ‘Do you feel safe?’ Most respondents said yes, they did, despite describing difficulties with access, communication and the environment (Fernández-Valderas, Macías-Seda & Gil-García 2017). This appears to contradict the lived experiences in Stoffel (2012), as well as the memoir material and Sense UK–commissioned reports. Anecdotally, PWDBDSI report dissonance, where there is a paradoxical tension between what safe means and the reality of their experiences—a contradiction as it were. Thus, feeling safe may in fact mean ‘I survived’, rather than ‘I was never put at risk’. From this examination of diverse materials and methodologies, however, it is not possible to explain or explore this dissonance.

Restrictive practices

The Royal Commission into Aged Care Quality and Safety's 2019 interim report on neglect states that restrictive practices are 'activities or interventions, either physical or pharmacological, that have the effect of restricting a person's free movement or ability to make decisions' (Royal Commission into Aged Care Quality and Safety 2019, p. 194). The varied literature details examples of such practices, even in children. The parent of a child with DB in Takahashi (2019) pleads, 'don't tie deafblind child to the bed'. Revell (2006) also describes restrictive practices, misattributions and neglect in psychiatric hospitals. The author chronicles a lengthy list of restraint, sedation and punitive practices, and failure to provide communication support; during her final hospitalisation before her death, from disputed causes, Janis endured almost daily neglect of her DB, which played a role in the mediating perceptions of and misattributions by staff (Revell 2006). Janis's mother, Audrey Revell, writes:

> In my research I discovered that a young man in the USA had died because of isolation and restraint while in a mental health hospital. He was also deafblind. People had fought for him and brought about changes in the law to outlaw isolation or restraint. And yet I saw first-hand that [restraint and isolation] … was used on my daughter. Isolated in her room until she stopped screaming and restrained by injection. It was the most appalling time of her life and mine. In my opinion she died without dignity or respect (Revell 2006, p. 1049).

Stoffel's (2012) contributors also describe restrictive practices in hospitals:

> At the hospital, they did many different types of tests, including a horrible spinal tap. My obese husband forced me onto my side and practically laid on me to keep me still, while his sister held down my legs. No one made any attempt to let me know what was coming; they just treated me the way a veterinarian might treat a dog. I was so scared and kept struggling because they were so rough. I think they could have made some effort through gentle touch gestures, like letting me feel an empty syringe with no needle and then poking me in the back with a finger, to let me know what was basically going to happen. I still have nightmares about that incident (Angela C. Orlando, cited in Stoffel 2012, pp. 105–6).

If appropriate communication support is provided, these practices are unnecessary. White (2014) affirms that no procedure should be performed on a deafblind person without their consent and without a full explanation.

(Lack of) communication support

Audrey Revell (2006) writes of her relief at being able to accompany her daughter all the way to the operating theatre, and to sign into her hand what was happening; however, she was not allowed into the recovery room, where the experience was different. She writes: '[Janis] heard them trying to tell her something and had thought they were trying to tell her to go to sleep; in fact, they had been trying to wake her up' (Revell 2006, pp. 686–7).

Alexander (Alexander & Alper 2014) writes of waking from her cochlear implantation panicky and confused; staff eventually agree to fetch her friend Carolyn: 'I grabbed her hand, relief coursing through me' (p. 2684). Having a communication partner in the recovery room clearly alleviates anxiety and distress, and sometimes, having communication partners saves lives. In Chambers (2012), Bert 'plummeted down' (p. 1331/3904) the stairs, sustaining a fracture to the first cervical vertebra. Chambers (2012) writes: 'if he had moved his head, he could have severed the nerves that control his breathing. Fortunately, Mary had thought to communicate the critical word *stop* to him [in American Sign Language/ASL]' (p. 1332/3904). This reinforces the value of having family as communication partners, even where the learning is recent (Bert and his family had only been receiving instruction in ASL for a short time). As a result, everyone had to be creative about communication, because sign language alone was not enough; therapists modelled his exercises by moving his arms and legs in the directions needed, or by demonstrating on themselves. Staff were asked to use the Powerbrailler and take time when communicating. Bert was in hospital for four weeks; eventually, the hospital arranged for Chambers (the author and his teacher) to attend most mornings, which 'eased John and Mary's anxieties' (Chambers 2012, p. 1368/3904). Yet staff adherence was patchy, as Chambers (2012) writes:

> … sometimes Bert asked me questions … he wanted to know more but was embarrassed to ask too many questions. People often didn't take the time to explain everything to him. They didn't understand that he was missing out on so much important information. They didn't know what it felt like to be trapped in a halo [metal head brace] in darkness and silence (p. 1416/3904).

Bert finds comfort in the dark times when his son and daughter-in-law visit, because they are learning to sign, and also when his sign-language teacher visits. Bert says to her: 'When you sign to me, I can hear the words in my head like you are talking to me' (Bert, cited in Chambers 2012, p. 2931/3904), illustrating the need for staff at all levels to be aware of patients' communication needs and take the time to provide support. In her advice for nurses, Todd (2001) also emphasises this, noting that the diversity of impairments and communication methods means that every patient must be approached individually.

The lack of interpreters disables positive communication. In much of the literature, the patchy, unreliable presence of interpreters in hospitals—often needed, but rarely arranged by staff—features prominently (Alexander & Alper 2014; Ellis, Keenan & Hodges 2015; Revell 2006; Sense UK 2016; Stoffel 2012; Takahashi 2019).

Despite the lack of consent forms in an accessible format, hospital experiences for CI are generally more favourable than others (Mascia & Silver 1996; Soper 2006). For nearly all participants in the two academic articles, as well as for Alexander (Alexander & Alper 2014), CI had the advantage of enabling communication in the longer term. Alexander has a later post-operative insight: after a difficult time in the recovery room with no aids, no hearing in one ear and no interpreter, she writes:

> I understood what a gift this implant was and what it was saving me from … because I saw a flash of what my life could have been like, completely blind and deaf and walled off from the world, having

> absolutely no real way to communicate (Alexander & Alper 2014, p. 268/309).

Burdens and costs

One quantitative paper, Huddle et al. (2016), demonstrates a strong association between DSI, hospitalisation and burden of disease. The study involved 1669 people, of whom 291 were adults more than 70 years old with DSI. This was the only large study found that relates to both hospital and DSI. While it contains no lived experience or co-creation, it was included because it is the only paper linking DSI and hospitals to poorer outcomes and costs to the system. Because it is based on a self-report questionnaire, the results are likely underestimated, both in prevalence of DSI and burden of disease.

The burden of hospitalisation is also demonstrated in the lived-experience accounts of Alexander and Alper (2014), Chambers (2012) and Revell (2006), where the risk and reality of falls and accidents is prominent. These relate to the loss of environmental cues and warning signals directly due to sensory loss. Alexander and Alper (2014) describes a horrific fall from a third-storey window, with a subsequent long rehabilitation stint. Similarly, Bert in Chambers' (2012) professional memoir, suffers a spinal fracture from a fall, requiring a lengthy rehabilitative hospital stay. Janis Revell has repeated falls and head injuries during her last hospitalisation, which culminates in her death (Revell 2006). This demonstrates that falls and injuries occur in hospitals, not just in the home and wider community. As well as the pain, distress and burden of further disability to patients, falls and accidents consume vast healthcare dollars. One participant in Soper (2006) attributes their new CI as reducing the risk of falls and accidents. The CI enhanced their environmental awareness and improved personal safety. Soper (2006) writes: 'Harry was satisfied that his ability to detect environmental sounds had improved his quality of life as he can now hear loud noises such as traffic noise as well as his telephone and doorbell ringing' (p. 24).

Liminal spaces

Ellis, Keenan and Hodges (2015) write that, while there is much health and social science literature about the 'patient experience', the same cannot be said of the patient-with-DBDSI experience. This review of the literature confirms their observation. There is a liminal space, or a threshold, where what we know is so very incomplete.

There is a marked absence of research interest in chronicling and examining the inpatient hospital experiences of PWDBDSI. There is also little that is salutogenic and focused on the enablers of positive hospital experiences by the expert-knowers themselves. In particular, there is an absence of literature from the Australian perspective. Alarmingly, there is little in the research literature that focuses on the personal hospital experiences of older as well as younger people with DSI. There is a void of these voices.

Conclusion

This chapter outlines the literature search process, demonstrating the need to encompass the wider social care literature as well as scholarly material. While meagre, the amalgamated articles in this literature review demonstrate the problems of the hospital experiences of PWDBDSI and, occasionally, posit solutions. Key themes that emerge are that hospitals are difficult spaces; lack of communication support compromises patients; there are many problems, though also salutogenesis, in action with solutions; patients are subdued with restrictive practices (instead of effective communication); there are significant burdens and costs of having DBDSI and being hospitalised; and, most prominently, there are large liminal lacunae in what we know.

Alexander and Alper (2014) write that ‘communication is a need. We are a storytelling people and need to tell others our stories’ (p. 93). Ultimately, this literature review shows that, without communication support and understanding, the stories of what happens to patients with DBDSI in hospital cannot and will not be heard. This research is positioned to provide the supports necessary to elicit testimonies, which add to the knowledge outlined above.

While the research question–specific literature is scant on lived experiences, the wider DBDSI literature has much to say on the risks that sensory impairments pose to the health and wellbeing of PWDBDSI. **Chapter 5**, which follows, explores these to show the reach of the threats and the ways research and impairment support communities seek to document them.

Chapter 5

Externalising the literature: Threats to the health and wellbeing of PWDBDSI

Introduction

The previous chapter demonstrates the scant canon of literature, in all health and social care types, on the in-hospital experiences of patients with DBDSI. External to this topic-specific literature is an abundance of material on the health and wellbeing threats posed to the individual resulting from co-occurring sensory losses. These risks are superimposed with the ills and woes of 'normal' life; they need consideration because they signify the additional health and wellbeing burdens that increase the risk of healthcare attendance and hospitalisations, which justify this research. As demonstrated in the topic-specific literature review, physically being in hospital further jeopardises health and wellbeing. Threats within the hospital include difficult spaces, psycho-emotional distress, whether or not solutions-focused, (lack of) communication support, restrictive practices and low levels of awareness.

These threats have an impact beyond the individual, as demonstrated by Huddle et al. (2016), who write about economic costs and burdens of hospitalisations: 'Addressing sensory impairments could have substantial implications for public health given that these impairments are highly prevalent, undertreated, and amenable to treatment with established, low- to no-risk rehabilitative interventions' (p. 1736).

There is also the health burden of Vehmas and Watson's (2014) 'insurmountable realities' (p. 27), which is accretive for PWDBDSI. As Wasserman et al. (2016) note:

> … disability reduces well-being, it is because of the stigma and discrimination it evokes. In contrast, other philosophers claim that disability is fundamentally different from race and gender in that it necessarily reduces well-being: even in a utopian world of non-discrimination, people with blindness, deafness or paraplegia would be worse off than their able-bodied counterparts.

The wider literature is littered with material on the external threats to the health and wellbeing of PWDBDSI. To paraphrase Franks (2009), what makes an illness with disability different, is that disability threatens in addition to the illness.

What follows is a compendium of health threat literature, which was identified in the research process and through reading widely. This is not, therefore, a systematic or formal literature review; it exists to demonstrate the multitude of existent material on these threats, in stark contrast to the absence of knowledge about hospital encounters. These accumulative threats fall into the following broad categories: general, including physical and public health threats; threats arising from communication failures; psychological and cognitive wellbeing threats; threats arising from the social determinants of wellbeing; and, finally, gender-based threats. Generally, in this population, intersectionality is poorly understood and rarely documented. Research of Indigeneity and the ‘double disadvantage’ of disability and racism is beginning, such as in the work of Avery (2018). Yet, because little is known about the experiences of Indigenous people with DBDSI, this population cannot be examined appropriately here.

In the following section, the five groupings of health threats are considered individually, with a list of examples from the literature within each category.

General and public health threats

Increased poor health parameters predispose PWDBDSI to more frequent hospitalisations than those with no sensory loss (Brennan 2003) or a single impairment (Huddle et al. 2016). People with sensory impairments generally experience greater rates of poor health and face varied risks from the environment, falls and public health failures (Berghs et al. 2016; Brennan & Bally 2007; Möller 2005). PWDBDSI are also subject to co-occurring threats to their physical and mental health and wellbeing from normal life, just as sighted-hearing people are. These include reproductive health issues, carer stress, mental illness and relationship issues (Ellis & Hodges 2013). Comorbidities and co-occurring other disabilities may further compromise health. Between 20 and 75 percent of people with DB have other impairments that may reduce wellbeing and quality of life (World Federation of the Deafblind 2018). DB may also be part of a syndrome that clusters several impairments and effects together, which decrease health and increase risk. For example, Usher syndrome 1 includes a balance disorder that increases the risk of falls; rubella syndrome and Usher syndrome have increased rates of cataract formation, which compromise residual sight and increase environmental risk, as well as needing surgical removal; and extreme prematurity/very low birth weight and/or birth asphyxia may have multiple non-syndromal impairments, which creates complexity and additional health concerns (Dammeyer 2012; Glass et al. 2015; World Federation of the Deafblind 2018).

Health and wellbeing of PWDBDSI is understood inadequately, as caused by, for example, the fragmentation of service delivery. This means that healthcare is focused on a single impairment rather than the multiple complexities and needs of co-occurring impairments (Gopinath 2019; Möller et al. 2009; Schneider et al. 2011; Wahlqvist et al. 2016).

Generally, people with disabilities are poorly served by public health research and practices (Berghs et al. 2016). As a specific subpopulation, those with sensory impairments have reduced access to alerts and information, which confers risk. For example, if they do not see a poster advertising flu season, they may not receive a potentially protective influenza vaccination; communication issues are a health and wellbeing threat in this population and hamper public health messaging and uptake.

The current COVID-19 pandemic is bringing to light heightened public health risks, with reports of the following difficulties:

- Reliance on sighted-hearing communication modes excludes those who use tactile communication methods. Compliance with public health directives require that this information is received in the first instance.
- Evaporation of community services threatens health and wellbeing by removing face-to-face communication, formal and informal welfare checks, and services PWDBDSI may depend on.
- Absence of infection control protocols and personal protective equipment guidance and training, meaning that tactile and hand-over-hand interpreters and their clients with DBDSI are unclear on navigating social distancing with tactile and face-to-face communication. This also deprives some PWDBDSI of access to public health messaging.

These deficiencies are effectively a ‘closed door’, resulting in both ignorance of messaging and increased social isolation. Both present additional risks to physical and mental health (Watharow 2020b).

List 4. General and public health threats

- *Lower health, quality of life and overall wellbeing* (Lehane et al. 2017; Lehane et al. 2018; McMahon et al. 2017; Tay et al. 2006).
- *Evidence suggests that hearing loss decreases an individual’s ability to self-manage chronic conditions and seek effective treatment* (House of Representatives Standing Committee on Health, Aged Care and Sport 2017).
- *‘Hearing impairment (HI) and vision impairment (VI) in older adults are independently associated with negative health outcomes, including physical disability, cognitive decline, hospitalisation, and mortality.’* (Huddle et al., 2016, p. 1735).
- *Public health campaigns do not reach the sensory impaired because they are not available in alternative accessible formats, e.g. health promotion and prevention campaigns on immunisation, non-communicable diseases and HIV are often inaccessible* (Berghs et al. 2016; House of Representatives Standing Committee on Health, Aged Care and Sport 2017; Möller 2005; World Federation of the Deafblind 2018).
- *Poorer self-rated health in the deafblind populations of the USA and Japan* (Crews & Campbell 2004; Harada et al. 2008; McDonnall et al. 2016).
- *PWDBDSI are at risk of developing the same illnesses and impairments as the nonimpaired population, e.g. those that come with advanced age* (Abley, Bond & Robinson 2011; Ellis & Hodges 2013; Simcock 2017a, 2017b).
- *Older people with vision loss are more likely to have hearing loss, raising the possibility of a shared biological marker* (Chia et al. 2006).
- *Poor early identification, and therefore delayed intervention, due to medical professionals’ lack of knowledge about DB. This is particularly seen in children* (World Federation of the Deafblind 2018).
- *Frequent misattribution of symptoms and misdiagnosis* (Campbell et al. 1999; Erber & Scherer 1999; Miner 1997; Möller 2003; Simcock 2017b; Swanson 2007; Wickham 2011).

- *Patients frequently are not communicated with, given uninformed treatment and have unnecessarily long hospital stays* (Huddle et al. 2016; Möller 2003; Swanson 2007).
- *DSI in the over 70s is associated with increased hospital admission, length of stay in hospital and burden of disease* (Huddle et al. 2016).
- *Increased incidence of additional impairments/comorbidities, e.g. 86% of children with DB in Montreal, Canada had additional disabilities* (Brennan 2005; Dammeyer 2014; Ellis & Hodges 2013; Simcock 2017a; Wittich, Watanabe & Gagné 2012; World Federation of the Deafblind 2018).
- *Increased mortality rates compared to nonimpaired population* (Gopinath et al. 2013; Lam et al. 2006; Wahlqvist et al. 2016; World Federation of the Deafblind 2018).
- *Increased mortality odds ratio for death:*
    - *3:4 for DSI*
    - *2:6 for visual impaired*
    - *2:0 for hearing impaired* (La Forge 1992).
- *Increased risk of falls, accidents and premature death* (Australian Institute of Health and Welfare 2018e; Brennan 2003; Brennan & Bally 2007; Campbell et al. 1999; Desai et al. 2001; Gopinath 2019; La Forge, Spector & Sternberg 1992; Lupsakko et al. 2002; McMahon et al. 2017; Rogers & Langa 2010).
- *Increased risk of functional decline* (La Forge, Spector & Sternberg 1992).
- *Increased risk of fractures; this is especially true in Usher 1 due to vestibular damage* (Australian Institute of Health and Welfare 2018e; Möller 2008).
- *Increased risk of experiencing violence. In a study of 21 individuals with Usher 3, 'being violated or disrespected was reported by 8 persons, and two persons had experienced physical violence'* (Wahlqvist et al. 2016, p. 248).
- *Higher risk of traffic accidents, both as pedestrians and drivers. This risk heightens with the age of the individual with DB* (McMahon et al. 2017; Möller 2005).
- *PWDBDSI are at higher risk of preventable accidents due to lower safety and security because of being 'unable to hear alarms, smoke detectors, sirens, fast moving vehicles, and other traffic noises'* (Tiwana, Benbow & Kingston 2016, p. 205).
- *Increased visits to hospital and physicians* (Brennan 2003; Ellis & Hodges 2013).
- *Studies show that 'healthcare providers tend to focus on a single impairment', which can result in 'fragmented' healthcare in which the complexity of DSI is not considered or addressed* (Möller et al. 2009; Schneider et al. 2011; Wahlqvist et al. 2016, p. 250).
- *Sensory impairments are 'highly prevalent, undertreated, and amenable to treatment with established, low- to no-risk rehabilitative interventions', meaning direct implications for public health if they are addressed* (Huddle et al. 2016, p. 1736).
- *Hearing impairment alone increased risk:*
    - *1.5 times more likely to have been hospitalised in past 12 months*
    - *3 times more visits to GPs*
    - *3 times more likely to need a prescription*
    - *4 times more likely to require home support services* (House of Representatives Standing Committee on Health, Aged Care and Sport 2017).
- *In this study, 94% of DBDSI population 'wanted more formal support'* (Bodsworth, Clare & Simblett 2011, p. 14).
- *Increased experience of headaches and tiredness* (Wahlqvist et al. 2016).
- *In Usher syndrome, 'retinal degeneration leads to contrast sensitivity, light sensitivity, night blindness, visual field limitations, impaired visual acuity, and cataracts'* (Wahlqvist et al. 2016, p. 246).

- *As remediation, CI is an invasive procedure that requires general anaesthetic and surgery, and includes risk of adverse events* (Gheorghe & Zamfir-Chiru-Anton 2015).
- *Cataracts are associated with the retinitis pigmentosa of Usher syndrome* (Boughman, Vernon & Shaver 1983; Wahlqvist et al. 2013).
- *Increased instance of headache and fatigue in a Swedish Usher syndrome population* (Wahlqvist et al. 2013).
- *Chain of consequences sees poor food preparation and hygiene issues, resulting in illness* (Möller 2005).
- *Limitations during activities of daily living* (McMahon et al. 2017).
- *Research found that 'one in four deafblind people have done without essentials such as medicine' due to difficulty of access* (Benson 2004, p. 35).

Communication threats

> Nurse: 'They think you have got gout'
> Patient (hard of hearing): 'They're going to kick me out?' (Slade et al. 2008, p. 282)

Communication failures have potential negative consequences for the health and wellbeing of PWDBDSI. Underpinning nearly all patient complaints about healthcare in Australia is communication failure (Slade et al. 2008, 2015). Citing a report by NSW Health (2005), Slade et al. (2008), state that most adverse events in hospitals are caused by 'poor and inadequate communication' (p. 271).

Poor communication experiences in hospitals have ongoing consequences. A study of sensory impaired Australians report that 'communication breakdown produces negative feelings' (Heine & Browning 2004, p. 121). Research on deaf women in the USA finds:

> Negative experiences and avoidance or non-use of health services were reported, largely due to the lack of a common language with healthcare providers. Insensitive behaviours were also described. Positive experiences and increased access to health information were reported with practitioners who used qualified interpreters. Providers who demonstrated minimal signing skills, a willingness to use paper and pen, and sensitivity to improving communication were appreciated (Steinberg et al. 2002).

A UK study, asking what 'good' looks like, found that the most significant factor in positive patient experience is communication (Cunnett 2010). Canadian researchers examined adverse events across 20 hospitals in Quebec, to determine whether communication failures leading to negative events were higher in patients with communication problems, including dual sensory loss (Bartlett et al. 2008). Their results note that communication barriers, deafness and blindness added considerably to the risk of adverse events in hospitals, noting that their findings are 'conservative' (Bartlett et al. 2008, p. 1561). Further, they write: 'Interventions to reduce the risk for these patients need to be developed and evaluated' (Bartlett et al. 2008, p. 1555). British researchers had similar findings (Steinberg et al. 2002).

Sense UK (2013) posits that poor communication experiences traumatise many deafblind patients, so they often delay seeking treatment in the future. Health services fail deafblind people; it has been reported that:

- 3/4 could not make themselves understood by health professionals
- 1/2 had procedures they did not comprehend
- 1/6 avoided seeking medical advice because of previous poor communication experiences (Sense UK 2013).

Good communication confers benefit and mitigates risk. Viable communication is essential when dealing with public health crises, emergencies, healthcare and decision-making. Patients seeking help require effective communication encounters, because they must answer a large number of questions from various staff, and clinicians need to convey significant information about differential diagnoses, tests required and treatments to them (Slade et al. 2008, 2015).

Research demonstrates that, in healthcare settings, effective communication results in:

- shorter lengths of stay
- fewer hospital readmissions
- reduced emergency room visits
- greater compliance with treatment plans
- adherence to follow-up
- less unnecessary diagnostic testing
- improved healthcare outcomes overall (Slade et al. 2008, 2015).

These benefits are lost if care and time are not taken to accommodate the person-specific communication needs of patients with sensory losses. It must be emphasised that the responsibility for communication resides with the clinicians and not with the patient who is sick. As Hersh (2013a) stresses:

> In the literature, there has been a tendency to consider the communication problems to be purely a consequence of the Deafblind person's impairments rather than the attitudinal and infrastructural accessibility barriers and other people's lack of knowledge about communicating with them (p. 460).

List 5. Communication threats

- *Difficulty communicating results in lack of information, difficult relationships, increased health issues and isolation, and decreased wellbeing* (Bodsworth, Clare & Simblett 2011; Dammeyer 2014; Figueiredo, Chiari & Goulart 2013; Hersh 2013a; Möller 2005).
- *Lack of accessible information about proposed treatment plans leads to individuals with DB having a limited understanding of their own medical history* (World Federation of the Deafblind 2018).
- *Decreased privacy and confidentiality when family members are used as interpreters or conduits of information* (Hersh 2013a).

- *Communication issues often results in psychological distress* (Dammeyer 2014).
- *Difficulty communicating is a strong predictor of depression among older individuals with hearing and vision loss* (McDonnall 2009).
- *Challenges in understanding and being understood are barriers to social inclusion and contribute to fatigue, frustration and stress* (World Federation of the Deafblind 2018).
- *Issues surrounding communication are key factors in the lack of attention given to mental health issues in the DB population* (Bodsworth, Clare & Simblett 2011).
- *When sign-language users attempt to communicate in sign language, they are often mistaken by medical professionals to be exhibiting 'bizarre behaviours'* (Swanson 2007).
- *Misdiagnosis because of miscommunication, e.g. the question 'Do you hear voices?' could be misinterpreted. An individual with DB may answer 'Yes,' due to residual hearing, as opposed to hearing voices as a symptom of psychosis* (Asherman 2012; Miner 1997; Simcock 2017b; Wickham 2011).
- *Miscommunication can see undue admissions to psychiatric facilities. Common misdiagnoses are psychosis, hyperactivity, ADHD and mental deficiency. This can delay or prevent the individual with DB getting appropriate treatment* (Swanson 2007).
- *Lack of accessible information/alternative communication methods presents challenges to accessing general health and rehabilitation services* (World Federation of the Deafblind 2018).
- *Lack of knowledge about specific communication requirements among healthcare staff often leads to the professionals talking to interpreter-guides or family members, rather than the individual with DB. This can mean the person is unable to explain their symptoms, and lead to further issues* (World Federation of the Deafblind 2018).
- *As a consequence of high communication support needs, there is a risk that 'other people may, with the best of intentions, act as gatekeepers and reduce the control DB have over their own lives'* (Hersh 2013a, p. 446).
- *Health providers who do not know how to communicate with an individual with DB can mean emergency situations are unnecessarily frightening for the person with DB, because they do not know what is happening* (World Federation of the Deafblind 2018).
- *Inequitable access to healthcare interpreters. Australia has a national booking service that enables individuals with DB to book interpreter-guides for healthcare appointments, yet the system is more effective in private than public facilities* (World Federation of the Deafblind 2018).

Psychological and cognitive threats

The literature strongly demonstrates that PWDBDSI are vulnerable to a number of psychological and cognitive health threats. Although these are extensively documented, the mechanisms are poorly understood. Is there a biological factor in Usher syndrome that compromises psychological functioning? Or, does the degenerative loss of hearing and vision impose sequential bereavement reactions? Is it a combination effect? These unknowns are further complicated by difficulties in diagnosing psycho-cognitive conditions accurately. Language deprivation and communication issues are often misattributed as psychopathology, resulting in incorrect diagnoses that can have a chain of consequences, such as the under- or overuse of medication and incorrect treatment regimens (Asherman 2012).

Diverse mental health threats (specifically outlined in List 6 below) are further complicated because PWDBDSI experience reduced access to mental health services and information; there are also few specialists with the awareness and skills to avoid communication breakdowns and failures (Mathos, Lokar & Post 2011). Additionally, the paucity of knowledge on whether psychological and cognitive assessment tools are valid for use in populations with DBDSI further complicates diagnosis and evaluations.

The links between sensory losses and cognitive decline are becoming clearer. Recent studies (Livingston et al. 2017; Mukadam et al. 2019) demonstrate hearing and vision loss as single impairments, and combined sensory loss is a potentially remediable risk factor of dementia and cognitive decline. In rapidly ageing populations with acquired DBDSI, the role of remediation must be considered in reducing health threats and disease burdens. Further research needs to clarify these associations and demonstrate the clear benefits of remediation. Promoting information, services and devices in accessible formats to affected and at-risk populations should become public health priorities.

List 6. Psychological and cognitive health threats

- *More likely to experience depression and other mental health conditions than nonimpaired, or those with visual or hearing impairment only* (Asherman 2012; Bodsworth, Clare & Simblett 2011; Capella-McDonnall 2005; Chia et al. 2006; Chou & Chi 2004; Cosh et al. 2018; Dammeyer 2014; Davidson & Guthrie 2019; Erber & Scherer 1999; Harada et al. 2008; Heine & Browning 2014; Huang et al. 2010; Lupsakko et al. 2002; McDonnall et al. 2016; Mener et al. 2013; Vernon 1969; World Federation of the Deafblind 2018).
- *Increased risk of loneliness* (Pronk et al. 2011).
- *Decreased perceived wellbeing* (Harada et al. 2008).
- *It has been said that disability reduces wellbeing 'because of the stigma and discrimination it evokes'. This results in psychological distress which, in turn, impacts general wellbeing* (Wasserman et al. 2016, p. 2).
- *Causes of psychological distress are present in both nonimpaired and DBDSI populations* (Ellis and Hodges 2013).
- *High degree of psychological distress; 61% of those with DSI compared to 34% in the nonimpaired population* (Bodsworth, Clare & Simblett 2011).
- *Associations reported between congenital DB and:*
    - *mental/ behavioural disorders (74%)*
    - *intellectual impairment (34%)*
    - *psychosis (13%)*
    - *mood disorder (11%)*
    - *obsessive compulsive disorder (5%)*
    - *anxiety (4%)* (Dammeyer 2014).
- *Increase in challenging behaviours seen in congenitally DB population* (Dammeyer 2014).
- *Increased risk of using unhealthy coping strategies, such as alcohol and substance abuse, which pose health risks* (Brennan & Bally 2007).
- *Increased rates of acute confusion and delirium* (Cacchione et al. 2003).
- *Increased rate of depression* (Asherman 2012; Bodsworth, Clare & Simblett 2011; Brennan & Bally 2007; Capella-McDonnall 2005; Chia et al. 2006; Chou & Chi 2004; Gullackson et al. 2011; Harada et al. 2008; McMahon et al. 2017; Miner 1995; Wahlqvist et al. 2016).

- *Increased rates of anxiety* (Bodsworth, Clare & Simblett 2011; Brennan & Bally 2007; Wahlqvist et al. 2016).
- *Increased depression, and suicidal thoughts and attempts in a Swedish Usher syndrome population* (Wahlqvist et al. 2013; Wahlqvist et al. 2016).
- *Suicide rate in Usher population was seen to be six times higher than that of control group* (Ellis & Hodges 2013; Miner 1995, 1997).
- *Increased suicidality in people with Usher 1 as they age* (Miner 1995).
- *In a UK population, 60% of participants with DB reported experiencing psychological distress* (World Federation of the Deafblind 2018).
- *Moderate rates of depression and anxiety seen in 60- to 92-year-olds* (Figueiredo, Chiari & Goulart 2013).
- *A lack of appropriate services exacerbates the risk of mental health issues* (Bodsworth, Clare & Simblett 2011; Mar 1993; Wickham 2011).
- *Complex adjustment process for older population becoming accustomed with dual sensory loss* (McDonnall 2009).
- *Increased risk of cognitive decline, resulting from reduced sensory stimulation* (Bodsworth, Clare & Simblett 2011; Chen et al. 2017; Dammeyer 2014; Gosney, Victor & Nyman 2010; Lin, Metter & O'Brien 2004).
- *Individuals with hearing impairments are 24% more likely to experience cognitive decline, 40% faster than the unimpaired population* (Lin et al. 2011).
- *Individuals with acquired DBDSI are 2.9 times more likely to develop cognitive impairments* (Lin et al. 2004).
- *Individuals with visual impairment have a 63% greater risk of dementia* (Rogers & Langa 2010).
- *Lack of access sees substantial numbers of DB individuals not receive the mental health treatment they need, e.g. only 16% of mental health providers in the USA had procedures in place to accommodate individuals with DB* (McDonnall et al. 2017; World Federation of the Deafblind 2018).

Social determinants that pose threats to health and wellbeing

When considering social determinants of health and wellbeing, people with disabilities are disadvantaged disproportionately. A public health and disability survey notes:

> The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries (WHO, cited in Berghs et al. 2016, p. 42).

People with disability experience reduced access to services in general and health services in particular, which contribute to reduced health and wellbeing (Berghs et al. 2016). PWDBDSI experience greater disadvantage and less access than both sighted-hearing people and people with other disabilities (World Federation of the Deafblind 2018). The combination of reduced access to information, difficulties navigating the environment and reduced communication have wide-ranging, far-reaching effects on an individual with DBDSI's social welfare, healthcare access and health risks. Studies and support organisation materials suggest that poor healthcare access, as well as poor experiences, can result in delayed presentation to hospital and failure to comply with health plans (Ellis & Hodges 2013; Sense UK 2001, 2016).

A person’s health literacy is socially determined (Sørensen et al. 2012) and influenced by ‘their cultural beliefs, language, disability, education, income and health status’ (Australian Institute of Health and Welfare 2018a, p. 1). No research was found that specifically examines the health literacy of PWDBDSI, but since access to health information is problematic for PWDBDSI, they may not receive the information needed to understand their own health and participate with confidence in clinical decision-making.

List 7. Social determinants that pose threats to health and wellbeing

- *Low level of social trust* (Wahlqvist et al. 2016).
- *Decreased functional independence, with a fragile balance between autonomy and dependence* (Brennan 2005; Erber & Scherer 1999; Figueiredo, Chiari & Goulart 2013; Möller & Danermark 2007).
- *Lack of knowledge surrounding own condition. Study found that 1/3 participants had only basic knowledge about their Usher syndrome* (Figueirido, Chiari & Goulart 2013).
- *Less capacity for help-seeking behaviours, resulting in high rates of unmet support needs* (Bodsworth, Clare & Simblett 2011).
- *High risk of being victims of crime* (Möller 2005).
- *Poor access in primary care settings, hospital outpatient clinics and community social services* (Ellis, Keenan & Hodges 2015; Sense UK 2013; World Federation of the Deafblind 2018).
- *Tendency in the literature to consider communication issues as a direct result of the PWDBDSI’s impairments ‘rather than the attitudinal and infrastructural accessibility barriers’ present in society* (Hersh 2013a, p. 460).
- *Social isolation and social inactivity* (Danermark & Möller 2008; Figueiredo, Chiari & Goulart 2013; Hersh 2013a; Möller & Danermark 2007; Stephens & Danermark 2005; Wahlqvist et al. 2013, 2016; World Federation of the Deafblind 2018).
- *Study found the DB population to be the most isolated group in the community* (Miner 1995).
- *Isolation and relationship breakdown within family/friendships, resulting from stereotyping and lack of knowledge about the realities of DB* (Hersh 2013a; Miner 1995; World Federation of the Deafblind 2018).
- *Increased dependence on a skilled communication partner, and increased risk if not present* (Erber & Scherer 1999).
- *Poor communication and family support can result in violence, neglect and abuse. In some extreme cases, individuals with DB may be sedated or locked away* (Miner 1995).
- *Restricted community participation resulting from accumulated barriers, e.g. limited access to meaningful education and employment opportunities, decreased income and leisure time* (Figueiredo, Chiari & Goulart 2013; Miner 1995; World Federation of the Deafblind 2018).
- *Reduced risk-taking behaviours and community participation due to overprotective families* (World Federation of the Deafblind 2018).
- *Isolation and a lack of independent living skills can result in severe anxiety among family members. NOTE: While this is an issue for caregivers, if they are unwell, unsupported and stressed, this chain of consequences may also impact wellbeing of PWDBDSI* (World Federation of the Deafblind 2018).

- *Low employment rate is associated with decreased wellbeing, e.g. Dammeyer reports only 5% of the DBDSI population under 60 years old is employed* (2014; McDonnall 2008).
- *Chain of consequences: increased limitations of activities of daily living (ADLs), leading to increased demand on institutions, which are often ill-equipped to provide care, leading to increased risk and vulnerability of PWDBDSI* (Campbell et al. 1999).
- *Lack of flexibility about using funded support hours, resulting in sacrificing support for entire aspects of life, including health* (World Federation of the Deafblind 2018).
- *A lack of support for interpreter-guide services creates a critical barrier to accessibility* (World Federation of the Deafblind 2018).
- *Occupational hazards are higher for individuals with single and dual sensory impairments* (Möller 2005).
- *Fear of stigma leads to non-use of aids (e.g. white cane or hearing aids), creating a greater risk of injury* (Desai 2001; Heine & Browning 2004).
- *Poor staff attitudes can compromise healthcare for the impaired* (Ubido 2002; World Federation of the Deafblind 2018).
- *Studies are mostly restricted to high-income settings, limiting research populations to a high socioeconomic status* (World Federation of the Deafblind 2018).
- *Lack of access due to high costs of general health and rehabilitation services. Often, insurance does not cover all expenses* (World Federation of the Deafblind 2018).
- *Concentration of services in cities, limiting access to those living in rural areas* (World Federation of the Deafblind 2018).
- *Lack of knowledge and training among health professionals about DB* (World Federation of the Deafblind 2018).

Gender-based threats to health and wellbeing

Women and girls with DB experience greater health and wellbeing threats, specifically due to their gender, than women without disabilities (World Federation of the Deafblind 2018). This is a direct result of how PWDBDSI communicate and the lack of educational and employment opportunities: '... few people with deafblindness are able to fight for recognition or the right to equity. Many women do not have access to information about healthcare or education. To these women, the universe is a silent, dark world' (World Federation of the Deafblind 2018, p. 43).

In developing nations, women and girls may face further healthcare inequities and risk, particularly regarding reproductive health rights, gender-based violence, and cultural practices and beliefs (World Federation of the Deafblind 2018).

Some studies demonstrate that suicidality and suicide are more common in males (Harada et al. 2008; Wahlqvist et al. 2013), while others show that women experience higher rates of anxiety and depression symptoms (Wahlqvist et al. 2013). Thus, gender exerts an influence on health threats and QoL for PWDBDSI. This effect is not always well understood, documented or accommodated in existing safeguards, policies and practices.

List 8. Gender-based threats to health and wellbeing

- *Women are four times more likely than men to live >80 years old, thus having a higher risk of DSI* (Dammeyer 2014).
- *Increased risk of sexual violence for women with DB than women without sensory impairment* (World Federation of the Deafblind 2018).
- *Women and girls with DB often experience gender-based violence* (World Federation of the Deafblind 2018).
- *Women and girls with DB often have unwanted pregnancies* (World Federation of the Deafblind 2018).
- *Increased healthcare vulnerabilities for women and children with DB* (World Federation of the Deafblind 2018).
- *Poorer reproductive health for women with DB than women with other disabilities without disabilities* (World Federation of the Deafblind 2018).
- *Women and girls with DB experience a lack of access to health services and facilities, health information and communication support* (World Federation of the Deafblind 2018).
- *Women and girls with DB experience negative attitudes from health workers* (World Federation of the Deafblind 2018).
- *There is a wide belief that a mother with DB cannot perform or participate in certain tasks with her children. This can lead to feelings of incapacity or guilt, when in fact the situation is 'socially invented'* (World Federation of the Deafblind 2018).
- *Higher rate of depression, especially in older Japanese males* (Harada et al. 2008).
- *Japan's traditional roles may result in differences between men and women in the uptake of preventative, rehabilitation and public health messages; specific strategies may be needed each gender. This issue may be applicable to other populations* (Harada et al. 2008).

Conclusion

As seen in the Lists above, the DBDSI population is subject to a multitude of threats to their health and wellbeing, which increase their risk of hospitalisation. Of these threats, some are obvious, while others are invisible and insidious. While there is substantive material on these threats, still not enough is known. More information is needed to be able to offer appropriate support (Dammeyer 2014).

So far, I have demonstrated what we know about PWDBDSI in general, as well as healthcare risks and what happens in hospitalisations in particular, using the available data and literature. I have canvassed the literature to demonstrate ways of theorising disability with the complex factors that interplay, entwine and influence the societal response to, and support of, its members with differing abilities.

As explicated in **Chapter 3: Standpoint theory** insists that we can only ever understand what really happens to patients with DBDSI in hospitals by seeking the perspective of the patient receiving care. It is obligatory to meet the communication needs of the research participants to avoid disempowerment and privilege the participants' voices. These considerations shape and shift this research to particular methodologies that honour their standpoints and foster social justice outcomes. **Chapter 6:**

Gathering the stories, which follows, details the methodological choices and conduct of this research.

Chapter 6

Gathering the stories: the research process

Introduction

This chapter explains the research methods chosen and how these comport in practice. The fundamental premise of standpoint theory is that social scientific research should start from 'the lives of unprivileged groups in order to gain more objective knowledge of social reality' (Harding 1991, p. 124). This means that, to understand the disabled patient's perspective, 'it is only disabled persons who are able to adequately describe their experiences of both inclusion and exclusion' (Smith-Chandler & Swart 2014, p. 422). Stories of lived experiences can, therefore, build knowledge, enable social change and translate this into practice (Thomas 2004).

On the role of the storytellers, Bochner (2010) writes: 'The standpoint of the storyteller promotes a sociology of caring and community, an engaged and passionate sociology that requires us to develop caring relationships with others instead of standing apart from them in the name of objectivity and rigour' (p. 663).

Co-creation

For inclusive research, as Berghs et al. (2016) continue, participants need to be active partners with the researcher in areas of concern and significance to them. To have practical value and improve the experiences of PWDBDSI in hospital, collaboration occurs at each stage of the research. Co-creation is defined by Pearce et al. (2020) as a research method in which the researcher and stakeholders collaborate at each stage of the research.

Co-creation comprises four processes: generating ideas (co-ideation), designing the project's research methods (co-design), implementing the co-designed project in accordance with research methods (co-implementation), and collecting and interpreting data (co-evaluation).

One year prior to beginning the interviews, I attended all the deafblind support group meetings at an impairment support organisation. There, we discussed the difficulties that PWDBDSI face, the proposed research and how best to approach the research practicalities, including what formats were most suitable. In February 2017, I took part in a World Café event, along with PWDBDSI, professionals, interpreters and others involved in research or care, which also addressed these issues. At all of these events, attendees iterated and reiterated concerns that the community, individuals, families, interpreters and workers held, regarding the prevalence and persistence of negative experiences in hospital and healthcare. This confirms the usefulness of this research to communities of PWDBDSI, affirming the social justice and salutogenic framings of the proposed research. As well as co-creation with members of PWDBDSI communities, collaboration occurs with interpreters. Two interpreters with long histories in these communities, who are also teachers of tactile languages, were consulted to contribute historical, linguistic and procedural advice for this work.

As an aide-mémoire, the following research questions were derived from community co-design, cultural immersion and discussions with key informants:

- What happens when a PWDBDSI goes to hospital?
- What does a good experience in hospital look like?
- What are the enabling conditions?
- What are the disabling conditions?

Using qualitative methods (narrative inquiry) gives almost limitless profundities of the patient experience in hospital for PWDBDSI; and using quantitative methods (a patient-experience question set) gives an objective count of fixed events from those hospital experiences. Thus, this research is composed via mixed methodologies—where the question set generates a breadth of quantitative data complementary to the qualitative in-depth analysis of interview transcripts.

The conduct of this research, which essentially gathered storied and unstoried data, follows the design and creation of safe research spaces, performance of interviews, and analysis of data both qualitatively, as inductive thematic analysis, and quantitatively, as a patient-experience measure.

Mixed methodologies

Combining qualitative and quantitative approaches promotes an understanding of and commitment to improving the world we live in. Mixed methodology is well suited to health research, where the phenomenon under study is often complex (Sale, Lohfeld & Brazil 2002). The two investigative processes used encompass more complexities and allow for canvassing a number of perspectives. While there is debate about the virtues and pitfalls of each method, Sale, Lohfeld and Brazil (2002) stress that it is better to avoid paradigm wars and use those methods that suit the project and get the research done: ‘truth is what works’ (p. 47). This research therefore uses storied language—signed, felt, written and spoken—as data, as well as yes/no binaries to gather frequencies of set events.

In quantitative research, an event is given a label and counted. In contrast, qualitative research is concerned with how an event is interpreted. Thus, these methods do not examine the exact same phenomena (Bernard 2013; Sale, Lohfeld & Brazil 2002). In the narrative inquiry component (participant narratives and creative nonfiction), I explore the quality of experience without restraints, then interpret this into themes.

In contrast, the quantitative data in this research demonstrate the presence or absence of care parameters from a constrained question set. Thus, the ‘results’—from both the narrative inquiry and quantitative question set—cannot be merged. Rather, they exist as two distinct perspectives. One is a snapshot of aspects of performance, while the other is a moving picture of individual experiences and what they might mean.

Quantitative methodology

> Quantitative research describes and explains social phenomena in numerical and statistical forms (Sukamolson n.d.).

This research applied a rigid question set—the Australian Hospital Experience Questionnaire Set (AHEQS)—to the participant-generated narrative data to deliver numerical values for predetermined aspects of the patient experience. Conducting a frequency count on responses to open-ended questions or transcripts is not a qualitative process, even though it is performed on qualitative artefacts (Sale, Lohfeld & Brazil 2002).

The AHEQS’s provenance is outlined later in this chapter, but its interpretation has some limitations. The question set was applied after the interviews concluded. This arose because the question set, which complements the narrative research so well, was discovered late in the research. Thus, the researcher examined the transcripts for the presence or absence of patient-experience factors, rather than the participants themselves. Notwithstanding this limitation, I was able, as proxy, to examine almost all factors identified as crucial to the Australian patient experience.

Qualitative methodology

Qualitative methodologies study the natural world’s social phenomena—lived experiences (Bernard 2013). Narrative inquiry is one overarching method for gaining knowledge, which solicits new knowledge in ‘a natural setting sensitive to the people and places under study’ exploring lived experiences that participants tell in their own words, signs and artefacts (Creswell 2013, p. 44, cited in Creswell & Poth 2018, p. 8. Furthermore, Cresswell (2013, p. 44, cited in Creswell & Poth 2018, p. 8) ‘the final written report or presentation includes the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution in to literature or a call for change.’

Stories may be garnered in a myriad of ways, such as via interviews (unstructured, semi-structured or structured), letters, stories, autobiographies, memoirs, diaries and journals, field notes, conversations, family stories, photos, videoblogs, blogposts and other artefacts. The lived experiences detailed in these items become the units of analysis. This study utilises three forms of narrative inquiry to gain perspectives on hospital experiences: semi-structured interviews with participants, a creative nonfiction assemblage of participant experiences, and a memoir piece on my own life and experiences. This is thus a hybrid doctorate, merging a population health inquiry with the hospital experiences of PWDBDSI and creative nonfiction narratives, which voice the intricacies of lives lived with sensory disabilities and their convoluted hospital encounters.

Underpinning both the nonfiction narratives and interviews is the practice of narrative medicine, in which narrative competence is essential to capture the stories and plights of others effectively. Simply recording the stories is not enough; they must be voiced, interpreted and acted upon. This colludes with standpoint methodology, social relational theory and critical realism. I want to honour the participants and keep them grounded as the axis on which this research pivots—I can only do this by telling their stories as both data and creative nonfiction.

Creative nonfiction components

This area comprises both autoethnography, where I present my story as a contexualising presence in the Note to the Reader, and the creative nonfiction piece in **Chapter 7**, in which a patient journey is described by merging snapshots of participants and slivers of their experiences with the travelling trope of a hospital journey from beginning to end. These pieces of ethnography aim to provide context to a picture that centres on the participants' experiences and diversity. My own perspective is rare; I view through the lens of clinician, patient and researcher.

The self as data

In *Storytelling in Medicine*, Rita Charon writes: 'In any bookstore, there's a wall of books that patients have written about their illness and a wall of books by doctors writing about their practice; I only wish they would read one another's texts' (Charon, cited in Nicol 2017, p. 41).

Doctors have written few books about their own illnesses; fewer still have written about their own disabilities. Recently, however, there has been an explosion in medical practice autobiographies—including those by Henry Marsh, Stephen Westaby, Rachel Clarke, David Notts, Adam Kay and Suzanne O'Sullivan—but only three doctor authors detail their own catastrophic illnesses. These include Paul Kalanithi's *When Breath Becomes Air* (2017), Rana Awdish's *In Shock* (2017), and Kate Granger's *The Bright Side* (2012) and *The Other Side* (2012). I could find no work by doctors navigating their own permanent disability; it is my view, founded on my experiences and those of medical school selection processes, the diversity of bodies seen in the community are not reflected in doctors. Within the profession, there is a strong culture of excellence, both physically and cognitively—a super-normative. There is stigma associated with the connotation of 'impaired doctor'; used by medical boards, this term is aligned with unfitness to practice and (in the minds of many professionals) punitive measures. Recently, the *Medical Journal of Australia* published work noting that 'it is unthinkable that most doctors believe they cannot disclose their distress to their treating doctor without fear for their career' (Rowe 2019).

Having demonstrated a clear gap in the literature of work by doctors with lived experience of impairment, I determined that a component of my doctorate must be a creative nonfiction piece—using myself as data, discussing the complexities of life with hearing and sight loss, ardours of concealment and denial, and despair of relinquishing much-loved parts of myself due to a degenerative disability. Because this gives my clinical practice a limited time frame, I must reinvent myself as my sight ebbs and hearing diminishes. I have recently discovered that writing these experiences is therapeutic for my own wellbeing, as William Shakespeare wrote, to 'give sorrow words'. I am adding to the scant canon of literature on the lived experiences of people with degenerative sensory loss (Watharow 2019a, 2019c, 2020b).

Writing of your own experiences can be a 'push back', an act of resistance against prevailing normative dialogues (Harding 2004). I am aware, too, that putting these words of sorrow and difference into the world helps to increase both the awareness of the self's capabilities and society's disabling barriers.

The patient-participant journey, a creative nonfiction piece

This appears as Part 1 of **Chapter 7**, and every participant is represented. I mined transcripts from narrative inquiry interviews, field notes and recollections of support meetings for incidents that illustrate an aspect of the hospital journey for the patient with DBDSI. I also demonstrate the heterogeneity of not just experiences but the people themselves, so that this doctoral project has greater meaning, colour and immediacy for the reader. It is my wish to provide a glimpse into the social and physical environments surrounding the interviews to contextualise the natural world in which these conversations occur. This encapsulation of a multitude of stories is the brainstem of this thesis. Without this artefact, there is no breath of life for the doctorate. Using patient portraits in this manner has precedent—Maple (2007) also chose to illuminate and position her participants, and their children who died, in this nonfiction form. Patient journeys can be presented in many ways, and Part 2 of **Chapter 7** uses touchpoints to present one journey for one participant, from a fall through to outpatient follow-up weeks later.

The participants as a language dataset

The semi-structured interview

The main narrative inquiry data collection method used in this research is the semi-structured interview. In co-design with impairment support group attendees, I chose this method to glean actions, feelings and events that occur in hospital, as well as information on lived realities to contextualise these experiences. This allows for comprehensive and thorough questioning without straying into discursive territory, for the purposes of specific research questions (Bernard 2013). While following a general script, these interviews covered the topic in-depth with open-ended questions and prompts where needed, to keep interviewers and interviewees on track with the research agenda. This method also let me manage limited participant energy, interpreter availability and everybody's time to ensure momentum within the research process.

The semi-structured interview technique enables participants to tell their stories on their own terms—in their chosen language, location and pace, while keeping some common questions for comparison and as prompts. Obtaining the perspectives of participants with DBDSI means thinking about what questions to ask and how to phrase them, as well as being cognisant of the language/s used, conventions and communicative assistance required to deduce the lived experiences. For this particular population, it was occasionally necessary to unpack unfamiliar concepts, recognising that English and its language structures are a second language for some.

Leech (2002) suggests that, in an ethnographic semi-structured interview, the researcher should approach the participants ‘appearing to know very little’ (p. 665) to enter their world more fully. As a consumer-researcher, I am already partway in their world, but it is possible to keep some judgement while half in (having similar sensory losses in a hostile world) and while half out (being a doctor being empathetic and engaged with sick and impaired patients). As Awdish (2017) writes: ‘It is entirely possible to feel someone’s pain, acknowledge their suffering, hold it in our hands and support them with our presence, without depleting ourselves, without clouding our judgement. But only if we are honest about our feelings’ (p. 239).

There is a problem going into this research with little knowledge, because it is not conceivable (and therefore disabling) to meet all the participants’ communication needs without some immersion in the different worlds of people with sensory loss. The co-implementation of interviews needed to be approached with forethought—planning across multiple modes, times and people; and considering technology breakdowns and unforeseen events when so many are involved.

The reflections of this research project necessarily include consideration of these areas, as well as the tensions that arise—the feelings provoked and how the participants’ experiences touch, wound and galvanise me. Becoming apparent is that the narrative spaces for these interviews were **different** from those described in texts and articles on qualitative methodologies.

Interview guide

I compiled an interview guide (**Appendix 5**), which comprises a written list of the questions needing coverage, in an order that ensures ‘reliable, comparable qualitative data’ is gathered (Bernard 2013, p. 182).

Sociodemographic detail

The participants’ demographic information was sought (age, gender, postcode, living situations), along with impairment history, identity, communication methods, education and employment history. These were obtained at the interview outset, prior to the hospital experience questions. This was to ensure that accommodation(s), communication, language and accessibility needs were met, along with respecting the identity/ies and culture(s) of each participant. This knowledge informed how the questions were asked, whether plain English was needed and endeavours to pre-empt any unpacking of concepts.

Impairment information

One of the many problems identified in the nascent literature about PWDBDSI is that specific information on the nature and history of sensory impairments is lacking. Larsen and Damen (2014) propose seven minimal criteria for reporting on participants with congenital DB and DSI to promote comparison and analysis; they advise that all future research should include:

1. Definition of DB used. Note that, here, DB is used as an umbrella term for DB and DSI.
2. Definition of congenital DB
3. Aetiology of DB
4. Severity of sensory impairments (as a minimum of best ear and best eye). This was not possible for this research, given the limitations of funding, testing expertise and time.
5. Level of ability regarding mobility, access to information and communication. The participants provided this indirectly as they talked about their lives; it was not formally measured in this research.
6. Onset of DB relative to chronological age
7. Communicative development at onset of DB. Because participants had language to tell their stories, this was not formally ascertained (Larsen & Damen 2014, p. 2575; abridged with researcher's comments).

While these distinctions were important to elicit, this research project has limitations, as mentioned above. Because the basis for this information is self-reporting, it is also expected some participant details are missing or limited.

Identity

Information regarding participants' identities was sought for both indigeneity and impairment—how they identify or describe themselves. Impairment identity may include, for example, deafblind, Deafblind, deaf with low vision, blind with hearing loss, dual sensory impairment, dual sensory loss, other or multiple. These categories were not proscribed; the sole aim was to represent participants' identities as they do themselves.

Key questions

The interviews began with an open-ended invitation to tell their truth in response to the question: ***Tell me about what happens when you go to hospital …***

The interviews concluded the formal telling of experiences with a 'Wish List' question: ***What could hospitals do to improve?*** This enabled the co-creation of a suite of solutions and strategies for dissemination after the research process concluded.

Formal prompt questions included:

- Did you have an interpreter when you needed one?
- How did this make you feel?
- List the spaces in hospital where problems occurred.

Informal prompts included:

- Mmm, yes, tell me more, that sounds distressing, and oh dear

Other questions were added as the research progressed. For example, it became apparent that touch was an important issue for many participants, so the next participants were asked extra questions. Another example, after hearing about several avoidable negative events, I wondered: ***Do participants ever complain?*** This question was added to future interviews and put to any already-interviewed participants via email. Another question was added to determine what kind of hospital the events took place in—***public? private? specialist? mental health?***

It should be noted that this research was not interested in the medical, psychiatric or surgical events and details prima facie, but in the *experience* of **being** in hospital. So, no questions were asked relating to symptoms, diagnosis or treatments. Any revealed details were redacted in the enduring transcripts.

Ethics approval

Ethics approval was sought and obtained (No. HREC ETH17-1398) in January 2018. This was amended to allow for accessibility and coding assistants to help with interviewing and conducting the research mid-June 2018 (see **Appendix 6**).

Inclusion criteria

Being cognisant that some inclusion criteria are, in fact, excluding (Berghs et al. 2016), there were only two:

1. Participants are over 18 years of age; and
2. They self-identify as deafblind, Deafblind or a person with dual sensory loss or impairment. The latter distinction was important because not all view hearing and vision loss as an impairment or disability.

Disability can be part of exclusion criteria, whether explicitly or not; for example, the Department of Health survey of hospital experiences (*NSW patient survey* 2016) unintentionally excluded participants by not offering accessible formats. In the author's own experience, I made three requests but never received a very large-print version. It seems that hospitals make negligible efforts to include PWD in reviews of care.

In the present study, no one who wanted to participate was excluded.

Accessibility

There was clear thought and community input regarding the accommodations needed in the research design. This included measures for print disability, language/s, interpreters and creating a safe space for participants to tell their stories. Collaboration with interpreters occurred before and during the research period, ensuring that there was adequate unpacking and that the intent and meaning of questions were cast consistently.

Sampling strategy

A purposive sampling strategy was adopted. Small communities, such as those of PWDBDSI, require a purposive approach (Bernard 2013). While a minimum of six interviews for phenomenological studies is recommended (Bernard 2013; Morse 1994), Bernard (2013) develops this further: ‘There is growing evidence that 10–20 knowledgeable people are enough to uncover and understand the core categories in any well-defined cultural domain or study of lived experience’ (p. 175).

This research included a purposive sample of 18 participants.

Recruitment strategy

Using support groups to recruit participants is justified in hard-to-reach minority and marginalised populations (National Department of Social Development [South Africa] 2015).

Participants were recruited from a Deafblind support group, through newsletters of impairment support organisations and via word-of-mouth (such as, people who learned about the research from other participants, impairment support organisations or key informants). This meant that snowballing occurred.

Participant consent

People with sensory impairment often find information sheets and consent forms too long, confounding and potentially intimidating. They are usually in non-accessible formats. Thus, 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. They were drafted using the UTS Ethics template, keeping jargon to a minimum. All sheets, forms and interview guides were vetted by Dr Alana Roy—a Victorian psychologist and 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?***

Co-implementation of a safe research space

To create a sense of security and safety for both the participants and researcher, attention was paid to the communication method, location, physical environment, trust and rapport-building. On findings from the 2017 World Café event on research with d/Deafblind participants, Roy (2019) notes: ‘The participants appeared to trust, respect and value researchers who came from within the field and despite challenges with engaging in conversations informed by Auslan interpreters, the Deafblind participants showed interest in participatory action research’. There were also added safety nets of support workers, partners and interpreters, as well as information sheets with the telephone and web addresses of support organisations such as Lifeline. The reality is, however, that while these are required by ethics, they were not necessarily useful or accessible to interviewees in this study.

Other strategies to promote interview safety included:

- Trust- and rapport-building
- Reassurance of anonymity and de-identification of data
- Presence of support person/s
- Presence of interpreter who is known to participant—we did not use any interpreters unfamiliar with the research or who were not approved by the participant beforehand
- Debriefing time at the end of formal interview
- Vigilance for signs of distress, as per my years as a clinician in mental health and psychological medicine
- Non-exploration of topics when signals were present that they were unwelcome or distressing

Chosen communication method

The communication method chosen was entirely participant driven and was the single most important factor to get right. This population is diverse; I offered to ‘match’ their preferences with my own, using whatever human or technical assistance was necessary to make that happen. The participants were already used to this adaptive process, but I was careful to preference the participants’ preferred mode/s. Note that different modes were used for different parts of the process; for instance, when setting up the interviews, confirming details and during the interview itself.

Location chosen for interviews

This was also entirely participant driven. Some wanted to be interviewed at the impairment support organisation, others in their home. A few preferred interviews over the internet or National Relay Service (NRS).

Environmental alteration

When interviews took place in homes or offices, the environment was altered to maximise communication and comfort:

1. Seating was arranged according to the needs of the participant, interpreter and support worker

2. Blinds up or down, depending on participant’s requirements
3. Lights on/off/dimmed, according to participant’s preference
4. Table/s acquired and positioned for participant and researcher purposes
5. Tactile table was positioned (if using)
6. Water bottles provided for everyone
7. Safe, comfortable space provided for any service animal
8. Adherence to guide dog etiquette, according to the following points (taken from the NSW/ACT guide dogs’ website):
    (i) The Guide Dog must not be the centre of attention. Please don’t pat, feed or otherwise distract the dog when it is working. A well-intentioned pat can undo months of training
    (ii) Please don’t grab the person or the dog’s harness. First ask if they need assistance
    (iii) When you provide guiding assistance, please walk on the person’s side which is opposite to the Guide Dog (Guide Dogs NSW/ACT 2020)

Honorarium

As early as possible, all participants were offered wristbands. These wristbands are from a project that began with the thesis but ended after the Confirmation of Candidature 2018, when I was advised to reduce my commitments. The wristbands are intended to act as an identifier and reminder to hospital staff of the patient’s communication needs, wherever the patient goes into hospital. Initial evaluations showed wide acceptance (100%) of the silicone wristbands, and early reports found them useful on the grounds that they improve in-hospital communication experiences (Watharow 2018).

The participants were able to select the wording/s they preferred, and as many wording variations as they wanted. Some chose separate hearing- and vision-loss wristbands, rather than one for deafblind, because this was how they identified.

The available wristbands are:

1. DEAFBLIND
2. DEAFBLIND—I NEED AN INTERPRETER
3. HEARING LOSS
4. I AM DEAF—AUSLAN
5. I AM DEAFBLIND
6. I HAVE A COCHLEAR IMPLANT—NO MRI
7. I HAVE A HEARING IMPAIRMENT
8. I HAVE A VISION IMPAIRMENT
9. I HAVE DUAL SENSORY LOSS
10. I HAVE HEARING LOSS
11. I HAVE VISION LOSS
12. VISION IMPAIRED

Figure 2. Wristbands

NOTE: The left-hand image shows a wrist wearing three wristbands, saying 'HEARING LOSS', 'VISION IMPAIRED' and 'DEAFBLIND'. The right-hand image shows two wristbands, saying 'DUAL SENSORY LOSS' and 'I AM DEAFBLIND'.

Some participants were actually able to use the wristbands and report back on them, because a hospitalisation occurred after receiving the wristband and prior to the interview. This enabled almost real-time evaluation of the wristband's performance but may also have contributed to bias.

Interpreters

Booking interpreters was through the Deaf Society and Tactile Terps, a private company. Interpreters were cross-checked initially that they were appropriate (Auslan, restricted-frame, tactile deafblind, fingerspelling, etc.) and that the participant was happy with this professional. As the research evolved, one interpreter was engaged more often. This professional had high visibility within the community and was trusted by the participants. All interpreters adhere to the Australian Sign Language Interpreters' Association (ASLIA) Code of Ethics and Guidelines for Professional Conduct (ASLIA 2007) and are adept at unpacking questions for each individual participant. The ASLIA values are as follows:

1. Professional accountability
2. Professional competence
3. Non-discrimination
4. Integrity in professional relationships
5. Integrity in business practices.

In addition, interpreters were given mandated rest breaks every 15 minutes, or two interpreters were booked to continue interviews more seamlessly. Participants who use interpreters are accustomed to these mandates and the consequent interruptions to flow were considered ‘normal’.

Funding

The researcher received funding from several sources for different purposes, as outlined in List 9 below.

List 9. Sources of funding

Item (Source/Amount)

- *Accessibility Assistants* (UTS/University funded)
- *Printing braille information, consent and survey forms* (Vision Australia/$0.00)
- *Thank-you cards* (Vision Australia/$0.00)
- *Wristbands for support groups and participants* (Self-funded/$800.00)
- *Wristbands for impairment support organisations* (The Deaf Society Community Grant/$990.00)
- *Further wristbands for wider community dissemination* (Go Fund Me/ $10,000.00)
- *Interpreters, Deaf Society booking service* (Self-funded/$2000.00 [2018 + 2019])
- *Tactile Terps* (Self-funded/$240.00 [2019])
- *Safe space for some interviews* (impairment support organisations/$0.00)
- *Advice on best practice for DB consultation* (Alana Roy/$0.00 [20 February 2018])
- *Columbia University Narrative Medicine short course* (HDR Grant/$3000.00)
- *Attendance and presentation at Deafblind International World Conference and the Usher Syndrome Pre-Conference* (Vice Chancellor Research Grant + Deafblind International grant + registration and accommodation costs waived/$3000.00)

Recording

An iPad was used for recording, with an iPhone as backup. There was one episode of technical failure across all devices in the last minutes of one interview. Both the researcher and accessibility assistant transcribed what remained of the interview and cross-checked the material.

Transcribing

First, one accessibility assistant transcribed all audio files; the transcriptions were then printed in large print (32-point Arial) for the researcher to read through and adjust any homonym mistakes, or other errors. The accessibility assistant who was present at the interviews also reviewed the transcripts as an extra layer of accuracy.

Data security

All audio files were erased once transcription and data collection were completed. Transcripts were deidentified with all medical information, hospital names, partner names and geographical identifiers (such as places of residence) redacted. Participants were given new names and all paper transcripts were kept in a locked cabinet (that is, the researcher's hard copies in large print). The electronic versions were kept on a password-protected cloud account. In accordance with current HREC guidelines, these will be kept for seven years before erasure.

Deidentifying strategy

As part of the pre-interview engagement with participants from a support group, I asked whether they would prefer numbers or new names as de-identifiers; all preferred names. Both Maple and Edwards (2009), and Wayland (2015), note the importance of pseudonyms due to the sensitive nature of the study, which includes hospital and health experience material. The varied communities of PWDBDSI are small; individuals may be linked to specific impairment support organisations or may be well known to each other and to interpreters. This means that all contextual identifiers, as well as sociodemographic data, are in aggregate form only.

A further consideration is that some participants could be traced if their impairment support organisation is known; in the transcript text, these organisations were given numbers or were simply referred to as 'impairment support organisation'. The interpreters were also given numbers but were referred to in the text as 'interpreter'.

Another potential identifier is age. Participant vignettes and quotes, therefore, are described with their pseudonym and age grouping: older age participant (over 65 years) and younger participant (over 18 and under 65 years). All quotations were carefully cross-checked to ensure, where possible, no identifiers remained.

Post-interview debriefing and sharing

At the conclusion of each face-to-face interview, a period of time was spent debriefing—by which is meant social conversation. This ensured that the interviews did not end on a distressing note and gave participants the opportunity to ask questions. A thank-you note, email or text was sent in the days following the interview. Braille thank-you cards were used for those preferring this mode of communication. After the research is completed, findings and recommendations will be shared within the communities via newsletters and presentations, so that this shared research becomes collective knowledge.

Analysis of interviews

Being a consumer-academic-researcher ensures that a co-evaluation lens is applied when analysing and interpreting research outputs. Data was extracted from the interviews using two different methods: inductive thematic and quantitative analysis. Bernard (2013) outlines the purpose of these methods, writing: 'There are three things one wants to do in any science: (1) describe a phenomenon of interest; (2) explain what causes it; and (3) predict what it causes' (p. 36).

Inductive thematic analysis

While there are no discernible rules for thematic narrative analysis, Reissman (2008) notes that, instead, 'attention is on "what" is said, rather than "how', "to whom", or "for what purposes"' (p. 53). Unfortunately, the researcher found that NVivo (Qualitative Data Software Analysis) was inaccessible. The analysis was therefore completed by hand. The first task of the analysis was to transfer the complete transcript (as a single document) to a spreadsheet to view the data line by line. Reading through the entire transcript multiple times gave the researcher a sense of standing alongside the data, and of beginning to realise the pattern and occurrence of themes. This recursivity enabled me to be open to diverse themes and connections. Once I became familiar with the transcripts, some initial key words and phrases were noted. These form the first concepts, participant-given, which resonate, move and shock.

The first transcript was coded in conjunction with one supervisor (SW). Each event in each transcript was coded into an analysis summary for each participant. Wayland (2015) writes:

> Taking the time to listen to the interviews repeatedly allowed the researcher to critique their own position within the three-dimensional narrative space, to listen out for the ideas not noticed within real time while the interviews were being conducted, and incorporate personal notes within the transcription—all necessary in order to begin to analyse the findings (p.184).

It was also important to record what was *not* said, as well as what was. Populations with non-normative senses may say things differently—they may use vibrations, hand gestures and silences to add nuance or emphasis. Field notes from both the researcher and AAs in attendance were also incorporated into the sheets.

In the second round of analysis, events were added into the categories they represented. See **Appendix 7** for a list of the initial concepts derived.

In the third round, more categories were added, as power relations and complexities emerged. In this round, events within a single category were sub-grouped; for example, Accessibility was divided into the subgroups information, communication and mobility. Emerging themes were noted and the relationships between these were examined. A mind map was created with linkages between power relations, ontological security and other themes. See **Appendix 8**.

In the fourth round, because of the researcher's DB, a coding assistant was brought in to help with the physical difficulties of managing hundreds of pages with very large print. This assistant corroborated the categories, subcategories and emerging themes for accuracy and completeness. Coded transcripts were compared to ensure interobserver reliability was high (Bernard 2013). Interview transcripts were then re-analysed using a hybrid approach of inductive and deductive thematic analysis (Fereday & Muir-Cochrane 2006). This hybrid approach was used to review and re-evaluate the previous coding and thematic analysis of the transcripts (deductive) (Thomas 2006, p. 238), and to generate new themes from the data (inductive) (Strauss & Corbin 1998, p. 12).

The resulting concepts were grouped into subthemes and then, as the bigger picture emerged, into overarching major themes. There was much interrelationship between the subthemes, which strengthened the internal validity of the resultant major themes (Bernard 2013). As Morgan (2018) also notes:

> Collections of connected concepts amount to low-level theories. More powerful theories go two-steps further. They explain why those particular concepts are the key elements that make up the theory, and they explain why those concepts are related to each other in the way that they are (p. 340).

By repeatedly re-examining relationships between events, concepts, subthemes and major themes, two models began to emerge. One arose out of negative events and feelings expressed by participants; the other out of their solutions-focus. **Chapter 12** and **13**, the discussion chapters, elucidate these models.

Quantitative analysis

A limited quantitative component was undertaken using an AHEQS, which was applied after the narrative data were collected. The provenance of this question set of patient-experience measures is as follows.

Patient-reported experiences and outcome measures derive information about the patient experience of health services and delivery, as described by themselves. Thus, this preferences the patient's standpoint, albeit within a constrained grouping. This information can be used to monitor performance, make comparisons and drive improvements (Australian Institute of Health and Welfare [AIHW] 2018). An integral part of the Australian Health Performance Framework (AHPF) comes from patient-reported experience data. The ABS contributes to the AHPF and undertakes a yearly patient-experience survey (PES). This survey examines views on waiting times and access to health services, as well as patient–clinician communication. Many jurisdictions encompass patient experiences in their health service assessments, such as the UK's National Health Survey and Canada's Patient Experience Survey (AIHW 2018). The NSW Department of Health conducts an annual NSW Population Health Survey to gauge hospital experiences from the patients' perspective, rather than those of the hospitals providing those services. Because this is state-specific data, the Australian Commission of Safety and Quality in Health Care (ACSQHC) hopes to roll out a national survey and website to add to the conversations and knowledge about Australian health services through the care recipients' eyes. Beginning in 2014, the ACSQHC commissioned the development and testing of patient-experience measures, which culminated in December 2017. The resultant Australian Hospital Patient Experience Question Set (AHPEQS) is 'tailored to the concerns of Australian consumers and the Australian healthcare context' (ACSQHC 2017, p. 4). In addition, the new core question set is developed from first principles, which includes subsequent adaptations and testing for CALD populations, Aboriginal and Torres Strait Islanders communities, those aged under 18, and people with intellectual disability or cognitive impairment (ACSQHC 2017). This appears to be the first time that the question set has been utilised for a population with DBDSI. While people with deafness are part of the consultation group, PWDBDSI do not appear to be targeted or included, nor were question papers available in accessible formats at inception. The quantitative arm of this research thus represents an addition, albeit with caveats, to the national conversation on the experiences of patients with DBDSI and their interactions in hospital care. From 2020, the AHPEQS is available in large-font format (AHPEQS 2020).

In total, 20 dimensions of patient experience were derived from focus groups with healthcare consumers that, collectively, contained 101 factors. Subsequent consultation and refinement followed to derive a final set of 12 questions, which represent those factors. Both the 101 factors and 12 questions can be accessed in **Appendix 10** and **11**, respectively.

Using the definitions of each factor, I re-examined each transcript with a coding assistant and, where participant responses demonstrate a factor's presence, it was counted.

For PWDBDSI, participating in any survey is limited by their communication methods and whether accessible formats are provided and easily available.

I only became aware of the AHPEQS during coding, so the narrative inquiry interviews did not have specific questions and answers coinciding with the survey. However, all interviews contain material that represent statements about the presence or absence of most of the 101 factors. By coding a ***yes*** or ***no*** response, the qualitative data obtained during this research were mined and quantified. They are presented in List 13, in **Chapter 11**. As discussed earlier in this chapter, hierarchies and Likert scales are generally not accessible to all PWDBDSI (Roy 2019); hence, the results generated from coding in a binary manner (yes/no), indicate only that a factor is present in the transcript, not its scale of magnitude. Absence, or a 'no' response, indicates only that the participant did not voice the concern, rather than it being not present, because it may not have been specifically asked about. These results inform this research as a general barometer of how hospitals are performing, but they are not comparable with other results or reports using the same hierarchical constrained question set.

Conclusion

This chapter examines the methodologies chosen to gather the stories and experiences of participants with DBDSI in hospital, then outlines the conduct of the research step-by-step. The chapter then charts the steps undertaken to obtain and analyse the participant narratives of being in hospital. The next chapter introduces the reader to the 18 participants and the patient journey. In so doing, I hope to voice experiences that previously were silenced or unsought.

The participant portraits use creative nonfiction methods: some of the participant's own words are combined with narrative techniques and a travelling trope to provide the reader with a sense of their living realities. Part 2 of **Chapter 7 The patient journey** uses touch point journey mapping to demonstrate in one short admission how many points of pain and emotion there can be. The remainder of the thesis then examines the data, addressing what we can learn from these stories of hospital experiences and interrogating the question: ***Where do we go from here?***

Chapter 7

The patient journey: Participant portraits and touchpoints

Introduction

The journey undertaken by patients can be represented in diverse ways. This chapter contains two parts: Part 1 includes portraits of the 18 participants on a collective voyage, with each individual showcasing an aspect of the hospital experience. Part 2 exemplifies one patient experience viewed through the lens of touchpoints, emotional points and pain points, after fully describing what these points are.

Part 1: Participant portraits

In her thesis investigating families after a child's suicide, Maple prefaces her findings with vignettes of the parent-participants (Maple 2005). Likewise, I structured the following 18 participant portraits using creative nonfiction narrative techniques, which allow the reader to acquire a sense of the interview, the participants' impairments and their identities. The portraits contain a travelling trope to illustrate, not only facets of their stories and living realities, but their voyage of an admission to hospital. We experience the journey from the participant's perspective, from worrying about what will happen in hospital to double-checking if it is necessary for them to go. After detouring to Accident and Emergency, we arrive at Admissions to fill in a myriad of inaccessible forms. We then explore a stay in various hospital wards, a trip to theatre and recovery, before returning to the wards. Finally, discharge. These portraits are not in chronological order and contain only a sliver of participants' lived hospital experiences. Truly emancipatory research keeps the participants' voices front and centre; therefore, these mini-portraits are situated to illustrate both the heterogeneity and commonality of the participants' diverse and distressing experiences, with a unifying imperative for reform.

A note on structure—in the text, ***bold italics*** indicate the participants' own words. Each participant is known by their pseudonym. Because some interviews were much shorter than others, the portraits differ in length. Most interviews were conducted with the researcher and an accessibility assistant. Where an interpreter was present, this is indicated in the text.

Barbara

The temperature in the car is in the high 30s; it seems to get hotter the closer we get to Barbara's aged-care facility. On my lap sits a round tin emblazoned with flowers—it contains six just-baked chocolate cupcakes swirled with chocolate icing. This is a special request from Barbara; I sense she is dependent on others to produce treats.

I am feeling anxious about this interview, I tell Sharon, my accessibility assistant, as she drives. This is the second time we've been out to this far-flung dusty suburb—previously, we had come to talk to Barbara about some aspects of the history and leading figures of the deafblind community in NSW.

That day, Barbara requested vanilla cake. I told her there were pink sugar flowers in the middle of the cake, which she could eat. Her hand moved over one. ***Nice,*** she fingerspelled.

I struggled with this first interview because so little seemed to be said. From conversations with Dr Alana Roy—whose research surrounds safeguarding children and adults within a disability service context—I knew that unpacking questions is critically important. I hoped I had done enough with the interview guide to ensure my questions were productive and clear.

We have a different interpreter today, which makes all the difference. Sharon and I have had a preliminary conversation about the research and outlined potential questions. Barbara's interpreter is a CODA (Child of Deaf Adult/s); she also has concerns about how members of the Deaf and Deafblind communities are treated in hospitals. With her lived experience as a daughter, relative, carer and friend, she is an ally.

Barbara has Usher syndrome, with no hearing at all since birth and no useful vision from 28 years of age. She has lived in an aged-care facility for decades, ever since her parents died. She once resided in a hostel for the Deaf, but this closed down and there was nowhere else for her to go; government funds are inadequate or non-existent for supported-yet-independent living. She has spent her forties, fifties and sixties in aged care, before finally reaching her seventies. At last, she is age-appropriate and with peers.

It hasn't always been a good place to live, because she doesn't speak but fingerspells. Sometimes, there is no one on staff who can communicate with her. Barbara is not a signer; she went to school at the old Darlington House on City Road, in Sydney's Newtown, where she was not taught to fully sign. (Darlington House is now the Institute Building of the University of Sydney. I have sat medical examinations there, not knowing about its legacies and ghosts.)

We are lucky today; our interpreter provides us with the history of sign language in Australia and explains how Barbara missed out on a full signing education.

Barbara is beautiful; she tilts her head to one side and places a palm on her cheek—***I am thinking.*** She tells us about her brother, who used to accompany her to hospital and insist that the nurses ***treat me with respect.*** She tells us about lying in bed, not knowing what is happening, what the plan is—***waiting, waiting, waiting.***

There isn't a traditional narrative—illness or injury, treatment, resolution—but a slow sensate series of falls, going to hospital where ***there are no braille forms*** (that is, no forms written in braille). She has spent long periods of time not knowing what is going on. Now, she is uncertain how to manage her future hospital admissions because all her family are dead. There is no one left to insist that Barbara is treated ***with respect.***

Our conversation is balletic—I ask questions, then the interpreter dances on Barbara's left hand. Barbara nods in response, then beats an allegro of jumps and sequences with her fingers. When our performance is finished, we are all tired. We eat the cupcakes.

Tess

This is the last scheduled interview. An interpreter is not needed so it was easier to arrange (only three people's schedules to accommodate, not four or five). Sharon and I head to the inner-city Sydney apartment where Tess lives with her guide dog, Gorgeous. Tess has congenital deafblindness due to a rare syndrome and identifies as blind with a severe hearing impairment.

Today, Gorgeous is off harness and off duty. She alternates between snuffling my knee and snoozing next to Tess. We are in the presence of an experienced patient—this past year, Tess has been admitted to hospital dozens of times. Unless she is under the care of a doctor familiar with her case and her communication needs, these hospital experiences prove problematic.

Tess has been denied accessible admission papers and consent forms. Doctors have not introduced themselves and talked over her, inducing ***panic attacks.*** She's been given incorrect instructions for medication and is ***anxious about communication issues.*** In hospital, she has not seen the food and drink left for her, so she has not eaten or drunk it. Or, she has spilled it. She has not seen her medication in its itty-bitty little cups, so she has not taken it. She ***feels frightened for my safety*** in hospital, she says.

Gorgeous doesn't like the hospital environment either, with its noise and her owner being sick. After one unspeakable stay, the guide dog needed retraining. Tess no longer takes Gorgeous to hospital; it's ***too traumatic*** for the dog. So, it isn't a surprise that Tess ***sometimes avoids hospital.*** She consults with ***healthdirect.com to get a second opinion whether to go or not***. Their website states ***healthdirect provides easy access to trusted, quality health information and advice, online and over the phone.***

The bottom line, Tess says, is that ***people with sensory impairments are extra vulnerable in hospitals and it is important for hospital staff do their jobs.*** When Sharon and I pack up, we give Tess wristbands with 'I am deafblind' written in large font, for her next hospital visit (hopefully in the distant future). We then leave—our interview is finished, but our work on ensuring better hospital experiences for the deafblind is just beginning.

Lachlan

I have been texting with Lachlan for a few weeks; we finally find a mutually agreeable Monday morning to meet at his home in an outer suburb. Lachlan knows himself well and says he's less stressed in the mornings so that will be the best time to spend with him. His impairment support organisation has already given him two wristbands from my project. One states: 'I have a vision impairment'; and the other reads: 'I have a hearing loss'. Lachlan loves the wristbands and now calls me ***The Professor,*** because he reckons ***it's about time someone wrote about this***—that is, the problems people with sensory impairments have in hospital. I cannot get him to call me Annmaree, so 'The Professor' will have to do.

Sharon and I are both here, and so is—for a brief time—Lachlan's support worker. This interview is very much a slideshow, with the projector throwing up a picture for a few seconds, then it's gone and we're onto the next one. What I mean is Lachlan's answers have no linear time progression. These are sad and shocking images of the long-time failure of institutions and systems designed to safeguard and heal.

Lachlan is blinded by medical misadventure in his twenties. His eyes were removed and replaced by prostheses. He is deafened by noise exposure from working as a DJ. We listen.

One story does emerge, albeit out of sequence. I piece it together afterwards. It may be many stories or a single one that repeats. ***Someone thinks I'm doing drugs and rings the police.*** Lachlan is disoriented, ***so he must be on drugs, he might be dangerous, they think.*** The police arrive and restrain him. Then, ***come on, come on. Hurry up. You're walkin' too slow.*** An ambulance is called. The ambo says, ***No mate, you can't take your white cane because you can use it as a weapon.***

But is Lachlan drug-affected and disorderly, or is he blinddeaf? ***Being blind and that, what's the first thing you do? You lash out.*** And so, Lachlan ***is dragged*** into the emergency department. Once there, ***they knocked me down … jabbed me with a needle***. Later. ***Nothing wrong. Discharged. Left outside the ED. How can I get home when I don't have my bloody mobility aids on me?***

While distressing to hear, it is worse to endure. We de-stress Lachlan by asking him for a ***show and tell*** of an adaptive smart cane he has devised. It is clever—a cane with a GPS and a miniguide (an ultrasound environmental awareness tool). I call Lachlan 'The Inventor'.

Rebecca
It’s a quiet weekend morning when Rebecca texts. She would like to use the National Relay Service[1] for our interview. I log on and we are away. Rebecca was born with a moderate hearing loss and had hearing aids fitted before starting school. An unfortunate encounter with meningitis two years ago left her with further hearing loss and severely restricted visual fields. She thinks of herself with two identities: one of ***dual sensory loss*** and the other of ***deafblind.*** Rebecca is a health professional and feels that using ***deafblind*** is necessary in situations where attention or help is needed.

Recently, Rebecca went into a public hospital for elective surgery. I can feel her bristling as she talks about inaccessible admission procedures: ***Stupid online admission form, zoom text did not work on this.*** The admission’s clerk then ***couldn’t or wouldn’t do a large-text consent form for me to sign.*** She describes feeling disempowered when she needed her partner to fill in forms because ***I couldn’t see.*** The consent form troubled her ***especially because I knew from being a health professional what was on it. But the concern for me was, I should have been able to read it, don’t you think?***

Yes, I do think, so here we are. The troubling start to her admission continues, then culminates in a small act of resistance. Despite the staff banning her partner from staying after hours, she says, ***I was too scared to stay by myself and made my partner hide in the bathroom till the afternoon shift had left, so he could be there with me … the night nurse was lovely; she pretended she couldn’t see him sleeping in a chair.***

This blind-eye-turning nurse is the only one who uses ***a notepad and pen to let me know what the plan was … and a touch on the arm to let me know she was there … I really appreciated that.***

It is a case of too little, too late, however. Rebecca found this stay so distressing she ***would have to be really crook before going back to hospital.*** She finishes the interview on a ***terrifying*** thought—***I do wonder what other people do when their partner or parent isn’t there, or they don’t have one.***

George
Sharon and I meet George and our Auslan interpreter in a small boardroom at his impairment support organisation. George has Usher syndrome and identifies as Deafblind, Usher or low vision, depending on the situation and company.

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[1] This free service allows Australians with hearing/speech impairments to make and receive telephone calls using an operator-assisted voice, mobile, text or internet. See: https://www.communications.gov.au/what-we-do/phone/services-people-disability/accesshub/national-relay-service

He is charming and there are strong visuals in his performance of his story. There is also incongruity; George says his hospital stay was ***good, smooth*** but, as his story unfolds, he is clearly and expressively distressed. When he bangs on the table for emphasis, I feel the vibrations and also, his pain.

George was admitted to a public hospital for surgery, which required him to be awake and communicate with the surgeon from time to time.

Day 1: Admitted. The hospital books an interpreter for surgery the next day.

Day 2: No interpreter. Staff apologise. ***Sorry, but we don't know what happened.***

Day 3: ***No interpreter available. We couldn't find one.***

Day 4: Staff try to book interpreter again. ***No interpreter available.***

Day 5: Finally, George can have his operation because there is an interpreter. ***The operation will be better with interpreter support,*** he thinks. But, 10 minutes into the surgery, the interpreter leaves, saying, ***Sorry, I have changed my mind.***

George had a cannula in his right arm, so couldn't gesture or write. Written English is his second, less-proficient language—Auslan being his first. With his arm immobilised, he couldn't even try to write. Finally, he creatively mimes ***wriggling his toes*** if he needs to signal for the surgeon to stop.

These events devastate George, who says, ***The interpreter should've stayed to look after me, because I am deafblind. I just can't look after myself … and I didn't want to be silenced completely.***

I can see that participating in this research helps give George a voice to his being silenced in the difficult space of the operating theatre on that dreadful, not good or smooth day.

Emma

There is a quiet room at Emma's workplace, where Sharon and I rendezvous for the interview. With us are Angel, Emma's guide dog, and our Auslan interpreter. The blinds are drawn to reduce glare. Angel has been with Emma for 18 months and is resting by her side. Emma has Usher Syndrome and a cochlear implant. Without her cochlear implant, she notes, ***My world is very isolated.*** She identifies according to her audience: To the hearing and people with deafblindness, she is deafblind. To the Deaf, she says, ***I am Usher, because they know what this is.***

Recently, Emma was in a public hospital but ***didn't get an interpreter because they didn't think I needed one.*** Without her cochlear implant on, all she could sense were ***all these mouths going a hundred miles an hour.***

Her mother was there and acted as interpreter, but Emma did not feel respected as an adult in her own right, because staff bypassed her and ***talked directly to my mother.*** When information was relayed back, she had no way of knowing if she was told everything, or if there was ***well-intentioned but heavy editing.***

William

William is a born storyteller. Sharon and I visit him after some delays, because his multi-impaired wife is in hospital and he travels daily to see her. She is home now, and we can meet in the community room of the hostel where they live, albeit ***twenty-five metres apart.***

William has led an interesting, international life but his travels came to an end with a bilateral optic neuropathy in his 60s. He uses a white cane because he has light perception only. He has hearing loss after ear-drum damage in his youth and through ageing. He wears hearing aids but is due to get new ones next week. We discuss the new Bluetooth technologies available, but William and his wife have already set up a creative communication system, using walkie-talkies with a range of 3 kilometres. They call each other with shopping requests and, ***if she has a fall,*** he says, ***she uses the walkie-talkie to alert me. So much easier for old fingers than a mobile.***

William identifies as blind, but notes with glee, ***I like it when people don't believe that you're blind, that's good.***

While William has had his own recent experience in hospital, after falling off a curb and being hit by a car (the perils of being blind), this interview highlights how people with sensory impairments can have multiple roles in hospitals. They may be patients, visitors or, like William, carers.

He advises there is a general lack of tactiling at hospitals and a loud talking elevator would be helpful. Hospitals are uncertain spaces—***there's always obstructions, there's always walkers and things all around the room that you can knock into.*** The location of beds is uncertain, too. William has ***to memorise his wife's ward layout and how to get there from the ground floor every time.*** Patients are moved around. His wife may be in the intensive care unit (ICU), then a bed next to the nurse's station and then moved again. He would go into visit and suddenly realise, ***You're not my wife! She had been moved to the next-door bed.***

William ***has visited the wrong wife*** twice recently! We have a good laugh about this. But William is right; more needs to be done to improve access to both the environment and information in hospitals. William is a problem-solver and gives me a long list of suggestions for improvements: ***wristbands are good,*** a daily update on ***what is happening,*** and ***I'd really love an accessible menu.***

Rhonda

Sharon has been in contact with Rhonda's partner via phone, because Rhonda and I cannot speak over the phone. They live by the sea in an area favoured by retirees. While Rhonda's sight loss is due to retinal vein thrombosis, her hearing deteriorated with age and Meniere's disease. She laments***, the hearing loss has been worse than the vision loss*****.** She defines herself as both ***dual sensory impaired*** and ***deafblind.*** Rhonda was a nurse before she lost her sight—I am interested to see how being familiar with, and a part of, the healthcare workforce impacts patient hospital experiences.

When Rhonda chooses to use the National Relay Service over the internet for today's interview, it proves to be a bumpy start, technologically speaking. The line drops out, necessitating a call back. Good humour prevails and rapport is re-established.

Good rapport with nurses and doctors, however, is not what Rhonda experiences as a patient in the hospital ward. As a patient, she struggled with the voices of staff—men, accents and doctors using computers and not facing her. Staff talked to each other and excluded her. Rhonda notes, ***they avoid you rather than communicate with you.***

While she needed her husband with her as much as possible, she recalls how ***staff spoke to the next of kin or the support person,*** again excluding her. Absurdly, Rhonda was also told ***to follow the yellow lines.*** When that did not work, she ***was grabbed by the arm and pulled along*****.** Procedures were performed without telling her, which made her feel alienated from her own care—***I was not worthwhile because I couldn't see or hear them*****.** ***Them*** being hospital staff.

Later, it occurs to me that I am not asking the participants if they ever complain about their negative experiences. We contact Rhonda again, and she answers: ***Yes, I did complain about one staff member, but it came to nothing.*** It is easy to see how trust in your healthcare erodes when you are not spoken to in an accessible way, and people do not listen to you.

Tom

We meet Tom at a community centre in a room with a long desk. I am on my own for this interview; my husband has escorted me here and waits nearby. He sets my iPad to record, and places a notepad and pen on the table in front of me, so I can scribble observations and thoughts. Tom arrives with his Labrador guide dog, Handsome. We introduce ourselves and settle into seats with bottles of water and a bowl of mints. Handsome is unharnessed, finds a corner and sleeps.

Tom has Usher syndrome, type 2. He has very restricted fields, less than two degrees in his one working eye. Misfortune in the form of an unrelated condition has reduced his other eye to light perception only. He goes to a specialist eye hospital for surgery in the faint hope of restoring some vision.

He says, ***[my] own family take me in and out to reduce the potential for misunderstandings.*** Having support is important, because Tom has ***never*** been given accessible hospital forms.

In this otherwise helpful hospital, Tom runs into trouble with the anaesthetist, who ***spoke terrible English, heavily accented, while I didn't have my hearing aids in. He clearly didn't know what I was saying and I didn't know what he was saying.*** This is then compounded by the anaesthetic not working, with Tom's surgeon stepping in to rectify the situation.

The rest of his stay goes well—nurses respond to buzzers and take him to the toilet at night. He doesn't endure any of the pushing, grabbing and dragging he has experienced in other hospitals. Tom leaves, ***moderately happy*** with the result and the professionals—***the people looked after me in the eye hospital, which is kind of what you'd would expect in the eye hospital, if I'm honest.*** The interview is short; Handsome wakes and needs to take his owner for a walk.

Jane

Jane texts me after hearing about the research project from one of her friends. She would like to use the National Relay Service for our interview. We fix a time and connect. Jane has Usher syndrome and Auslan is her first language.

People with impaired vision and hearing live with the real threat of falls. Late one night, Jane fell in her bathroom. At the hospital, there was ***no interpreter because it was very late … no support as friends couldn't come.*** Jane requires pinning and plating of a complex fracture of her humerus (upper arm bone).

Jane wakes up from her surgery confused. ***I was very frightened,*** she types. The recovery room staff say she ***was aggressive and that wasn't allowed in the hospital.***

Things aren't better on the ward. Staff don't take her to the bathroom, ***they just pointed.*** Discharge, too, is problematic. Inaccessible instructions—therefore incomprehensible discharge medications and directions. Jane plays it safe and doesn't take any of them.

She struggles to cope at home because no one in the hospital considers what another impairment (loss of the use of a limb) might mean to a deafblind person's ability to go about daily life activities. Luckily, a friend comes to the rescue.

Despite all this, Jane exhorts, ***You should talk to the people in the aged homes, they have a worse time.*** I have noticed this, too.

Ben

Ben is a younger man with Usher syndrome, who lives interstate. He chooses to be interviewed by email, in his own time and place. This is the shortest interview. Ben went to a specialist public eye hospital for surgery. He had a good experience; he ***was allowed to keep my hearing aids in throughout*** the procedure, and staff were ***helpful*** and ***respectful.***

He considers how the hospital experience might be for others and gives me a list of useful suggestions for improvements. Among them is his idea of using iPads and speech-to-text recognition for those staff with accents or soft voices—this is inspired.

Sally

I am interstate to talk with Sally. A fellow researcher assists me to provide access and acts as a communication-guide when necessary. Sally has brought her support worker. Our interpreter is well known to Sally. We meet in a small private room at the local disability hub, where we borrow a tactile table for Sally and her interpreter. Ours is a dynamic conversation—Sally is witty, wise and committed to seeing change in our hospitals. ***I don't want your work to sit on a shelf getting dusty,*** she insists.

Sally was born prematurely. The blood vessels of her retinas grew abnormally, leaked and scarred. The retinas detached, leaving baby Sally blinded.

As a young child, she experienced numerous middle-ear infections, which compromised her hearing. Finally, after tumours were removed from her ears, she was ***deafened.*** She now has a cochlear implant but prefers to use Auslan and meet people face-to-face. She smiles and affirms, ***I am Deafblind and bloody proud of it!***

Recently, Sally took a tumble down an escalator. She ended up in hospital then a rehabilitation unit for four months; after that, in an aged-care facility while awaiting modified accommodation for the newly acquired mobility impairment.

The rehab doctor comes on his daily round. Sally is fed up. ***It is written in big thick letters on my file—SALLY IS DEAFBLIND AND NEEDS AN INTERPRETER***. She recognises him ***as he would use the same aftershave, so I knew it was the same doctor, going Barp, Barp, Barp, Barp,*** her version of blah, blah, blah.

Sally regains control by asking him, ***Have you got an interpreter? He sometimes shouted into my cochlear implant,*** but Sally was firm. ***No interpreter. No conversation***.

We have an interpreter and we have a stellar conversation!

Rose

Rose arrives in a rush—she went to the wrong venue for our interview. We have a familiar interpreter, who today is using hand-over-hand Auslan for our conversation. Rose has Usher syndrome; presently, she has no hearing and only light perception sight.

Her story is a tale of two hospitals. At one (public), she has no interpreter—***I feel like I'm in panic because I don't know what to do, I don't know what's happening around me. I really need an interpreter by my side.*** The worst of times.

But then Rose has surgery at a private hospital. She used her NDIS funding to pay for an interpreter at the admission process and ***right into theatre.*** After she came out of theatre, the interpreter was ***still there. I felt comfortable; I felt like I wasn't in an isolation situation; I felt like I was privy to all the information that another sighted-hearing person can see and hear.***

Rose arranged for a communication-guide to be with her the whole time she stayed in hospital. ***So, I was still able to be told what was going to happen … Also, the comm. guide stayed and slept in my room as well, stayed overnight***. The best of times.

We end the interview, chatting about the upcoming Deafblind International World Conference on the Gold Coast. Rose is going and so am I. It is the spring of hope.

Linda

Today, Sophie, my Head Accessibility Assistant, comes up the north coast with me to visit Linda who has Usher syndrome. Linda thinks, ***life with Usher is complicated.*** I agree. She identifies as low vision (she has left and right light perception only) with moderate hearing loss. So, if necessary (such as when in hospital), she will say, ***I'm deaf, too.***

Not long ago, Linda had a complicated emergency hospital admission that lasted a week. While experiencing some good care, significantly, she was subjected to neglect and, on one occasion, plain meanness.

Linda couldn't see the buzzer; she couldn't find the buzzer to ask for help with going to the bathroom. When she finally found it, ***no one answered the call for help … other patients in the next beds screamed out for the nurse.***

The next occasion she needed the bathroom, she buzzed the nurse, ***who came and said, 'Oh, for God's sake, can't you wait?' Afterwards,*** Linda felt ***she couldn't press the buzzer because I was a nuisance … I was in tears.*** Like many of the other interviews, this unfolds as a series of sketches about moments of disempowerment.

Hospitals are unreliable places. Another nurse, who is kind, says, ***'Just buzz whenever you need me,' and she responds.*** It is not just environmental support and orientation that is unpredictable in hospital, however, it is the skill set and awareness of staff.

Linda was very ill for the first few days of her recovery, yet she still had to educate the carers. ***And what I found most difficult—every single shift, new nurse, new doctor. You had to explain to every single nurse and every single doctor that you couldn't see properly, and you couldn't hear properly.***

Linda is facing the issues of ageing with Usher syndrome; her bare residual senses are threatened, so she may need new communication methods. We chat about how I too am facing this, so I am learning tactile sign language.

Ava

Ava has escaped her aged-care facility, as she does regularly. We meet in the office of the organisation where she is a volunteer and board member. She is a younger person and is ***very angry*** about the housing and funding issues that consign some people with deafblindness (like herself, at 30 years of age) to living in aged care. She has multiple impairments after birth asphyxia—cerebral palsy, vision and hearing loss. Ava identifies as ***Deafblind. One word.***

Ava is another experienced patient. She is a true expert-knower, but staff almost never recognise this. She speaks of many things—about the work of being a patient with disabilities who has ***to educate the staff.*** She takes umbrage with the assumption that ***disability equals stupid.***

There are common-sense observations: ***Staff need to let me know they are there and give me time to put on my hearing aids. Doctors come on ward rounds and stand at the bottom of the bed, talking to each other and not to the patient in the bed.*** She sees that ***staff don't have the time to access understandings of patient needs, nor do they have time to be trained or have access to training.***

What is needed, Ava says, ***is for people with disabilities to talk to staff and students.*** She walks the talk, too, getting involved in medical student education. This interview is not a narrative, but a problem list with a focus on solutions.

Yet, after this generous sharing of insights, Ava looks down and whispers. I am not sure what she says, but I know it is important because of her change in tone and register. When I read the transcript, her words are underscored: ***<u>I don't like hospitals.</u>***

Amanda

Amanda's story is the tale of two hospitals, part two. They are called ***terrible*** and ***marvellous, respectively.*** She received an ***I am Deafblind*** wristband and has two recent hospitalisations to talk about today—before the wristband and after.

Sharon and I meet with Amanda and one of our favourite Auslan interpreters on a warm Sydney day. We have manipulated the room environment—blinds down, lights dimmed and the seating arranged so that Amanda's interpreter is on her right-hand side. She uses a close-frame Auslan. Amanda has Usher syndrome with an atypical expression. She has problems with her central vision (the reverse of what is commonly experienced, where the central vision is the last to go). She has a severe hearing loss, exacerbated by age-related hearing changes on top of her Usher congenital deafness. She also must deal with balance issues.

Without the wristband to alert staff that she has deafblindness, Amanda says, ***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.*** The hospital only gets an interpreter for ***special occasions—*** not necessarily when Amanda ***needs*** one. Admission—no interpreter, so her father filled in the admission forms. The rest of the stay—no interpreter, ***so I didn't know what was going on.***

Her next hospitalisation was the polar opposite. Amanda was in a private hospital, with an interpreter for four hours when needed and an orange silicone wristband with bold blue lettering, identifying her as deafblind. ***So much easier, once staff saw it around my arm. It encouraged them to read the notes … and it goes wherever I go.***

There's icing on the cake, too. This last time, Amanda was allowed to ***keep her hearing aids on in theatre.*** So, the best of communication times is doable.

Belinda

Arrangements are complicated for our visit to Belinda at her new home in Sydney's south. We use a new interpreter-booking system and a new interpreter. We are caught on the hop, because the service notifies us that the interpreter needs to come earlier than planned, so there is no time for a detailed briefing—something we are doing for all the interviews.

I am worried; I have a sense that Belinda is not keen to participate. I am considering cancelling but, she explains, she only has people she trusts over to her home, and she trusts us. So, my intuition is wrong here.

Belinda has a genetic syndrome that includes hearing and vision loss, plus a constellation of other impacts. She was born Deaf and has a cochlear implant in one ear. She has no sight in one eye and some residual vision in the other.

Belinda has a strong family whose members support and accompany her to hospital. She is utterly ***unable to imagine what it would be like without having them there [in hospital].*** She says it is a mixed bag with staff in hospital—***some are rude, and some are lovely.*** She is frustrated that interpreters aren't there when you need them, ***because the hospital doesn't book them.*** This is a problem because, ***sometimes, family don't understand all the medical terms.***

Sometimes, the interpreter can be a part of the problem. Belinda recounts an episode where the hospital booked an inexperienced interpreter, which caused significant distress. Not all interpreters can provide tactile language. Since then, she is very specific about her requirements.

For discharge, ***the hospital usually hasn't booked an interpreter,*** so Belinda has learned to ***take great care to lip-read the doctor, and in writing notes.*** Belinda is discharged with her family's help.

Annie

This is the hardest interview to arrange—we need a specific interpreter because Annie has her own unique tactile language style. She can fingerspell and respond to print on palm, but the spelling has to be accurate—a problem with staff who don't have good English skills. New support workers learn Annie's idiosyncratic language and her present worker 'speaks' Auslan because he is Deaf. So, we need a relay team—Annie, who tactile signs to her support worker, who then Auslan signs to our interpreter, who then verbalises for Sharon and me.

Throughout the interview, each person identifies who is speaking, so we hear Annie's voice as distinct from the respectful ones of her support worker and the interpreter, who clarify and corroborate points made. Annie is in a wheelchair so, one-by-one, we bend down for her to touch our faces and hair. She loves the feel of Sharon's long tresses. Annie lives as a younger person in an aged-care facility. She says, ***I don't like aged care at all. It's bad.***

Annie was born extremely prematurely and lost all her sight and hearing then. She identifies as ***Deafblind*** but, usually, is never asked. ***The last time I was in hospital, the staff never talked to me at all, no one. No interpreter.***

The unyielding theme of Annie's accounts of her many hospitalisations is powerlessness. Sedation and restraints are used. (Here, her support worker says, ***Yes, we think that happens a lot as she gets anxious and disoriented at night.***) Additionally, night sedation makes Annie groggy during the day.

Annie waits endlessly for interpreters whom no one has booked. ***I don't like waiting,*** she says, ***I have to wait for the nurse, and I have to wait for the toilet. Sometimes, I have to wait so long that I wet myself.***

Once in a rehabilitation hospital, Annie went three months without a shower. ***Hospital doesn't give me my preference of a shower; they tend to just wash me because I'm in the too-hard basket. They don't know how to support me and so, therefore, they just neglect me.***

It is not simply waiting that Annie must abide; it is forcible management. ***I don't like people touching my body all over, without letting me know what they're intending to do,*** she says. She doesn't like it when staff ***push my chin down and shove medicines in. I am able to take medication in my palm.***

The only time hospital was any good was two years ago, when her old support worker stayed overnight—***otherwise, I would have been oblivious to what was going on around me.***

I can bear it no longer. On behalf of my fellow health professionals, I apologise for the inhumane treatment Annie has borne. ***It's not your fault,*** she tells me.

After a long goodbye—a norm in the Deafblind community, where members are never sure of the circumstances of their next meeting—Sharon and I drive home. We are shaken. Branded upon me is how necessary and important this research is.

Part 2: Touchpoints

A touchpoint is any contact between the user of a service and any aspect of that service, such as persons, virtual or environment (Sudbury-Riley et al. 2020). A patient journey can be described, therefore, as all the contacts a patient has before, during and after their hospitalisation. Touchpoints can be physical experiences of care, or psycho-emotional reactions to the care (or lack of care) at that contact. An emotional touchpoint is how patients feel during that experience (Dewar et al. 2008). Dewar et al. (2008) describe responses to touchpoints or contact with a range of words, both positive and negative, including *numb*, *powerless*, *bewildered*, *happy*, *curious*, *hopeful* and *encouraged*.

Pain points are areas in a patient's journey that need improving and/or where they experience difficulties (Dewar et al. 2008). Mapping out patient journeys to examine touchpoints, emotions and pain points can do the following:

- Capture patient experiences and emotions.
- Provide whole-of-service delivery data (before, during and after admissions), including aspects of the journey directly influenced by hospitals, as well as those influenced or controlled by third parties, such as ambulance services, health departments, referring doctors and community services.
- Recognise that other professionals and organisations can affect the patient experience.

- Identify points of improvement.
- Identify points of difficulty (pain points).
- Go beyond an exploration of just clinical encounters.
- Help gain a better understanding of what a ‘good’ experience is. (Dewar et al. 2008; Nakata et al. 2018; Sudbury-Riley et al. 2020).

Touchpoints are used by health services that provide palliative care (Sudbury-Riley et al. 2020), older age care, dementia (Dewar et al. 2008), and care and chronic disease management (Nakata et al. 2018). No papers were found that demonstrate touchpoint framings either being used with or validated for PWDBDSI. Note that Sudbury-Riley et al. (2020) use a ‘rich picture methodology’ of cartoons in their study, which are inaccessible for most of the present participants, and require unpacking by interpreters and researchers prior to use.

Patient journey mapping: an example from this study
While evaluating and mapping patient journeys to identify system touchpoints and pain points is beyond the scope of this present study, this represents a future research direction. In this thesis, I illustrate one mapped journey (see List 10), Jane’s short overnight admission. Where the transcript describes an emotion, it is added to the map. Studies using embedded researchers in hospital departments (Slade et al. 2008; Slade et al. 2015) show that even a simple emergency department admission brings hundreds of actual communication encounters and touchpoints: doctor and nurse shift changes and breaks; food and beverage deliveries, five or six times daily; allied health and therapy; x-rays; visitors; hospital pharmacists; and other patients. The patient journey described here is not complete, because it is derived by breaking down a transcript into the points of contact disclosed, from beginning to end.

List 10. Jane’s Journey

Note: Emotion points are highlighted in ***bold italics***; these are the participant’s direct quotes.

Before

- A fall at home results in Jane calling triple 0 for an ambulance. She describes ***frustration*** at making herself understood, because she is unable to understand the operator’s questions.
- In pain, she repeats the need for an ambulance and her address.
- The hospital destination was most likely chosen by paramedics as the nearest geographically.

During: ‘pretty bad’

- During triage, Jane is unable to understand instructions and requests for information.
- Staff shout. Jane is ***stressed and upset***.
- Jane asks for an interpreter.
- ***In pain***, Jane seems to have waited a long time for pain relief.
- She sees a doctor.
- Nurse gives pain relief via injection.
- Jane has an X-ray.

- Sees doctor again, unsure of diagnosis but understands she needs an operation.
- Requests an interpreter but is told ***it is too late***.
- Sees another doctor.
- Sees a different doctor for a consent form.
- Consent form is not accessible; Jane signs it ***not knowing what is going on***.
- Sees admissions clerk to do admission; Jane doesn't understand the clerk, so her forms are incomplete.
- Transfers to theatre.
- Theatre: Jane feels ***frightened*** because she doesn't know what is going on.
- Recovery: Feels ***really frightened*** and ***confused***, but understands from ***mean*** nurse she is ***aggressive*** and that is ***not allowed in this hospital***.
- Ward admission: sees nurse (it is now 2 or 3 am).
- Post-operative observations: different nurses do frequent checks on Jane.
- Jane is not oriented to her room or shown where the bathroom is.
- Jane feels nurses are ***not kind: I told them I couldn't see or hear very well***.
- Jane asks where the toilet is: ***no one would take me and show me, they just pointed***.
- Seven am: nurses change, ***I just wanted to go home***.
- Jane did not ***see*** or ***hear*** breakfast come, so she did not eat any.
- Doctors' ward round: decision made to discharge. Jane understands she can ***go home***, but nothing else.
- Pharmacist dispenses three days' supply of medications, but Jane ***didn't know what they were for***; instructions were given on wound care, but Jane ***didn't understand***.
- At discharge: Jane is collected by a friend.

After

- At home: Jane doesn't take medication because ***I didn't know when or how much***. Jane says her ***arm hurt for a few days***.
- Friend stays with her because Jane is unable to manage activities of daily living with an additional impairment (even though it's temporary).
- The friend makes lunch and sandwiches, and helps her dress.
- Jane goes to see the GP (a friend makes the call and goes to interpret because no interpreter is available at short notice).
- GP makes a phone call and finds out the orthopaedic clinic date and time details.
- Jane books an interpreter with her NDIS allocation, to accompany her to outpatients' follow-up.
- Outpatient follow-up: Jane finds out exactly where her breaks/fractures are, and why they were necessary to pin—to maintain bone alignment and function.
- Jane is given a date for removal of the metalwork in her bone. This is the first time she understands that she needs to return for another operation.

While this patient journey contains limited information, it does illustrate three germinal points:

1. There are a minimum of 42 touch points in this limited information journey.
2. Each contact point for Jane, and for other PWDBDSI, is a real or potential pain point.

3. The presence of an interpreter or support person reduces pain points.

Within the present research, time and budget constraints limit the mapping of all participant journeys. The storytelling style used in this study by many participants is not traditional beginning-middle-end narrative, also limits the mapping of contact and pain points with these participants. This means adapting the methods for documenting events and emotions, and likely necessitates the researcher being embedded in real-time in the hospital for the duration of the stay. Mapping patient journeys may also be useful to resolve dissonance by exploring so-called ‘good’ experiences to see points that demonstrate the real experience, whether positive or difficult. The participant George, for example, recalls his hospital stay as ‘good and smooth’ but, when examining his points of contact throughout the five days, it becomes obvious that George is angry at repeated interpreter failures, complicating and permeating every day he spends in hospital.

These observations on touchpoints and patient journey mapping demonstrate multiple encounters. For patients with DBDSI, all encounters represent potential or actual pain points, where communication, access to information and movement in the environment are compromised.

Conclusion

So now to discharge my commitment to the participants and communities of PWDBDSI. In **chapters 8, 9, 10** and **11** which follow, I present the patient-participant experiences as data: examining the performative elements, living realities, border concerns, and coded themes, then delivering their Report Card on patient experiences and Wish List of desired improvements to make hospital experiences safe and tolerable.

The point of making any examination of patient journeys from their personal standpoints is to identify difficulties and make improvements where they really matter.

Chapter 8
Findings 1: Performing narrative inquiry

Introduction

As the participants with DBDSI collaboratively engaged in this project, they added their individual voices to a collective narrative, calling for better ways of communicating and caring in hospital. It is critical to remove participation barriers in the research space, and vital to acknowledge and respond to the participants' different storytelling techniques. They live lives complicated by a range of impairments, languages and communication modes, and residual vision and hearing, illustrated further in **Chapter 9**. These complexities impinge upon and alter both the narrative space and the performance of the narratives within that space—at variance with the spaces and performances of the sighted-hearing. This chapter is the story of how these patient-experience narratives were sought, heard and reflected upon.

Narrative refers to the spoken, signed, touched and written accounts of connected events and emotions. In this chapter, the participant interviews are considered as the performance of a narrative, in contradistinction to the performance of other hospital/medical narratives. These performances have both embodied and nonembodied elements. The first concerns the narrative inquiry space itself—place, voices and bodies, co-creation, necessitous storytelling aides, protracted time, and centrality of touch in almost every story and its performance. The second involves the language elements and devices used to tell the participants' hospital stories. This chapter reveals the process of collecting, witnessing, receiving and reflecting on participant stories, through my researcher-as-audience perspective, part-insider and part-outsider. The complexities of my position as researcher precipitate tensions in the research performance space; these are explored separately in **Chapter 14: Where to from here?**

Performance elements

Two components of the act of narration are corporeal and noncorporeal.

1. **Corporeal** (or embodied) elements are the live presentation of events in the presence of an audience (researcher and accessibility assistants [AAs]) 'at a specific place and time—visually and acoustically' (Berns 2014). For participants with DBDSI, these performances include tactile elements, vibratory modes and necessary storytelling aides—including interpreters, communication-guides, assistive technology and service animals.
2. **Noncorporeal** elements are written narrative components that evoke a performance in a reader's mind (Berns 2014). Here, noncorporeal performative elements include written interpretations of tactile and visual signs, second languages, written and spoken

> language, and vibrotactile elements. These shape language and storytelling.

In this chapter, these corporeal and noncorporeal elements sit uncomfortably alongside conventional ideas of what constitutes a good narrative. 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). Theorists favouring the eponymous ‘good’ storytellers empower native speakers, the sighted-hearing, educated and articulate over other communicators and forms of communication. This favouritism harms those who are less privileged, leaving their stories unsought and unheard. I challenge these notions.

The following sections convey some of the embodied features of the performative act of gathering stories, before discussing the noncorporeal narrative components. They explore the dissonance between words and experience because, for many of the participants, there is jarring in the narrative space.

Corporeal/embodied elements

This section discusses the space where stories are performed, specifically considering touch-centricity, time, place, co-creation, storytelling aides, and plurality of voices and roles.

1. Touch-centricity

Touch is a central sense, which forms part of how many participants get to know others and tell stories. For the participants, touch-centricity transcends cultural limits because, with co-occurring loss of hearing and vision, touch becomes a vital communication conduit, even for those who do not use a tactile language. They touch doors, doorways, tables, chairs, canes and guide-dog harnesses to ascertain environmental information.

Participants touch chairs, tables and the researcher’s hand or arm to emphasise points. Additionally, participants touch interpreters when retelling events. Participants touch parts of their own bodies to illustrate thoughts, such as touching the side of the face to indicate ‘I am thinking’; one participant has idiosyncratic touch signals that only her support worker can understand. Hands are always moving through the air as signs, gestures and messages: there are clenched fists in the air for anger and on the table as vibro-tactile emphasis. I touch participants hesitantly at first, spelling out letters in palms and fingertips, getting faster as my confidence grows.

One participant likes to feel people's hair and face to tell who is engaging with her. Many like a long goodbye hug—a Deafblind cultural custom from when gatherings were less frequent and you did not know when you would see each other again. Four interviews ended with long goodbyes, both with me as researcher and the accompanying AA. In this research, there are also things that we **do not** do, such as holding participants' hands down (if they sign). For many, this harkens to past times when teachers and/or parents held children's hands with force to stop them signing.

Touch and vibration, such as banging on the table for emphasis or turn-taking, were evidenced in two interviews. One participant banged on the table at several junctures to reinforce their point about feeling abandoned. By contrast, tactile performative elements were absent from the remote interviews via NRS or email; perhaps, those who need multiple sense communication choose face-to-face contact.

2. Time

Hospital events took place within the preceding two years for 17 participants and within four years for 1 participant. Participants generally experience multiple hospitalisations; only one described just one episode. Generally, in this population group, multiple hospital admissions are expected over time, as illustrated in **Chapter 5,** which reflected on the additional risk and burden of sensory disability to health and wellbeing. While explicit health and wellbeing data were not sought, seven participants divulged falls spontaneously as the reason for an admission, and one sustained a fall when in hospital.

Time is protracted in this altered narrative inquiry space, both in the organisation and expression of stories. The action of time in interview preparation and conduct emulates that which is needed for hospital care and communication. Increased time is needed to organise storytelling aides and participants; rest breaks for interpreters (5 minutes every 15 minutes); and relay via interpreters, NRS or communication partners, as well as to debrief with participants. Communication is prolonged when relaying stories through aids and aides, and when using tactile communication, such as the deafblind manual alphabet (Hersh 2013a).

Time is thus both a facilitator (more time equals better preparation and delivery of participant requirements) and a barrier (not enough time equals no research generation). Time also has a finitude. Time spent in interviews is limited by fatigue in participants, interpreters, and researcher. In general, the interviews took between 30 and 70 minutes, with most terminating at a natural conclusion. One interview ended with elapsed availability of the interpreter.

3. Place

If we consider the narrative space as multidimensional, then there is a physical dimension to staging the interviews. These interviews demonstrate how, for participants with DBDSI, the physical elements of inquiry spaces differ from those of the sighted-hearing population. Spatial elements include recruitment and interview location, environmental alteration and communication to navigate spaces.

Recruitment occurs ‘off stage’ and, for 72% of the interviews, is characterised by interactions with interpreters and/or support workers within impairment support groups. Some researchers have written about the potential for bias when recruiting from impairment support organisations (National Department of Social Development [South Africa] 2015; Simcock 2017b), but both insider and outsider researchers need to engage in these places to immerse themselves in the cultural world of PWDBDSI as a desirable and necessary prelude to co-creating research.

PWDBDSI require different communication modes and technologies for different tasks, audiences and places. To arrange times, dates and interpreters (if needed): three participants provide their preferences via interpreters or support workers; the AA rings three participants, who have residual hearing or communication partners, to foster inclusion; five participants use texting; and the remainder use email.

Participants have full control over the location, timing and how the environment is arranged for their optimal communication and comfort. Face-to-face is the preferred mode of interview (78%), which reflects findings noted previously by Roy, McVilly and Crisp (2018). Six participants conduct face-to-face interviews without an interpreter, while eight use an interpreter. The remaining four use email or the NRS.

Control and choice in location ensures a safe space is created, necessary for truth-telling. Many preferred their homes (44%), an early indicator of the trust participants placed in the researcher and AA, and the value of the research. Other chosen locations were impairment support organisations and community hubs (33%), workplaces (11%), and virtual spaces (11%).

Some chosen locations required environmental alteration. Elements that improve accessibility for one may not benefit another; for example, one person with low vision may need bright lighting, but another may need it dimmed to reduce glare. How people and service animals are positioned also affects communication outcomes. The 14 face-to-face interviews all required some form of alteration to place.

To illustrate these manipulations, one participant with DBDSI required a space both away from their home (because they live with others) and that they know well (so they can speak freely). Their impairment support organisation has a meeting room, which they chose. Blinds were pulled down and lights dimmed because the participant’s retinal disease and cataracts make bright lights and glare uncomfortable. Because the participant uses a restricted-frame interpreter, the seating was adjusted so that the interpreter, wearing a plain dark top to enhance contrast between her hands and the background material, sat to the participant’s right side. On the opposite side of the table, the AA was positioned to the researcher’s left-hand side. While this was not optimal for the researcher (who has better residual hearing in the hearing-aided right ear), such manipulations provided a setting that promoted the participant’s ability to share their story. The AA acted as the researcher’s voice interpreter and safety net.

4. Co-creation

The narrative inquiry space requires a collaborative approach. The four elements of co-creation (co-ideation, co-design, co-implementation and co-evaluation [Pearce et al. 2020]) occupy immersive, physical and temporal dimensions (see ‘Co-implementation’ in **Chapter 6: Gathering the stories**). These elements are necessary to gain the participants’ trust and consent, and to attain their stories in socially just and participatory ways. Consent to participation is essential, with the format of forms varying according to residual sight and hearing, and the interviewee’s main communication method. Eleven participants read very large print, four prefer braille, two use an interpreter to convey information and one participant with blindness but no braille background had the AA read out the plain English consent form.

Rapport and trust are built through attending support group meetings and with the initial phone, email, text or personal contact. Without exception, there is keenness to share experiences and participate in the research. There are many moments of non-research-specific conversation before, during and after the interviews, in the debriefing period. Some of this content relates to wider community concerns, which is discussed in **Chapter 9**. We also share experiences of sensory loss, which helps to situate the researcher as insider and compatriot.

I find I can establish rapport by being ‘one of the tribe’, even if that tribe is somewhat scattered and not all from the same village. The AA and I begin learning tactile sign language, so we can say hello and introduce ourselves to those who use the manual alphabet. This involves touch and trust. Trust is also evident from the personal and, at times, traumatic experiences the participants disclosed, because they have the power to choose what they speak. The participants trust me to ‘do right’ with these stories. One participant says, ‘I hope they can do something … I hope they don’t … put (the research) away in the drawer and it never gets touched. I hope something comes of it.’

Another interview provides an example of reciprocity and shared experience. A participant told of difficulties with Usher, and I said, ‘I agree 150%,’ to which they replied, ‘Thank you, I knew that you would understand.’ There is also mutual support:

> Participant: ‘The Deaf Blind International meeting’s on the Gold Coast, I’m registered to go, so I’m going. Are you going?’
> Researcher: ‘Yes, I have a few papers.’
> Participant: ‘I’ll support you.’

The honorarium invokes trust because of its contribution to safety in hospital and the community. A participant expresses his thoughts on the wristbands: ‘I’m really glad. I think they’re cheap, they’re easy and I think it’s important that people know so that they treat you with respect.’

It is not just the researcher who must secure trust and rapport, but the AA, too. The AA engages with and is interested in the participants' lives and stories; they attend all the support meetings and 75% of the interviews. Another AA attended a regional centre interview and a research assistant well known to the Deafblind community assisted me at one interview.

Acquiring trust and having rapport with interpreters is important. Professionals encountered in this research space are invested in the welfare of the community generally, and the participants particularly. Beforehand, all four interpreters receive briefings on the research objectives and conduct; they are bound by the code of conduct (see **Chapter 6: Methodology**); and the participants know and have chosen them. All have long histories of work, travel and social activities with the participants.

Another important part of co-creation is clarifying concepts by unpacking them before and during the interviews. Despite analysing questions with Dr Roy in the early design phase, and later through pre-briefings with interpreters, some further unpacking is required with individuals. With their heterogeneity in life experiences, residual sensory capacities, education and languages, individual participants may not be familiar with certain concepts and words.

One participant did not understand what 'boarding' or 'residential' school is, despite having been to one—to them, it's just 'school'. When I talked about ward-to-ward and staff-to-staff handover in hospital, the interpreter unpacked the concept into the movement of information from admission to the ward bed. One participant did not understand the words 'injection', 'needle' or 'jab', but recognised 'shot'. Unpacking the questions was individual, not general; no concept needed unpacking by more than one participant, so I could not pre-empt the need.

Performances are evolving entities. Concepts emerging from past responses begin to drive questions in future interviews, such as complaints made or explicitly asking about episodes of pushing, shoving or unwanted touch, for example:

> Researcher: 'Oh good, it's just that other people have mentioned being pushed and shoved when they didn't understand what was going on, so we're just looking into that aspect a bit more.'

The participant responded by describing how the round-the-clock presence of the communication-guide (using her NDIS funding) at the private hospital enabled a positive hospital experience and prevented episodes of negative touch.

> Researcher: 'These are good experiences because you had the support with you?'
> Participant: 'Yes.'

Co-creation is not a one-way activity. Specific incidents occur where I can give back, in an advisory or information-sharing capacity, to some of the participants (and vice versa). One participant was getting new hearing aids, although has trouble changing batteries. We talked about new rechargeable hearing aids that do away with small batteries covered with sticky paper.

I provided some ideas for how to improve a specific difficulty that a participant has with their doctor, who touches the participant's knee to signal 'stop talking'; the participant experiences this negatively. I suggested they write a list beforehand with another touch signal or haptic, which does not involve any off-limits personal spaces, for their doctors to use:

> I mean, you could have a conversation with the interpreter and the doctor, saying, 'We've got some new touch signals that I think you'll find useful', and tell him what the new signals are—stop talking or keep going … that way you're not saying, 'You're a terrible doctor', what you're saying is, 'Here's a better way of doing it'.

It is important to me—as the recipient of stories, time and wisdom—to give back, not just in two or three years' time, with new knowledge and publications, but in these here-and-now situations.

A highlight of this research is seeing how one of the participants creates technology hacks and adaptations to make his 'smart' cane truly smarter—personalising it with satellite navigation, MiniGuide ultrasonic input, vibration and amplification of all modalities. He also has a backpack shopping trolley that enables handsfree use, so he can use his smart cane and reach shopping shelves while still having somewhere to store groceries.

5. Storytelling aides

Generally, narrative inquiry performances for sighted-hearing adults do not require multiple storytelling aides. For PWDBDSI, however, both technological aids and support aides are likely needed to enable voices. Thus, the storytelling spaces may be crowded with extra bodies and multiple voices, and be dependent on working technology.

A. Assistive devices as storytelling aids

Assistive devices (as examples, hearing aids, cochlear implants and accessibility software are required by 89% of participants, as well as me, the researcher). The importance of appreciating the fallibility of technology cannot be overstated. For all the connectivity and benefits that modern communication and assistive technology bring, fails and breakdowns are a common occurrence (Möller 2005; World Federation of the Deafblind 2018). Technical glitches affected three interviews.

The iPad recorder failed in one interview, but a smartphone was used for the second half, after a few minutes of trouble-shooting. In one internet relay chat interview, the call dropped out, but rapport was unaffected, with everyone laughing about 'epic fails'.

Towards the end of the last interview, my hearing aids ran out of battery power unexpectedly. The AA's notes were used to corroborate the transcript and my impressions of what I heard. The interview guide kept the last two questions on track and demonstrated the importance, with multiple impairments on both sides of the research space, of having a script and sighted-hearing backup, both with the AA's notes and transcript.

B. Extra bodies

In most interviews, extra bodies as storytelling aids were physically present. With the exception of the three virtual interviews (via email and NRS) at least three people are physically present at each interview location, with a maximum of five recorded. The relay conversations have an operator, who is present virtually as the third or fourth body. Eight participants require an interpreter, partners are present in two interviews and support workers in four. Three guide dogs snooze in corners or under tables while their owners are interviewed. An AA is present at most (16) interviews, including two relay conversations.

C. Interpreters

Good interpreters are essential to reach PWDBDSI. Professional integrity and client expectation all demand that interpreters privilege the participant/client as the principal narrator, thus positioning interpreters as storytelling aides. For almost half of the participants, if there is no interpreter, their voice cannot be added to the research. In effect, the research would be far weaker, muted and less comprehensive. Some researchers comment that it is not always possible to know 'who' is speaking, the inference is that interpreters are fabricating questions and responses. Citing Temple (2002), Simcock says, 'interpreters are not neutral' because they are 'constructers of knowledge in the interpreting act' (2017a, p. 1726). Sheppard (2011) writes that using 'carefully trained', independent interpreters eliminates many problems in qualitative research with Deaf participants. In that research, unexpected issues arose, including examples of participants asking for 'my interpreter' instead of the interpreter supplied, or issues about the small communities from which clients come and interpreters work (Sheppard 2011).

For PWDBDSI in Australia, these communities are very small indeed and so-called independent interpreters may do harm, because not all are equally literate in all forms of sign and tactile languages, and individual idiosyncrasies. Because many participants use tactile methods, trust becomes paramount and personal. The use of known, trusted interpreters enhances inclusion because interpreters have knowledge of idiosyncrasies, personal styles, preferences and meanings, while also providing a safeguard against inappropriate touch and communication failure. In this research, two participants disclosed instances of an interpreter's unwanted touch and unprofessional conduct. Both involve unknown, hospital-engaged interpreters, and both cause distress. To create a safe space for all participants, it is therefore necessary to give them choice and control over their interpreters.

In practice, using interpreters changes the narrative inquiry area, for example, needing a larger physical space. Sign and tactile languages are kinaesthetic and energy expensive. Occupational health-and-safety regulations mandate rest breaks every 15 minutes, providing a rest for both participant and interpreter. These necessary interruptions to interview flow are normal for interpreters working with PWDBDSI. My immersion in Deafblind culture helps me understand these norms.

Heterogeneity of communication language is seen among and within interviews. Partway through one interview, a participant switched from hand-over-hand to fingerspelling, explaining, via interpreter, ‘I get more out of English than Auslan. It’s my preference now.’ Another participant and interpreter use a tactile table for some of the interview, reducing their kinaesthetic burden. These events reinforce the decision that participants should choose their interpreters to build trust and familiarity into the best-for-the-individual communication support. Four participants are nonverbal; the AA and I ensure the first-choice interpreter is present, so the participant is voiced according to their preference and intent. This is not unusual, as noted by Lahtinen and Ojala (2018): ‘In order to produce a coherent end product in interpreting, one has to be able to combine different interpreting methods and change them when in need flexibly and creatively to accommodate the changing situations’.

D. Multiple voices

The extra bodies occupying the narrative inquiry space brings the likelihood of other voices engaging in the conversations. And as well as external additions, internal voices arise out of the roles and identities the participants may occupy within an interview. In six interviews, the interpreters added their voice; in four interviews, the support workers did so; and in two interviews, partners contributed. Each voice adds an identifiable strand to the narrative. Both myself and the AAs were attuned for instances of extra people talking or, indeed, taking over narratives, but that did not occur. Transcribers reported no instances of being unsure who was speaking. This absence is remarkable.

There is always a clear identification of an external voice and a privileging of the participant’s voice as principal narrator. The role of those added voices is to corroborate, add contextual detail and support the participant in telling their experiences. The partners, support workers and trusted known interpreters are key informants because they witness the system failures, and few successes, that directly impact the participants.

Some examples of added voices in the research conversation follow:

- 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.’ The worker was not just corroborating what is said, but was witness to a situation in which they, too, experience distress alongside their client.
- Interpreter requested to ‘add a little bit’ in another interview—this ‘little bit’ aims to enhance our understanding of the early history of Deaf education in NSW, and the evolution of Auslan. This explains the participant’s education history, because I am confused which language the participant learned at school and how they communicated. This interpreter asked the participant’s permission to speak and acted as a key informant. During the explanation, the

interpreter stopped and fingerspelled, both what she was saying and what I was responding, back to the participant. This is inclusive and it provided an opportunity for the participant to add, terminate or agree with content. This participant also nodded and, on a few occasions, patted my hand to emphasise what the interpreter was saying and signal agreement.

- In another interview, the interpreter asked, ‘Could I please interrupt?’ then explained the difference between interpreter funding in public versus private hospitals. This pertains to the participant’s two diverse experiences: disempowerment in the public system and empowerment in the private. The participant nodded her head in approval during this exchange.
- One partner leaned towards the iPad, 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 her 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’.

6. Plurality of internal voices and roles

An unexpected finding in the research is that some participants have more than one voice or role identity. Initially, I envisioned participants occupying the singular role of ‘inpatient’ in hospital, but it became apparent in the interviews that this is a major misassumption. Participants with DBDSI occupy many roles in hospitals, as in life, and have many experiences in those roles, both positive and negative. Demonstrating the breadth of roles that participants disclose: all experience being a patient; seven are informal educators about disability; four are present or past healthcare workers; three care for others; three advocate for others; two are visitors to hospital; two are formal educators of health students or nurse educators; and single participants are support workers to PWDBDSI or a research participant (additional to the present). PWDBDSI are often assumed to be passive recipients of care and support, but they also occupy roles as carers and or advocates for others (Hersh 2013a; Schneider 2006; Simcock 2017a), thus demonstrating a willingness, as evidenced here, to contribute to society.

It must be noted that these roles were not explicitly solicited; they represent only a minimum of possible roles and frequencies.

One participant who is a health professional voiced two personae in their interview: their patient and professional selves. 'Be kind to people with disabilities' (patient voice), followed by: 'Ask and find out what the patient needs and be consistent' (professional voice). This participant commented on handover: 'Tell everyone at handover this patient is disabled, not a difficult patient'; the professional voice was evident again. This voice knows how staff reduce patients who do not conform to the easy 'compliant model patient' by labelling them as 'difficult'. Difficult patients are easier to dismiss. Finally, after a disempowering experience, the patient voice said: 'No one should be allowed to be rough and brutal with any patient', but ended the sentence with the professional voice: 'I never was and don't see why anyone else should be.'

In addition to their expert-knower/patient perspective, another participant added an expert-educator voice: 'You are going to experience a lack of understanding from medical staff because they're not trained in disability … what is needed is people with a disability to go and talk.' For one interview, the researcher negotiated dividing the experiences into the three different roles (patient, carer and visitor), for clarity and to examine each role effectively. As a result, this interview gave great insights into multiple roles and complexity of experiences in hospitals.

Noncorporeal elements

Narrative inquiry seeks to appreciate human experience 'by understanding how the individual story has been put together within the mind of the teller' (Minichiello, Aroni & Hays 2010, p. 276). There are many elements in how participants with DBDSI produce then tell stories. The narratives the participants use to illustrate the patient experience in hospital include the use of style, words, metaphors and emphasis. For many, there is evidence, too, of a dissonance between words and experience. As the interviews progressed, it became evident that these elements do not take the form, frequency and style that sighted-hearing research participants report, as described in texts such as Bernard (2013); Bochner and Ellis (2016); Denzin (2001); and Minichiello, Aroni and Hays (2010). This is a large body of expert-researcher work, imbued in sighted-hearing sense-ness, that does not always align when working with participants with DBDSI.

1. Storytelling style

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. Interestingly, the four who do have healthcare backgrounds give a traditional health history–style narrative of their hospital experiences, beginning with a presenting problem, continuing through a 'therapeutic emplotment' of diagnosis to treatment, and thence discharge.

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).

The participants experience chaos as a result of their lack of access, power imbalances and not knowing what is going on; the experience of the illness is almost subsidiary. Frank's story 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 barriers to orientation and mobility.

For many participants, there is tacit acceptance of 'this is how things are', as well as relief at surviving hospital experiences—with no mention of surviving the disease, injury or surgery. Experiences of actual bodily disruption are mostly absent from the stories, except when they contextualise problems. One participant was well enough to toilet themselves: 'recovered from (surgery), drip out but moved to another bed and not oriented'. As a result, they needed assistance but 'pressed the buzzer again and again but no one came'. Participants do not seem at all concerned about their illness-care, but the person-care(lessness) they experience.

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. Another participant, who has post-traumatic stress disorder (PTSD) from multiple institutional abuses and neglect, offers experiences as snapchat-shots in nonlinear order. They describe an event from one time period in brief, quickly followed by another in a different time. They know what happened but do not relay it in traditional narrative style.

Through reading and rereading the transcripts and putting events on cards, I construct a narrative of their experiences. 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. Debriefing was very important in this particular interview, because I wanted to leave the participant in a positive emotional state. This was achieved by him demonstrating his invented devices.

A second 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 hospital's 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.

Yet another participant has multiple layered experiences; these are only possible to navigate by dividing them up at the outset. Again, not a linear narrative but illustrative events centring around accessibility, communication and mobility; barriers to entry in hospital (signs, lifts and absent tactiles); barriers to finding loved ones in their right beds when moved around; barriers to receiving and giving information; 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 disease or injury or the treatment, but the indignities.

2. Words

Minichiello, Aroni and Hays (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).

Words, gestures and signs are the smallest unit of narrative content but, in this research, they are also the most powerful. Examining the way participants use words is grist for the development of subthemes and themes. The following are examples of terms used, highlighting the verbs describing negative touch experiences in hospitals. Each line represents an individual participant.

- Frustrated.
- Shove. Force.
- Push. Grab. Take.
- Pain. Push.
- Bypassed. Frightening.
- Frightened.
- Dragged. Lash out.
- Confused. Brutal Shoved. Rough. Terrifying.
- Grabbed. Pulled along.
- Shaken. Touch. Grab. Poke. Push. Shove.
- Frustrated. Anxious. Frightened.
- Freaking out. Shoved. Panic attack.
- Grabbing. Pushing. Shoving. Dragging.

Here, a group of concept words—such as 'push', 'poke' and 'shove'—form a subtheme of negative touch, because they are all linked by the participants' distress at episodes of unwanted, unexpected and unnecessary touch. The perpetrators are health professionals. The overarching theme is one focusing on the patient's powerlessness but also the communication failures and power exertions that underpin these events. This is discussed in more detail in **Chapter 10**.

Several participants make word associations: a staff member doing their job is 'nice' or 'lovely' but one who, by attitude or action, gives poor or no service 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.

A participant with healthcare experience observes that a person with sensory losses is a ‘patient with disabilities, not a difficult patient’. As a healthcare worker, they know the loading of the word ‘difficult’. In the introduction to *Management of the Difficult Patient*, Haas et al. (2005) write:

> All physicians must care for some patients who are perceived as difficult because of behavioral or emotional aspects that affect their care. Difficulties may be traced to patient, physician, or health care system factors. Patient factors include psychiatric disorders, personality disorders, and subclinical behavior traits. Physician factors include overwork, poor communication skills, low level of experience, and discomfort with uncertainty. Health care system factors include productivity pressures, changes in health care financing, fragmentation of visits, and the availability of outside information sources that challenge the physician’s authority (p. 2063).

Sensory impairments are not explicitly mentioned in Haas et al. (2005), but communication is recognised as a contributor. The transcripts show that several participants’ responses indicate they are frightened of being ‘difficult’ or ’demanding’ or ‘too needy’. One participant described difficult behaviour as a consequence of communication failure: ‘When you don’t know what is going on because you are blind, you lash out.’ Other participants describe being misperceived by staff as ‘aggressive’, often in the context of operating theatres or recovery rooms. One was told, when confused and disoriented, that being aggressive was ‘not acceptable behaviour in this hospital’.

Another participant described: ‘I woke up and I remember seeing hundreds of blurry shapes … I didn’t know who they were and why they were all around my bed … apparently I was agitated and aggressive.’ Thus, aggressive becomes a misnomer—a label that dumps responsibility of failed professional care and communication on the participant with DBDSI. This reflects what Hersh (2013a) calls the ‘tendency to consider communication problems to be purely a consequence of the deafblind person’s impairments rather than the attitudinal and infrastructural accessibility barriers and other people’s lack of knowledge about communicating with them’ (p. 462).

3. Metaphors

Great store is set by visual and auditory metaphors, generally in literature, and particularly in narrative medicine (Charon et al. 2017). In our interviews, however, metaphors prove few. Narrative medicine exhorts me to be alert to storytelling conventions and devices, and what their presence communicates—here, I am wondering what the paucity of metaphor and lack of conventional structures of storytelling signify. Participants often say what they mean unembellished, metaphor-free, 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-hearing, privileged language. Linear stories and metaphor-laden narratives are designated as rich, but if you need communication supports, your story is less likely to be heard, valued or legitimised, regardless of how endorsed or relatable it may be within your own community. The sole examples of metaphor in the interviews are as follows:

- ‘I’m in the too-hard basket’
- ‘Felt like a bird in a cage’
- ‘all those mouths going 100 miles an hour and how I just couldn’t understand what they were saying’
- ‘It’s a lucky dip’ (with the staff you get in hospital)
- ‘Led astray by misinformation’ and led ‘like a dog on a leash’
- ‘it was just talking about someone they thought was on paper’.

As well as a marked dearth of metaphors, the analogies used are simple. It appears that stories are told, almost exclusively, using action words (push, poke, shove, ignored) to describe what is done to the participants; and emotion descriptors (panicky, anxious, scared, relieved) to show how this made them feel. These are the pain points in the patients’ journeys.

4. Emphasis

For PWDBDSI, their means of emphasising feelings and events are often different in mode and frequency to those of sighted-hearing narrators. The repertoire of emphasisers include repetition, gestures and signs, touch, vibration, louder or lower vocalisations, expletives, or an interpreter flagging added weight. Repetition is the most commons and principal stylistic device employed for emphasis. Examples include:

- ‘No no no’ (in response to ‘Did you have an interpreter?’); ‘They (the doctors) just talk, talk, talk’; ‘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.’
- ‘It is not right, not right.’
- Fists clenching and moving in the air repeatedly
- Signing getting more theatrical and quickening when emphasising distressing parts of story.
- ‘I’ve taken in the medical report a number of times, with me, and they’ve never ever read it. **Never**. **Never**.’ (Bold added for emphasis.)
- ‘deafy, dumby, deafy, dumby’
- ‘I don’t like that; “I don’t like that” and I just push them away.’
- ‘it’s more tiring than trying to recover, having to start at Ground Zero all the time. Same thing again. Same. Same. Same. Same.’
- ‘They didn’t always communicate with each other, so you’d have to start again, start again.’
- Repeating the upsetting details of a story.
- Hand up in front of face, talking of previous negative touch experiences from ‘aggressive, aggressive staff’.

Banging on the table is a social norm for indicating both turn-taking and emphasis. In one interview, the participant banged the table repeatedly. The vibration sent its own message of distress and displeasure. Some participants touched the researcher's hand, signifying emphasis of a particular point; for example, four participants touched my hand while the interpreter was relaying what was said.

Participants who are verbal and/or oral English speakers often raise their voices to make a point. One raises their voice when saying 'I had **no idea** what the treatment plan was' (bolding added to indicate emphasis). Conversely, one participant spoke in a whisper 'I don't like hospitals'. I don't hear the whisper, but later read the words in the transcript and am moved by their power.

Keening sounds came from one nonverbal participant (a rising pitch sound when discussing her anxieties and fears, underscoring their depth). This sound was not made when she signed about pleasant events such as meals or excursions with support workers. Similarly, an interpreter for another participant flagged a change in emotional range by relaying: 'she is saying this loudly: **it isn't right, it isn't right**' (here, the participant used both a louder tone and word repetition for emphasis).

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."'

Emphasis, in its varied forms, is used more than metaphors or tropes for highlighting examples of ill treatment, and as a device to convey the emotional responses to these experiences.

5. Dissonance between words and experience

The contradictions and tensions between what is said (the words) and what is experienced is known as dissonance. There are many examples of dissonance in the transcripts and interview notes. Where participants, and PWD 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 has implications for patient-experience evaluations.

Avery (2018) discusses how the persistent and pervasive experiences of racial discrimination of First Peoples with disabilities lead to internalised dissonance. This results in them avoiding situations where there is the potential for racism and/or ableism. Avery's participants do not make formal complaints, a result of intergenerational mistrust of the police and other government institutions. These experiences are then not believed, valued or heard (Avery 2018).

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. My clinician persona is astounded at the volume of negative experiences tacitly accepted as okay, good or normal. Examples include participants:

- Demonstrating tacit acceptance of the repeatedly abusive and neglectful experiences endured
- Describing experience as ‘good’, before describing nearly suffocating and being unable to get help from staff
- Describing experience as ‘good and smooth’, with an obvious disparity with the traumatic experience recollected
- Experiencing multiple communication failures, misattribution and neglect, but these are ‘okay’, because those in aged-care homes ‘have a worse time’
- Describing response to complaint as being told to ‘go away’
- Describing experience as ‘okay’ because ‘I survived’ it, not because care was predictable and good
- Complaining and not being listened to. Feeling disempowered but describing experience as ‘alright’
- Describing ‘good’ care received but then detailing the hard work and time it took to receive communication from medical staff in accessible ways, over a four-week period
- Describing experience as ‘good’ but then detailing problems communicating with staff, which confer added risk.

One participant reconciles this dissonance, noting: ‘Overall, they [hospital and staff] did not look after me and I came out of it OK, but I don’t look forward to going to hospital anytime soon, thinking I’ll have to go through that again.’

Conclusion

This research is founded on the principle that only PWDBDSI are able to adequately tell their own stories. This means 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. So, we must listen for nuances and newness in the altered narrative space of these participants with DBDSI.

The performance elements of the interviews give insights into the different spaces that PWDBDSI occupy, and the communication and other adjustments provided during this research. These have fundamental differences from the spaces that the sighted-hearing occupy. Interviews take place in safe places, both real and virtual, with trusted supports. There are many voices in the rooms, but these are identifiable, and the voice of the participant is always privileged as the principal narrator. No story can be told without aids and aides; for most participants, these are necessary if their voices are to be heard, read and felt. The narratives that unfold do so with the diversity of the tellers—snapchat-shots, moving pictures, collages—few exhibit therapeutic emplotment and many are chaotic. Metaphors of visual and auditory richness are largely absent; in their stead, powerful action words and descriptors paint pictures of distressing events and emotions. Finally, there is a jarring discord between some of the words and what really happened to many participants with DBDSI when in hospital.

These performances and their elements, both embodied and nonembodied, tell us much about the stories, but less about the participants themselves. The next chapter will present some of the living realities and concerns of the participants—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). This situates the participants, giving evidence to the stratification and complexity of their reality.

Chapter 9

Findings 2: Living realities and border concerns

Introduction

The previous chapter presents the findings through an observational reflective analysis into ‘doing’ and ‘being’ in the interviews. This second findings chapter begins to situate the 18 participants within their sociodemographic domains, then examines the heterogeneity of their sensory impairments to give a clearer view of who they are. This research recognises and demonstrates the participants’ heterogeneity in their living realities, communication impairments, function and identities. Here, the term ‘living realities’, instead of the usual ‘lived realities’, denotes that the participants’ lives, impairments and circumstances are not past; they are very present.

While the interviews focus on hospital experiences, the participants are candid about a range of social factors that add complexity to their lives and pose threats to their health, wellbeing and flourishing, in what they considered to be a safe space with an insider-researcher. They discuss border concerns of ageing and aged care, employment and education, the NDIS, access to healthcare, stigma and shame, interpreters, falls and accidents, acting as a carer, misattribution, and social isolation. This doctorate has limited space, however, so it surveys only three of the concerns pertaining to the situations of this research population: (1) ageing and aged care, (2) social isolation, and (3) healthcare access.

PWDBDSI have situational vulnerabilities because of reduced access to information, communication difficulties and mobility limitations—a noxious combination of impairment effects and social barriers. These living realities are complex.

About the participants

While the 18 participants displayed extreme heterogeneity and inhabit plural realities, they represented only a portion of all the populations of PWDBDSI.

Sociodemographic information

Age

Participant ages ranged from 25 to 71 years. Only four participants are over 65, thus the group does not display the same preponderance of over 65s seen in the sensory impaired population. As discussed in **Chapter 1: Complexities**, under 65s represent one-third of the population with sensory impairments; this proportion increases rapidly with age from 65 onwards. Yet, this research group has only 22% over 65 years.

Gender

There are more females than males, 13 and 5, respectively. No one identifies as non-binary. These are similar distributions to those of Wahlqvist et al. (2016) who write: ‘15 participated in the study (72%), 11 females and 4 males’ (p. 246). This may reflect gender differences in those who use impairment support organisations because these are the study’s principal source of recruitment—securing 13 participants. Two of the males were recruited by word-of-mouth (from friends involved in impairment support organisations, even though they were not).

Location

The participant distribution differs from previously reported geographical spread, which places one-third of PWDBDSI in rural and remote regions (Dyke 2013). In this study, 83% are from an urban setting and 17% are from regional or rural areas. No one is from a remote community. This demonstrates the difficulty of access and funding for such a reach, as well as showing that remote dwellers with co-occurring sensory losses are difficult to identify and hard to reach geographically.

Identities

1. Indigeneity

None identify as Aboriginal and/or Torres Strait Islander; this is a major limitation of the study. As identified earlier, First Peoples of Australia experience high rates of sensory disability and multiple disadvantage. This substantial gap would be best addressed in future research with the leadership of, and in collaboration and conjunction with, the First Peoples disability community themselves.

2. Impairment identity

Smith-Chandler and Swart (2014) write:

> A dominant conundrum in disability research is the assumption that all participants in a particular study will form part of a collective ‘disabled identity’. This expands Singal’s (2010) powerful statement that the very act of research can be disabling in itself (p. 424).

This is certainly true of PWDBDSI, who occupy multiple identities of sensory impairment or loss. While diverse, they may change over time, with different audiences and purposes. Some do not consider DB as a disability, but rather a normative state-of-being; for example, ‘Deafblind and bloody proud of it’, as one participant avows.

A total of 12 participants identify as d/Deafblind and 4 as dual sensory impaired. The low rate of dual sensory loss/impairment reflects the low number of participants aged over 65 years. Blindness is both a singular identity and one paired with hearing loss for five participants, and low vision for one. No one identifies with ‘just’ a hearing loss, but one participant sometimes describes themselves as having hearing and sight loss.

Six, or one-third of the group describe multiple identities, with two participants describing more than two. There is a bias towards discussing what identity participants gave to hospital staff, which is not unexpected, given the focus and purpose of the research interviews. One participant identifies as low vision but says ‘I’m deaf’ as well, if they had trouble hearing in hospital settings. Another participant switched when in hospital, saying ‘I use dual sensory impairment generally or hearing and sight loss, but if I want to get proper full-on-attention or service, I will say deafblind.' Another who uses a dual sensory impaired orientation generally shifts to deaf and blind for hospital visits. Still another says, 'I am deafblind' to doctors but otherwise is 'blind with hearing loss'. One younger participant has three identities, using 'Deafblind' in general healthcare settings, 'but if talking to Deaf people I will say Ushers because they know what this means', with their most tightly held and used identity: 'I am Deaf with low vision.' A final participant, adopting multipurpose identities, uses hearing and sight loss, deafblind and dual sensory impairment.

Living situation

Of the participants, 56% live by themselves. In 2016, 24.4% of Australian households are single occupant (ABS 2016). The higher rate (more than double) of PWDBDSI living solo has implications for policy and supports, because isolation may constitute a threat to health and wellbeing. A further 28% reside with family and/or a partner. This lower rate of partnering may reflect that there are more female than male participants, because males with DBDSI are more likely to marry (World Federation of the Deafblind 2018). This study does not capture the experience of those in group homes because no participants dwell in one. However, four (22%) are in residential aged care and only one of these entered aged care at an appropriate age (over 65 years). The others entered the aged-care system up to four decades earlier: two had been in aged care from age 20; one from age 40; and one from age 66. These individuals give worrying insights into the care they receive. While not the focus of the present research, they are examined later in this chapter to contextualise the living realities of some PWDBDSI.

Education

The participants received diverse types of schooling. Less than half (44%) were mainstreamed, and not always happily so, with some reporting bullying and/or lack of learning support. One participant comments he did not like high school and 'preferred one-on-one teaching'. Another reports being unhappy in mainstream high school and experienced bullying with other students chanting, 'deafy, dumby, deafy, dumby'. More than a quarter (28%) attended a specialist school for the deaf, blind or deafblind. One was educated (if that is the correct term) at a specialist school for her other impairment and comments: 'I wasn't considered intelligent enough to learn braille, it was thought.' This situation of institutions and organisations overlooking sensory impairments and remediation for other impairments/disabilities is present in the literature (Dammeyer 2014; Fellinger et al. 2009); as well as in **Chapter 1: Complexities**.

Five participants left school before completing Year 10. Some participants comment how impairment effects, hospitalisations or technological breakdowns (where hearing aids took 'weeks or months even to repair') impacted their education.

Multiple TAFE courses serve as a default setting for employment support; one participant was about to undertake his fifth course but is yet to find employment and finds this 'very depressing'. Another participant is yet to find work after completing three TAFE courses. One interviewee 'loved university' but had to discontinue due to new impairments that impacted mobility.

Occupation

Generally, meaningful work is a major contributor to identity and wellbeing for PWD (Smith-Chandler & Swart 2014). The issue of employment, or rather the lack of opportunities for paid work, preoccupy the participants as well as the broader communities of PWDBDSI and PWD. One participant is employed, albeit casual part-time, and would welcome permanent full-time work. Another participant works in a volunteer capacity but would rather a paying position. Three are retired. All other 13 participants are unemployed and would like to work.

As impairments worsened, a pattern of employment opportunity attrition emerged. Eight participants describe losing their jobs when impairments deteriorated. Those in aged care do not work, but one had unpaid volunteer work. One younger participant says: 'I can't find anything that would let me work … employers won't believe someone with hearing and sight loss could possibly have brains that are okay.'

Healthcare background

From my own experiences, the question arises: Does occupational healthcare experience safeguard a patient from negative events in hospitals? Four participants have healthcare work backgrounds. While conducting health literacy assessments is beyond the scope of this research, examining the experiences of the four participants who have some 'insider' status and experience in the health system could lead to preliminary observations that might direct future study. Thus, participants were asked if they had ever worked in the healthcare sector. The Australian Institute of Health and Welfare (AIHW) (2018) reports that low health literacy 'can be associated with higher rates of hospitalisations and emergency care use' and 'undesirable outcomes, such as premature death among older people' (p. 183). Participants with healthcare backgrounds still reported negative experiences, although two of the four complain about their care—one fails to secure communication improvements and the other is invited to contribute to nurse education sessions to improve care and communication.

Communication/language

The participants use varied languages, which may change over time. Participants adapted language and communication methods in different circumstances and for different audiences. The participants often did not use the same language today as their first language, but their second (or third) language. In addition, the communication language used for organising interviews was often different from that used during the interview itself.

Four participants (22%) are nonverbal and use no spoken language, relying entirely on tactile signed language to give and receive communication. For 67% of the participants, their first language is spoken and heard English (oralism). This reduced to 39% at time of interview. Sign language (all forms—tactile and visual) is the first language of four participants in childhood, but this number increased to eight at time of interview, as the language in current use. Changes within the sign language–using group are also evident throughout time, with restricted-frame, hand-over-hand and tactile signing used as participants' vision deteriorated throughout their life course. Auslan is the first language for four participants and, as such, written English is a second language for them; because Auslan is not a visual English language—it possesses its own idioms, norms, grammar and forms—there is no straight transliteration.

Impairment information

The participants show the expected heterogeneity of causation. Half have Usher syndrome (USH), four have congenital DB and the rest have acquired hearing and/or vision loss later in life, after attaining speech and language. One has congenital hearing loss with acquired vision loss, and another has congenital vision loss with acquired hearing loss. However, the present cohort fails to capture the breadth and extent of the population over 65 years. Less than 10% of participants have both their hearing and sight loss acquired in older age. This low representation is likely due to how different subpopulations use impairment support organisations (or not use them, in the case of older Australians).

The USH classification is based on self-reporting; that is, what the participants understand to be their diagnosis. Only two have genetic confirmation. This reflects the age of the cohort because genetic testing is relatively new, very expensive, infrequently offered and unsought by those who 'know' their diagnosis. As indicated in **Chapter 1: Complexities**, new protocols are increasing genetic testing and at younger ages—in particular, for babies born with sensory loss (House of Representatives Standing Committee on Health, Aged Care and Sport 2017; Grigg 2019). The present low genetic confirmation rate will change over time, as new babies are diagnosed and adults participate in gene therapy, bionics or other therapeutic research, which requires genetic confirmation (Grigg 2019).

One noticeable finding is the number who say they were told they had presbycusis (age-related hearing loss) on top of their USH diagnosis. I can find no academic documentation on this but wonder if it is a feature of some subtypes of USH, and not age related. Researchers from the Netherlands have demonstrated that USH2, while traditionally believed to have stable hearing loss, does in fact have both stable and declining hearing subgroups (Hartel et al. 2016).

The participants commonly mentioned cataracts as concomitant to USH. This is well documented in the literature (Boughman, Vernon & Shaver 1983; Lamey 2019; Nikolopoulos et al. 2016; Vernon 1969).

Multiple impairments

Because this research does not endeavour to obtain personal medical details, participants were not asked about the presence and nature of any additional impairments, which are commonplace (World Federation of the Deafblind 2018). However, many participants (33%) disclosed additional impairments in their stories or histories about their hearing and sight loss. Thus, the real incidence of other impairments in this group was likely to be higher.

List 11. Impairment information

Impairment = Number (%)

- Congenital DB = 4 (22%)
  - Birth asphyxia = 2 (11%)
  - CHARGE syndrome[2] = 1 (6%)
  - Prematurity = 1 (6%)
- Congenital hearing loss/deafness with acquired vision impairment = 10 (56%)
  - Usher syndrome Type 1 = 2 (11%)
  - Usher syndrome Type 2 = 3 (17%)
  - Usher syndrome Type 3 = 0 (0%)
  - Usher syndrome Type Unknown = 3 (17%)
  - Atypical Usher syndrome = 1 (6%)
  - Congenital hearing loss, followed by meningitis at 30 years = 1 (6%)
- Congenital blindness with acquired hearing impairment = 2 (11%)
  - Rod-cone dystrophy with hearing loss in childhood = 1 (6%)
  - Retinopathy of prematurity with ear tumours in late childhood = 1 (6%)
- Acquired hearing and vision loss = 3 (17%)
  - Iatrogenic vision loss and occupational/recreational hearing loss = 1 (6%)
  - Optic neuropathy and age and trauma related hearing loss = 1 (6%)
- Age of onset over 65 = 2 (11%)
- Other impairment = 6 (33%)

List 12. Impairment frequency

Impairments = Number of responses (%) / Percent of cases

- Congenital deafblindness = 4 (13%) / 22%
- Congenital hearing loss and acquired vision loss = 10 (32%) / 56%
- Congenital blindness and acquired hearing loss = 1 (3%) / 6%
- Acquired = 3 (10%) / 17%
- Acquired age-related = 2 (6.5%) / 11%
- Multiple impairments = 11 (35.5%) / 60%

Border concerns

PWDBDSI may hold grave concerns about healthcare and hospitalisation, but they also lead complex lives with additional encumbrances. Slightly more than half the participants describe concerns separate from the present field of inquiry that still impinge upon their health and wellbeing, both directly and indirectly. Border concerns are many and diverse, including:

- Ageing and aged care
- Low employment and fewer education opportunities

- Navigating the NDIS (brickbats for those who found it difficult to get funding for much needed support and bouquets for those who obtained support efficiently and sufficiently). Note, two participants remark on the failure of the NDIS (at the time) to acknowledge and categorise DB as a distinct disability, forcing them to choose between deafness or blindness as their prime disability.
- Difficulty accessing primary healthcare
- Stigma and shame, both related to using hearing aids and perceptions about how their families and others feel about them
- Interpreter supply (not enough) and demand (very high)
- Risk of falls and traffic accidents
- Acting as carer as well as being cared for. Note, care and caring are not dualistic: an either/or situation. Some participants are carers as well as needing support for their disabilities. Three of the participants cared for older parents or partners, while four were parents themselves.
- Misattribution by others not in a healthcare situation; for example, the police or a boyfriend. This usually entailed being thought of as drunk or drug-affected.
- Social isolation.

This list of living realities comprises a number of social determinants of wellbeing, which link to earlier discussions in **Chapter 5: Externalising the literature**. There is neither scope nor space within this doctorate to explore these border concerns in detail. Ageing and aged care, social isolation and poor access to healthcare are linked ineradicably, however; they locate the participants with DBDSI in a specific social reality and are discussed below.

Ageing and aged care

Increasing age brings increasing burdens and vulnerabilities for PWDBDSI (Simcock 2017a). Some age with DBDSI but most age into sensory impairment. Ageing brings with it the real prospects of further impairments, hospitalisations and residential care.

Ageing

For five of the participants, ageing is a looming or present anxiety. These participants allude to some of the difficulties for those who are ageing with DB. First is the loss of traditional support networks. One participant notes, ‘My mother is elderly so she can’t help me as she used to.’ Then some may lose the visual language they use and love. A participant describes getting older as a watershed issue; they hadn’t yet adopted or adapted to tactile language: ‘I learned sign language and I did Auslan … but, unfortunately, the eyes deteriorated.’ One participant lost friends in the Deaf community when she could no longer see to use a vision-based sign language. The loss with age of fine motor skills, fingertip sensation and proprioception have consequences for the older person. One, an older participant, observes: ‘Hearing aids are hard to use … very hard, small buttons … batteries are difficult to change … I have to get someone to help tear the sticky paper off the back [of the battery]'. Another is 'unable to learn braille because [they] just couldn't get "the touch".'

Aged (no) care

One participant, not living in aged care, says: 'You should talk to the people in the [aged-care facilities], they have a worse time.'

Five participants experience neglect and/or problems in residential aged care, four as permanent residents and one as a temporary stay. This is a contemporaneous wider community concern with the Royal Commission into Aged Care Quality and Safety (RCACQS) currently underway. Given the similarities among the vulnerabilities of PWDBDSI in hospitals and residential aged-care facilities, this border concern is examined now.

For three participants, residential aged care is something they were forced to contend with at a young age (before 65 years) because there was nowhere else to go, or no funding for alternative accommodation. One participant entered aged care at 66 after losing their sight. Another spent time in aged care temporarily as a younger person, while waiting for modifications to community housing.

For context, approximately 6000 people under 65 years of age with terminal illness or disabilities live in aged-care facilities in Australia (RCACQS 2019, p. 233). Of these, about 3000 are PWD. That number remained 'relatively unchanged' for more than a decade (RCACQS 2019, p. 233). The Royal Commission's first interim report describes the situation of younger persons entering the aged-care system as 'a human rights issue' (RCACQS 2019, p. 241). The CRPD clearly sets out that PWD have the right to choose their place of residence. In this study, the participants presently living in aged care did not have that choice; three of the four express a strong desire to live elsewhere. 'I don't like [nursing home name] at all. It's bad … The nursing home focuses on end-of-life care, not on my life,' says one participant. Another echoes this, describing 'living with people of advanced years, very short life spans and high dependency needs, such as advanced dementia, is so very unsatisfactory for a younger person.'

There are many detriments to placing younger PWDBDSI in residential aged care, which stem from two components: first, residential aged care lacks the environment to provide a younger person with a home life. Second, aged care is ill-equipped and not inclined to provide for the communication needs of younger PWDBDSI, or to adapt to changes in their communication methods throughout the life course, as evidenced by the participants' stories of life in aged care.

Two key aspects of 'aged-no-care' are examined: first, how the participants' residences lack an environment for flourishing and are devoid of communication partnerships, plans and practices to foster social participation. Second, how social isolation is a direct result of these poor environments and deficient communication. This is a general concern for

PWDBDSI, particularly for those in aged care (Jaiswal et al. 2018; Möller & Danermark 2007; Simcock 2017a).

In regard to ageing and aged care, an official corroboration is currently underway, via the Royal Commission, of the pressing disquiets voiced by these four participants. The interim report, released in October 2019, led with the plight of the younger person in aged care, stating that urgent work is needed to stop the flow of young PWD going into the aged-care system. The government responded in November 2019 with $0.5 billion in funding.

A separate Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is also examining the plight of PWD, who endure abuse and neglect in the community and institutions. These are emerging and developing situations, but the National Disability Insurance Agency (NDIA) is now aware that there are human rights abuses in denying PWD a choice in their housing (RCACQS 2019, p. 242). For some of the participants in this research, however, human rights abuses are not a risk but a fact.

A deprived environment

For the participants, residential aged care is not an environment where they could flourish with their peers. 'I've been here twenty years already,' says one participant, just over 50 years old. Another participant observes that, being a PWD, there is a need 'to constantly educate the staff' in both hospitals and residential aged care.

Residential facilities use restrictive practices to 'manage' residents. As set out in the Royal Commission (RCACQS 2019), restrictive practices cover sedation and restraint. Participants living in aged care do not just experience isolation, with no communication partners at all in their 'home', but also endure forcible management: unexpected, unwanted touch and other restrictive practices. The participants describe restrictive practices in residential aged care as including unwanted touch: 'I don't like people touching my body all over without letting me know what they're intending to do'; forcible medications: 'push my chin down and shove medicines in'; and sedation. There is a suspicion, voiced by both participant and support worker, of being given sleeping pills at night because 'I am sleepy during the day.' This participant describes sedation and restraint in the hospital setting as well. They elaborate further about the frustration of being unable to change their situation, with one participant saying, 'I am not invited to speak on any reviews of my care.'

However, being age-appropriate for residential aged care is no safeguard from neglectful practices. One participant, who is over 65 years old, compensates for his institution's neglect by trying to support other residents with advocacy and supervision: 'I'm the only one here able to do things. Unfortunately [the rest] are all too sick or too old to do anything.' Management is described as neglectful, where residents die but no one notices: 'Everyone here is old and has disabilities … It is isolating … I've found three people dead here—I've got it going that if you haven't seen your neighbour … we need to know about it.' A participant living in residential aged care with their partner, who has multiple disabilities (including DSI), is concerned that their partner might fall. They use a walkie-talkie system to call each other in emergencies; thus, the participant, not the staff, is the one to call an ambulance.

Devoid of communication partners, plans and practices
One participant had lived in aged care for three decades and was age-appropriate at long last. She notes that it 'has not always been a good place'. Despite having many Deaf and a few d/Deafblind residents over time, there was a lack of staff members who could communicate with them: 'A few fingerspell or write on my palm or my arm. They will use a rubbing-out motion when a mistake has been made.' In 30 years, 'only two people have ever learned to use my braille teletyper.' This, at the very least, was a 'sometimes' communication experience, even if there were periods of time when no one was able to fingerspell, sign or use the brailler. Another participant has no communication partners at all in their 'home' (a term used pejoratively here) unless support workers or volunteers came from impairment support organisations. 'No one fingerspells … they don't communicate with me at all.' If staff do fingerspell, 'they often don't have good English and spelling, so I don't understand what they are saying … Sometimes. Staff print into my hand … but they don't get a tactile interpreter for me.'

Another participant who was in aged care temporarily, discharged there from hospital (with no discharge planning, advanced discussion, communication plan or choice) to await home modifications, tells me that no one at the facility was conversant with Auslan, deafblind manual alphabet or tactile communication methods. Residential aged care is a petri dish for social isolation and its dire consequences.

Social isolation

In the social science and health domains, almost all the literature on DB and DSI acknowledges isolation as a concern. The lack of communication partnership makes social isolation a certainty for PWDBDSI in aged-care residences. Social isolation is experienced by many participants, however, either generally or in specific situations, such as hospital, or both.

Eleven of the participants identify feeling isolated when in hospital, a result of the decentring of patient care for this population group. This is discussed further in **Chapter 10**.

For the participants, isolation takes many forms. One aged-care resident describes how 'family [don't] want [us] (with multiple disabilities) living with them in their homes.' Another tells how he only gets three family visits a year: visits from a support worker and impairment support organisation volunteer outings are the only non-staff contacts.

Those not in aged care are also isolated; for example, when parents and/or extended families do not learn to sign. One participant uses gestures to talk to his parents. Another tells how 'friends and family won't learn tactile language [so even if I learn] I won't be able to communicate with them.' Another explained the benefit of having a mother who signs. A younger participant says, 'my family embraced all types of communication.' Both of these positive experiences belonged to younger participants, with strong family connections fostered by shared, adaptive communication practices.

While the lack of common communication methods is isolating, a cochlear implant can reduce isolation. Two participants have cochlear implants, with the youngest in the research cohort noting, 'without the cochlear implant, my own world is very isolating.'

Healthcare access

In addition to poor hospital experiences, seven participants raise the concern of poor or no access to health services. One tells how she had no access to a GP of choice and must use the one provided by the aged-care residence. Recently, she attempted to change doctors, but it was not allowed without the permission of a guardian. The GP is only called when the staff see a need, not when the participant requests one. Both the participant and her support worker raise further concerns as to poor/non-existent handover between the aged-care facility and hospital, meaning access to vital health information is compromised in both directions.

There is a strong link between interpreter funding and availability, as well as access to healthcare. Many PWDBDSI need support and assistance to access healthcare, but do not have adequate hours of assistance from the NDIS to do so. One participant says there is a need for more interpreter support hours per week, because 'four hours is not long enough for an outpatient appointment at hospital because of long waits'. Another participant has limited support despite significant disability; this is due to the catch-22 of needing disability documentation but being 'too traumatised' to go to doctors and health services for the certification required to prove eligibility and need. In addition, there is no support to help participants get to healthcare because there is no funding without certification. Those with family and friend support networks talk about using them to help with NDIS shortfalls. For example, one participant's sisters step in and help with transport, sighted guiding and healthcare interpreting with visits to the GP. Another wishes the NDIS would provide her with more hours of interpreter-guide support to access both healthcare and other activities.

One participant talks about difficulties with the GP once they had taken transport there. The GP would 'tap me on the leg to say, "move along, move along," because I was taking too long.' He does not like this unwanted touch. One participant speaks about having to visit the GP to find out what the hospital's discharge and follow-up instructions were 'as they did not think that an interpreter was needed'. These observations are incidental because access to primary health services was not specifically asked about in the interviews.

Conclusion

This chapter situates the reader into some of the participants' living realities. The data presented here demonstrates a little of who they are, how they came to have losses of hearing and sight, what they use to communicate and, finally, what they are worried about—their border concerns. Many border concerns are raised, of which aged care, both for younger and older participants, is most pressing from a human rights perspective. Collectively, the border concerns are representative of many social determinants of health and wellbeing. This confirms previous findings in the literature, in which PWDBDSI are socially disadvantaged and disabled by society's structures and inequities. Paying attention to those in residential aged care reveals that these are deprived environments devoid of communication partners, practices and plans. These are currently the subject of a Royal Commission inquiry, however, and not the central focus of this work.

Chapter 10 will next contend with the establishment of concepts, subthemes and the three final overarching major themes. These demonstrate multiple cross-linkages that strengthen these observed connections and relations between power, ontological security and knowing what is going on. If PWDBDSI are going to know what is going on, accessibility to information and communication support is paramount.

Chapter 11 concludes the findings chapters and incorporates the quantitative components in a hospital experience 'Report Card' and salutogenic categorisation of the participant-derived 'Wish List' of solutions, strategies and supports needed to promote positive experiences for patients with DBDSI. This suite of solutions has practical implications for society, ministries and departments of health, hospitals, and professionals.

Chapter 10
Findings 3: ‘Not knowing what is going on’

Introduction

This chapter presents the concepts and themes that arise from the patient-participants’ stories of being in hospital. The concepts derive from words and phrases that group together as ideas; constellations of these ideas form themes. To find them, I use transcripts, notes and observations—both my own and those of AAs. Minichiello, Aroni and Hays (2008) write:

> The themes can be expressed in single words, phrases, sentences, paragraphs or even entire documents. When the researcher uses themes as the unit of analysis he or she is primarily looking for the expression of an idea irrespective of its grammatical location. It is often made up of concepts which are linked together either by the informant and/or the interviewer (p. 262).

The participants’ patient journeys involve many, many points of contact, or touchpoints. Where difficulties arise, these are pain points, and where distress, relief, panic and fear occur, these are emotion points. In this study, the most common touchpoints are pain and negative emotion points, which can be understood in terms of themes of accessibility, power and ontological (in)security:

- Accessibility comprises concepts that relate to communication, access to information, aids to communication, environment, mobility and orientation.
- Power derives from stories and words describing participation and inclusion barriers and enablers, dignity, power imbalances, negative touch, neglect, abuse, dehumanisation, fear, and distress. Mitigating these power disparities, which most participants reference, are agency, positive touch and educating others.
- Ontological security, that is, trust and confidence, is strengthened by minimising imbalances, having support networks, and promoting trust and predictability in communication and care; or by adopting a solutions-focus.

These three central leitmotifs are as interlinked as the sections of a Venn diagram. The subthemes and concepts often belong to more than one major theme; they also exhibit cross connections with each other, strengthening the major themes’ internal validity. For example, issues of accessibility may arise out of power imbalances and result in ontological insecurity. In concert, lack of accessibility, pervasive power disparities and ontological insecurity contribute to the patient-participant ‘not knowing what is going on’.

A note on the quantification of themes and subthemes

The participants’ words, signs and phrases are used extensively to generate and illustrate each subtheme and ensure participants’ perspectives are represented qualitatively.

The deduced subthemes are also described with a frequency count, which is a quantitative analysis according to Sale, Lohten and Brazil (2014). When considering thematic frequencies, these are coded as yes/no binaries. This means that, if a participant experienced the theme or event, it is coded 'yes' and, if not, 'no'. If a participant experienced multiple events belonging to a theme, however, it remains coded as a single 'yes'. Thus, these frequencies only show how many participants endorse the theme at least once. A 'no' response does not mean that the participant did not have issues related to the theme, simply that the theme does not explicitly appear in their interview.

Accessibility

Accessibility comprises access to communication and information; aids to communication; and environmental information, mobility and orientation.

Communication and information

'Information is important,' says Barbara, one of the participants. 'The Deafblind need access to communication and access for the different ways of communication.' By not providing accessible formats, orientation, interpreters and consistent staff, hospitals are neglecting people with sensory disabilities. These failures result in all, or almost all, points of contact between the patient-participants and the hospital system becoming pain and negative emotion points. Problems with accessing information is a concern raised by 18 participants (100%). Common areas of difficulty pertain to admission processes; consent forms; accents of staff; and absence of aids, interpreters and/or support networks. Staff attitudes and behaviours also determine if participants' access needs are met. Most participants (89%) describe multiple failures, which have a chain of consequences for them, culminating in 'not knowing what is going on'.

Nowhere is the dereliction of duty of care, and the flouting of legal requirements to provide comprehensible information, more evident to the participants than in the failure to provide accessible admission forms generally, and consent forms specifically.

About pre-admission forms, Ava says, 'someone has to do your form'. Ben finds them 'difficult and not accessible'. George's sisters come along to do his and Tess 'needs my family present to read the forms'. Rebecca says, 'Stupid online admission form, zoom text did not work on this … so disempowering because [partner] had to fill forms in because I couldn't see, and they weren't accessible'. When Amanda went to hospital, her father 'filled in admission forms' then staff asked her 'to read something, knowing full well I couldn't see'. Belinda says: 'Large-print forms would be so nice, so I could be independent and answer questions myself.'

Emma went to hospital and 'signed the consent form, not knowing what was on it'. Rebecca says: 'Admission clerk couldn't or wouldn't do a large-text consent form for me … I knew from being a health professional what was on it, but the concern for me was, I should have been able to read it, don't you think?' George, for whom written English is a second language and a struggle, says of his consent form: ‘Some writing wasn’t clear, and I didn’t quite understand what was written.’ Barbara says there are ‘no braille forms for me’; and Tess ‘would like forms in braille’ as well. Tom believes that consent forms and paperwork need to be accessible, because ‘often they are glossed over very quickly, and you often don’t know what you are signing. Large print should be standard practice when people give you forms’. I ask him: ‘So you signed things and you don’t know what you’re signing, like consent forms?’ Tom replies, ‘Absolutely.’ No participant is ever offered or receives an accessible consent form.

Discharge is another point at which accessibility failures cause risk. Tess uses a friend to ‘advocate for a discharge summary in braille’. Rebecca’s discharge instructions are inaccessible, so she ‘could not read any of it’. Belinda states that the hospital did not provide an interpreter at discharge: ‘I would have to write things down.’ She goes on to say that the staff ‘weren’t listening to me, although they told me to tell them if I didn’t understand’. Jane has no accessible discharge information about her medications so she ‘didn’t take them’, and information on follow-up was verbal and inaccessible to a sign-language user, so ‘the GP had ‘to ring to find out when I had to go back’. George knows discharge is difficult, so both his sisters come to help: ‘They were working as interpreters, so I felt included.’ This reflects how support networks often do the job of staff.

Accents are a pronounced difficulty, especially if participants use residual hearing (which may not have the necessary frequencies) or depend on lipreading. Lachlan comments: ‘It’s very hard to pick up what people are saying when you wear hearing aids.’ Amanda has problems with accents and Linda struggles with the voices of ‘Asian, foreign and soft-spoken people’. Tess agrees. Ben says, if people have strong accents, there is ‘no communication’. Rebecca developed a complication in hospital and ‘the nurse came in and said something and then said it louder and I said I don’t understand you … she had an accent’. George and Rhonda have difficulty with men's voices as well as accents. Rhonda notes that this ‘reduces the capacity to hear information’. Tom talks about feeling ‘ignored’ when the anaesthetist speaks ‘heavily accented, terrible English’ and jokes that he needed an interpreter to understand the anaesthetist.

For those who rely on fingerspelling, print on palm or who have limited skills in written English, poor spelling is problematic. Annie says: ‘If staff do fingerspell they often don’t have good English and spelling, so I don’t understand what they are saying. Sometimes they print into my palm.’

Staff behaviours and attitudes impact participants’ access to information. Rhonda finds she is not able to understand doctors when they ‘use the computer while talking’. She also says staff talk to each other, ‘excluding the patient’. Ava notes that staff congregate at the bottom of the bed, talking among themselves, ‘excluding the patient’. Tess laments that staff don’t introduce themselves: ‘Staff need to introduce themselves as this is common courtesy, common sense but not common practice.’ Rhonda says: ‘Lack of knowledge in how to communicate is the source of the problem,’ commenting that, in hospitals, 'lots of staff avoid you rather than communicating with you'.

Rose notes: 'Hospital staff sometimes don't know what they are doing; they can sometimes book the wrong type of interpreter such as someone that doesn't do tactile or hand-over-hand.' For George, a nurse on one shift for one day 'could fingerspell', making communication easier, but only for a limited time. Linda says:

> Staff talk over you, not to you. They talk to someone else and here I am thinking, *I'm the patient! Speak to me please!* I might be too hard for them to bother to take the time to explain what is going on.

Aids to communication

Reduced or denied access to interpreters, hearing aids, cochlear implants and support networks means no or poor communication. Amanda says: 'If I had an interpreter, I would know what was going on,' but interpreters are only booked by the hospital 'for special occasions'. Amanda recounts: 'In the [private hospital] recovery room last time, I had an interpreter there and it was good. Without an interpreter previously [public hospital], it was very, very hard.' Despite having written confirmation that she needs an interpreter for consultations, Sally says: 'Doctors wouldn't [book a tactile interpreter] and would go "bah bah bah" and they would try and shout into my cochlear implant.' Emma is made to take her cochlear implant off 'when staff knew I needed it'. Belinda finds it 'frustrating when the interpreter is not there when you need them as the hospital hasn't arranged one.' Emma says: 'No interpreter equals no communication'; as do Amanda, Barbara, Sally, George, Jane and Rose. Barbara 'rarely' has an interpreter when in hospital but, on her last admission, she showed the staff her bracelet that states: 'I am deafblind' and they arrange an interpreter.

Both Tess and Ava need time to put on their hearing aids but find that staff don't wait. Tom doesn't have his 'hearing aids on for the surgery area, therefore had difficulties receiving communication'. Ben, however, is able to have his hearing aids returned to him after his operation and that 'helped to orientate and communicate'. Linda says: 'When I am in hospital, I need my partner to be my ears.' Annie notes that, when her old support worker stayed in the hospital with her, she would say: '"You are going to get an injection," otherwise I didn't know.'

Participants often take responsibility for communication at a cost to themselves. For example, Linda begins wearing her hearing aids at night to be able to hear the night staff, 'so I didn't get good sleep because hearing aids are uncomfortable to sleep in, but I was so paranoid that I would not hear them'.

There are links between these concepts and the broader themes of power and ontological security, as some participants begin to allude. The chain of consequences where those in authority ensure reduced or no access to information culminates in uncertainty, as Jane says: 'I didn't know what was going on as I couldn't have an interpreter because it was too late.' Ava, speaking loudly, emphasises: 'I had **no idea** of the treatment plan' (bold added for emphasis). William notes from his roles, as both a patient with DSI and partner of a patient with multiple impairments: 'The ongoing problem I have had is finding information. Getting information from doctors and nurses. This is the hardest thing.'

The environment, mobility and orientation

PWDBDSI are dependent on others to provide information, not just about their healthcare and treatment plans, but also about the surrounding environment. Of the participants, 71% describe issues with mobility and orientation. There is an unpleasant dance between the dangers of the unoriented staying in bed for prolonged periods and those of trying to navigate the hostile hospital environment without support. They also experience difficulties around the location of meals, misplaced medications and missing aids.

Forced staying in bed is commonplace. Annie is not mobilised because 'I am left in bed'. Barbara talks about very long waits in bed: 'I was always very patient, but it was a long time laying there.' If there is not an interpreter, says Amanda: 'I am forced to lie in bed, not knowing.' Linda observes that staff want her to stay in bed:

> … not walking around with a cane because of occupational health and safety reasons … I actually didn't get up. I only got up to go to the toilet and I sat up in bed and stayed put … for one, because you could be knocking over a trolley or get into someone's road.

Getting out of bed results in a nurse telling Linda off: 'I had a male nurse yell at me that I shouldn't have gone without assistance. He said, "You shouldn't be going anywhere".'

Given what is known about the many risks of prolonged immobility for patients, it is concerning that participants are left in limbo for so long; not knowing what is going on; not knowing where things are; and facing the risk of clots, muscle wasting, deconditioning and other sequelae.

William discusses how being told about the environment is not the same as being shown where things are: 'Things like the toilet and they'd tell you where it was … it is a lot different for me finding my way there in the middle of the night.' Emma agrees: 'The lights are off. I can't see,' because night blindness is a hallmark feature of Usher syndrome. With a communication-guide staying around the clock, however, Rose says: 'If I needed to go to the toilet, I knew where I was going.' Tess and Annie comment on privacy concerns with bathrooms and curtains; Tess says: 'I can't see whether curtains are open or closed'; and Annie wishes for a single room on her own so she is 'not exposed' to others.

Participants need to be told and/or shown tactilely when a meal or medication arrives. Rose says: 'I can't see when food and drink comes,' but when she has a communication-guide staying with her, they 'would say to me that my food had arrived'. The communication-guide continues doing the job of the staff by ‘cutting up food’. Without support, Rose accidentally ‘pushed the food onto the bed’ and ‘missed my meals’. Linda, too, has missed meals because ‘staff plonked the food down and no one would tell you it was there. Then it would be taken away again and then you’d think I’m hungry, I haven’t had any food!’ Linda did not take medications, because ‘they were put down and I didn’t see them’. Tess, too, misses or spills medications.

Lachlan tells of how, getting into the ambulance to go to hospital, paramedics take his white cane off him and say: ‘“No, you can’t take your white cane because you can use it as a weapon”.’ On discharge, Lachlan is left standing outside the ward—no cane, no orientation, no discharge plan and ‘no way of getting home’.

Ava is ‘taken to places with no information’. Likewise, William not only has no idea about the treatment plan, he ‘did not even know where I was going’. Staff say: ‘Follow the yellow lines’ (to a blind person), say both Rhonda and Rebecca. Jane says that staff wouldn’t take her to the bathroom: ‘They just pointed.’

Annie is sent for an X-ray with ‘no communication at all’. Sally tells: ‘Of course, when they sent me to different places, they didn’t book an interpreter, so I wouldn’t know,’ adding, if there ‘was no interpreter, I was just confused’.

Linda reports that she got orientation one time, on one shift, where: ‘One nurse was really good. She said, “You’re the second bed from the left, near the window.” Once you have got it into your head, you feel a little bit more secure’. Note here how Linda uses the word ‘good’ to describe a staff member simply doing their job. Ben comments that, on his admission to a specialist eye hospital, ‘staff were helpful and attentive to [my] safety’. This made him ‘feel safe’, too. Yet Tom, even in the specialist eye hospital, has trouble ‘finding the room’.

The environment of the hospital troubles William, who observes,

> … in hospitals, there’s always obstructions, there’s always walkers and things all-round the rooms that you can knock into … and it’s not like in railway stations where you’ve got a lot of tactile markers, which you can feel. Why aren’t there tactile markings?

Linda talks of the different bathroom layouts as a problem, specifically where ‘I can’t find the soap dispenser, bin, sink, exit, et cetera … I can get disoriented in the bathroom and get trapped’. It seems ‘you have got to relearn, as each one is different’. She adds, staff move things, too: ‘Buzzers, moving tissues, moving your water, your DAISY player (a device for the blind that reads audio books) … and it is also disorientating moving beds from ward to ward.’ Linda is moved many times and ‘they didn’t tell me anything [about where I was]’.

Annie explains the consequences of absent support: ‘I have had falls in hospital because nobody is around to orient me or to help me.’ This illustrates how uncertainty exists for participants, because staff cannot be relied upon to provide basic orientation, care and communication from shift to shift. As a consequence of not meeting support and communication needs, participants with DBDSI are exposed to additional risks and actual harm—when in hospital, they are not receiving the same level of care as the sighted-hearing.

Power

In this research, power is understood as that which is wielded by others to prevent the participants' ability to act. This is further discussed in **Chapter 12 (Discussion 1: Deaf, blind and mute)**. From the material on accessibility, it is clear that hospitals and staff wield power that constrains participants. There is power at play in every service not provided, despite legal and policy 'safeguards' and 'assurances', and in every decision that leaves a ward too poorly staffed to provide person-centred care, or that employs staff with few communication skills. Here, I present the participants' standpoint on the lack of power parity, agency, exclusion and participation, dignity, and the duality of touch—negative touch is disempowering but positive touch confers reassurance and security. Then I discuss their experiences of abuse and neglect, dehumanisation, fear, and distress.

Power imbalance

All 18 participants experience power imbalances, even if only half mention episodes directly. Power is exerted over the patient-participants in many ways—such as the refusal to provide accessible forms, communication, support, care and understanding. The lack of understanding is seen in misattributions, where staff negatively interpret confusion and distress, and respond with force, both physically and verbally. Emma tells how, in her post-operative confusion, 'it took four people to physically manhandle me and lock me down'. Jane is told that being 'aggressive' is 'not acceptable behaviour'. If staff can't make you understand what they want you to do: 'They tend to have an arm-grabbing effect, whether it's getting me into a lift, or talking or dragging you to the right location,' says Tom. Every participant experiences staff members forcing compliance via exerting their power.

In situations where you don't know what is happening and people are suddenly touching you painfully, Lachlan explains: 'being blind and that, what's the first thing you do? You lash out … that's happened several times'. Rather than efforts to communicate, restraint and sedation are used on Lachlan: 'They jabbed me with a needle.' When Lachlan complains about the forcible sedation and rough treatment, 'the hospital didn't listen to how I was pushed and shoved'.

It begins to emerge that, not only do participants not know what is going on, neither do the professionals and hospital-institutions. Even when informed, however, staff can still choose to continue to wield power over participants.

Agency

The capacity people have to make their own free choices is agency; this is clearly linked to the power exerted by others over an individual or group. Agency is raised as an issue by 12 participants (67%). Promoting agency is positive, but patients with sensory impairments are disempowered, both by systems and lack of access to information. Lachlan says: 'What they have to realise, OK, when you can see, you're not doing it as hard as people who can't see or wear hearing aids, or people in wheelchairs or elderly people in wheely-walkers.' In this research, participants are less likely to be partners in their own care, because they have less agency and are subject to the will of the hospital and its staff. Staff are not reliably aware, as Lachlan points out, that people with sensory impairments and disabilities have a harder time in hospital.

As a person with sensory losses, being without orientation in unfamiliar hospital wards erodes independence and agency, over and above being sick or injured. This is especially noticeable around the help needed showering and toileting, not because of the patients' illness and surgeries, but because of the missing information, lack of orientation and poor support. Tess has a long wait for help to go to the toilet, as do Linda, Ava and Annie. These waits leave them powerless and distressed. Ava and Linda are saved by other patients who shout out for nurses; but not Annie, who is nonverbal and unable to communicate her need to others in the ward.

Agency is eroded by failures to engage with participants as partners in their own care. Ava notes: 'I am not recognised as an expert in my own care'; this lack of insight leads staff to act as though Ava has no capacity of her own.

Participation and inclusion

A lack of participation and inclusion is mentioned by 10 participants (56%). The previous section showed how failure to provide participants with access to information is a powerful form of exclusion. Ava explicitly states: 'I felt left out of my care'; Linda wants to scream: 'Hello! I am still here!'; and Annie is 'never communicated with', and thus is never included in hospital or at her residential aged-care facility. Belinda feels 'ignored' when staff dismiss her as she tries to explain her 'pain and distress'.

Dignity

Loss of dignity takes many forms, resulting from the many ways staff in positions of power act or fail to act. Dignity is elusive for 11 participants (61%). Misattribution of DB as drunk, disorderly, difficult or dangerous results in some participants receiving undignified treatment, as mentioned earlier. Lachlan tells how 'the police have knocked me down, handcuffed me and dragged me to the emergency room door' because of an erroneous belief that he is drug- or alcohol-affected. Once there, the misattribution continues and he is forcibly medicated.

Without thinking, busy staff deny dignity—as Annie describes, by 'putting me on a commode chair and leaving the bathroom [door] open and everyone can see, and I can't, and they don't care'. Annie also tells of the protracted indignity of waiting for help: ‘I don’t like waiting. I have to wait for the nurse, and I have to wait for the toilet. Sometimes, I wait so long I wet myself.’ Linda, too, is distressed by incidents of waiting for toileting assistance: ‘I was in tears.’ Tess tells of the indignities of doctors who don’t respect privacy and discuss private health issues in a public space, such as ‘loudly by the bedside’. William talks of watching his wife being treated poorly because the hospital does not understand her issues: ‘You can wait. You don’t deserve a bed pan,’ he says, ‘she’s had that.’

Rhonda says she is not told about a procedure being performed, which made her ‘feel not worthwhile as I couldn’t see or hear’. Barbara’s brother would tell nurses to ‘treat Barbara with respect’ whenever she was hospitalised; now that he has died, she is anxious about who will do this in future. This demonstrates the crucial role of support networks in ameliorating attitudinal, communication and care barriers.

Denial of aids and information strips dignity; negative touch, abuse and neglect deny dignity; and being dehumanised erodes dignity. There are links between many of these subthemes within the overarching theme of power.

Negative touch

Touch is a contentious modality, with both a duality and individuality. Positive touch has the power to bring comfort and reassurance and convey information.

Half the participants (50%) note negative touch, which is unwanted, unwelcome or unexpected. Negative touch has power and can startle, frighten, debase and harm. The concept words in this subtheme speak volumes: *poke*, *push*, *shove*, *pull*, *drag*, *grab*, *pulled*, *jabbed*, *slammed*, *blocked*, *hurt*, *frightened*. Even participants who had ‘good’ hospital experiences sometimes used these concept words to describe touch experiences. This demonstrates the existence of dissonance between words and experiences, as discussed in **Chapter 8: Performing narrative inquiry**.

These concepts link to become the subtheme of negative touch. In turn, this is related to the power that professionals exercise over the patient-participants. It should be noted that ‘not knowing what is going on’ may make the experience of touch negative, even when it is necessary as part of an investigation or treatment. This exercise of power remains while access to information is in the hands of professionals and hospital-institutions.

Cross linkage is observed here—experiencing negative touch can confer distress and fear, as well as erode security and trust. Insecurity is exacerbated by the concomitant uncertainty of ‘not knowing what is going on’. Rose tells of how ‘people touch you and grab you’ when in hospital, and how she is uncomfortable with not being able to see the gender of the nurse who is doing ‘intimate touching [such as] cleaning [the] breast area ahead of surgery’. Annie says: ‘I don’t like people touching me all over without letting me know what they're intending to do.' Rebecca recounts how a nurse 'shoved me and did something with the drain and it hurt so much'. Belinda tells of being 'frightened' by an episode of inappropriate touch in hospital: 'I didn't know this person,' she says.

Not all negative touch is aggressive. Rose doesn't like 'poor you, poor you, poor you' touching either; nor does Lachlan: 'I don't want any pity.' Rose points to the mediating influence of support networks in this situation: 'If I was in hospital on my own, I wouldn't know what was going on around me. People would be touching me. I'd be in panic mode and it's important for me to make sure I'm okay.' She uses her NDIS-funded communication-guide when hospitalised, because knowing what is going on helps to avoid some or all instances of negative touch.

Abuse and neglect

Abuse refers to mistreatment of patients by cruelty, violence or improper means, and is prohibited in the CRPD (United Nations 2006). Abusive behaviours by hospital staff are raised in six interviews (33%) and so is fear. Abuse is interlinked causally with the exercise of power by one person over another; for example, Rhonda describes an aggressive negative touch where she is 'being grabbed by the arm and pulled along'. Annie, Emma and Lachlan describe restrictive practices, such as forcible sedation and/or restraint by staff. One participant goes for three months in a rehabilitation hospital without a shower 'because I am in the "too-hard basket".' Annie is touched repeatedly without knowing by who or what for. Lachlan describes being 'pushed', 'shoved' and 'slammed'; Rebecca was also 'shoved', resulting in pain that 'wouldn't stop … [she] just didn't feel safe there'. Neglect is encapsulated by abuse and is raised by 15 participants (83%). Neglect takes many forms, including failure to provide comfort when distressed by negative touch, information when confused, access to interpreters when needed, orientation when in a new space or notification to participant-patients about meals, drinks and medications.

Dehumanisation

Dehumanisation, or depersonalisation, is noted by 15 participants (83%). It occurs when patient-participants are treated as though they lack capacity and human characteristics. Linda tells how some staff 'will make the decision for you without treating you as a person'. Ava complains of infantilisation: wanting 'to feed myself' but not allowed. Rose says: 'I don't need to be pulled along like I am on a leash,' referring to staff who grab her and drag her like an unwilling dog. Even the seemingly small act of temperature-taking can abuse and dehumanise. Tess describes a staff member 'shoving a thermometer into my mouth. The staff member does not care how it felt and is able to be brutal because there are no consequences.' Sally feels depersonalised: 'It was like they were talking about someone on paper; it was like I wasn't there.'

Fear

Fear features explicitly in five interviews (28%) and is linked to power imbalances and abuse, provoking uncertainty about personal safety. Sally is frightened about going to the hospital-organised nursing home 'because they are not well trained, and I'd have to start over again' (teaching them about DB and communication). Rebecca is 'too scared to stay one more night by myself in hospital'; after an episode of negative touch and communication failures: 'I made (partner) hide in the bathroom till the afternoon shift nurse had left so he could be there with me.' Support networks can mediate the fear and distress consequent to negative experiences. Jane doesn't have any support network; and she says the hospital told her that 'it was too late to book an interpreter'; friends also were unavailable. She awakes from her anaesthetic 'very frightened'. When there is an unexpected procedure or touch, Linda says, 'you jump'. Annie says: 'Sometimes, I push the needle out because I don't know what is happening and I feel like I am trapped.' Such a fear reaction is similar to Lachlan when he 'lashes out'. Linda describes how a nurse ticks her off for needing to go to the toilet and not waiting: 'I was in tears and I was frightened of annoying her because I thought, if I got on her wrong side, she might just leave me there.'

Distress

Distress is extreme sorrow, anxiety or pain, which is raised by 15 participants (83%). This distress is not related to the illness or injury that resulted in the hospitalisation, however. Participants spoke of distress in the context of staff behaviours, communication failures and/or feeling under threat. When staff behave aggressively, or withhold information or comfort, it causes anxiety, pain and distress. These emotions are closely connected to fear, confusion, and loss of power and agency. Not only do they arise out of how participants with DBDSI are treated but also 'not knowing' due to lack of information.

Some participants link their avoidance of future health encounters to the distress they felt at what happens to them in hospital. Rebecca says: 'I would have to be really crook before going back to hospital.' Tess states: 'Now, if I think something's going wrong, I'll call healthdirect and get a second opinion from a doctor or a nurse, before I decide to go in. Because sometimes, I just don't want to!' Lachlan has had multiple traumatic experiences, so avoids going to hospital. He says: 'I get panic attacks in hospital waiting rooms and I've got to get out. I got no choice.'

Sally says that 'not knowing increases anxiety'; Amanda is 'anxious'; Tess 'panics'; Rose goes into 'panic mode'; Belinda has unacknowledged 'distress and pain'; Jane is 'very frightened'; both Rebecca and Linda 'cried'; Tom puts his hand in front of his face when talking about his distress and Annie feels 'trapped'. Distress is closely connected to neglect because none of the participants are comforted or reassured by staff.

Not only humans get distressed by hospital experiences, but guide dogs, too. Tess tells how the combination of her distress, noise and people traumatised her guide dog, Gorgeous, who needed retraining and support after Tess was in hospital. Now, Tess leaves her with family. Tom, too, recognises that while he can take his guide dog into hospital ('anywhere except ICU'), he 'doesn't want to put Handsome through it'.

Mitigating power disparities

The power disparities that participants feel during hospital stays have extreme negative consequences, as described above. Participants describe the mitigating force of educating others, using positive touch and promoting agency. Reflecting on this, hospital-institutions can take action in these areas and thus work to lessen the impact of imbalances of power.

Educating others

Participants attempt to redress power imbalances by educating staff on their impairments and support needs. Educating others is raised by eight participants (39%). Again, participants are taking on the job of health institutions. Yet, these efforts can only ever be partially effective, because of staff non-compliance, lack of professional development and ward handovers. Patients educating staff only works if they have enough 'wellness' to do so. These are power influences at work.

William does not 'feel that staff understood the needs of a person with sensory impairments'; Tess points out that 'patients expend emotional energy educating others when sick'; and Linda says that 'you can't educate staff in the same way, because of the high turnover and short time'. Belinda says doctors who have known her since childhood 'are OK' because they are 'familiar with the communication needs', but new doctors are 'difficult and **need to read the notes** to know how to communicate with me' (bold indicates participant's emphasis). Sally says: 'I don't mind teaching people but I'm thinking that hospital staff should just read the notes.' Lachlan says that, when he brings his medical notes to the hospital, 'no one reads them, not ever, not once'. This adds to the weight of participants educating others. Amanda is vocal about staff needing to 'read the bloody notes' and is pleased that wearing a wristband stating, 'I am deafblind' makes a positive difference—causing staff to read the notes, redressing a little of the power imbalance.

Educating others comes at the cost of emotional labour and fatigue for participants. Emotional labour is the physical and emotional work of an unwell patient staying safe in hospital, which is raised by five participants (28%). Sally summarises this concept when she explains: 'It's more tiring than trying to recover, having to start at Ground Zero all the time. Same thing again. Same. Same. Same. Same.' Ava concurs, saying, 'you have to work hard to educate others'; clearly, learning opportunities for staff would ease the burden on patients with DBDSI, though Ava acknowledges that 'staff don't have the time' to be educated or made aware. The question arises: is it not under the purview and within the power of the institution to enable staff time and learning opportunities to provide patients with DBDSI accessible and safe care and communication?

Positive touch

Positive touch, which is reassuring or comforting touch, is noted by seven participants (39%). Rebecca tells how 'the night nurse was nice and touched me on the arm to let me know she was there, although I could smell her perfume'. Rebecca and her partner use touch signals (social haptics) to communicate when she is in recovery, alleviating distress and bringing reassurance. The power of positive touch cannot be overemphasised for participants, although it is person-specific. Annie prefers to be touched when people come into the room. Rhonda talks about the Catch-22 of touch, saying: 'There is a lack of acceptability about touching … touch gives positive information. Reassuring touch lets you know they are still there.' Linda asks staff to 'tap me on the shoulder and say, "I'm just taking your blood pressure, I'm just taking your temperature," so as not to frighten me'.

Touch can also be a cloudy action. George discloses multiple incidences of unwanted touch, when his doctor 'puts his hand on [George's] knee to signify "stop talking/signing to the interpreter"'. George does not like either this touch or interruption when signing. He feels doctors need to understand that 'deafblind communication takes longer'. George is uncomfortable and wants this to stop.

Touch preferences are individual as well as dualistic: Rose does not want people touching her in pity or sympathy; but Annie, Rebecca and Linda do.

Promoting agency

Only a few participants have agency and act to complain about their treatment (or lack thereof) at the hands of hospital staff. Four participants (22%) make complaints. Tess complains to the patient-experience unit, receiving an apology and invitation to educate the educators. Lachlan's complaints are not listened to, however, the misattributions about him are too embedded; he is told to 'go away'. Rhonda's complaint, too, is dismissed.

One participant who retains his agency, and advocates for others, is William. He carries his 'lawful authority', his marriage certificate, to show staff that he has the right to be involved in the care of his multiply-impaired wife. William undertakes small acts of resistance, standing at the nurses' station until he gets the information he needs about his own or his wife's care. Furthermore, William advocates for others in his aged-care hostel, as described in **Chapter 8**.

Ontological (in)security

Ontological security is the desired state of trust, reliability, predictability and information that promotes 'knowing what is going on'. The participants voice that the presence of support networks (mostly) contributes to security, that trust in healthcare systems and staff proficiency is essential, and that participants provide solutions to improve the system and staff failures. This is explored further in **Chapter 13 (Discussion 2: 'The healthcare system should look after us').**

Support networks

So often, partners, family, friends, interpreters, support workers, communication guides and even other patients are doing the work of staff—

plugging gaps, averting failures, preventing disasters—but this is mostly incidental support, and only two participants experience this around the clock. Seven participants (39%) have family support at some time during their hospital experience. Support networks are not present for 50% of the participants.

Yet, even for those participants with partners or family support, all but one still had negative experiences when that support was absent. Three participants (17%) describe partners as providing advocacy. Generally, the presence of support promotes ontological security for participants.

No support presence at all invokes terror and fear. Belinda cannot imagine going to hospital without support from her family: ‘No. Not ever. No.’ Jane says no support is the ‘worst time’. George says, without his sisters, ‘it would have been terrible; if a deafblind person didn’t have any support, that would have been really terrible, really disadvantaged’. Rebecca agrees, saying: ‘I do wonder what other people do when their partner or parent isn’t there, or they don’t have one … that is a terrifying thought.’

For hospital-institutions and staff, respect and providing accessible information are part of the job, but the patient-participants did not experience this. Support networks make up some of this shortfall. Amanda’s father ‘is needed to fill in forms’ and, without him, ‘I wouldn’t have been able to talk to anyone’. Tom explains that, when he prepares for hospital visits: ‘The main thing is having my own family take me in and out, reducing the potential for misunderstanding.’

Rebecca insists ‘it is best when my partner is present when I wake up as he is usually able to reassure and orientate me’. Her partner uses a personal touch signal for: ‘It’s OK, calm down, stop worrying, he has got it and will explain later’ and this meant ‘I was reassured,’ says Rebecca. Her partner also deals with problems and contacts the surgeon on Rebecca’s behalf. Nights without his presence in hospital, she says, ‘these were the worst’.

Linda needs her partner to ‘be my ears’. Tess has said to hospital staff, on occasion, ‘I can’t hear very well. You will have to wait for my partner to come in’. Friends and volunteers from impairment support organisations ‘fingerspell what is going on’ and break the ‘long waits in hospital’ for Barbara.

Yet, the presence of family and friends is not without complication. Belinda’s sister comes and helps several times when there is no interpreter at the hospital. This is problematic, Belinda says, because ‘my sister didn’t understand all the medical terms’. Emma notes that, without an interpreter or her parents, she does not have the ‘same opportunity’ for information as other patients. She has to, however, ‘trust that her mother is telling her all the information’. This is another reason that hospitals need to book interpreters for *all* conversations, instead of relying on support networks to perform this role. ‘Staff talk to relatives or friends without talking to you,’ says Linda, who wants to say: ‘Hello, I’m still here!’ Rhonda needs the support of her partner but ‘staff speak to him rather than the patient, me’.

Support workers and communication guides
During their hospital stay, two participants (12%) have a communication-guide (1) or support worker (1), who stays during the day as well as overnight.

Rose and Annie have better hospital experiences when their supports are with them day and night during an admission. Both describe distressing experiences without this support presence. If hospitals don't notify support workers of an admission, then Annie has no knowledgeable help with language or specific care needs. Conversely, if supports are not involved in discharge planning, participants such as Lachlan are put at risk. His support worker must ring the hospital for information because no one informs her of Lachlan's discharge plans, what is happening or even where he is. Lachlan says: 'I am just left outside the hospital.'

Other patients
Prior to this research, it did not occur to me to include other patients in a support network matrix (notwithstanding my own experience of fellow patients alerting staff on my behalf). In the absence of staff assistance, however, two participants detail how other patients make up the shortfalls. Linda talks about how other patients 'screamed out' for nursing assistance when her buzzer remained unanswered. Ava is grateful to other patients helping out, because staff are 'not helpful, don't have time or don't understand'.

Interpreters
At some time during their hospital stay, 55% of participants who require or request an interpreter receive such support. None receive an interpreter at any time one is needed. The benefit of a known, trusted and person-specific interpreter being present cannot be overstated. Rose emphasises that having an interpreter or communication-guide support makes her feel 'comfortable' and 'like I was privy to all the information that another (sighted-hearing person) can see and hear … I had access to everything that was happening around me'. Sally concurs: 'I felt included with the interpreter, rather than sort of being on the edge, saying, "What the hell is happening?"'

The participants who use interpreters describe a multitude of issues surrounding hospitals and interpreters, additional to the failure of being provided whenever needed. These are:

- Using family and friends as substitutes, which can be problematic (Belinda, Emma).
- Using incorrect interpreters. 'Sometimes, you will get an interpreter who has no experience with hand-over-hand' (Rose).
- Not having an interpreter causes 'confusion' (Amanda, Sally, Rose, Barbara).
- Prolonging of hospital stay caused by interpreter delays (George).
- 'Feeling isolated' (Amanda, Sally, Rose, Barbara, George).
- Touching inappropriately by unknown, hospital-engaged interpreters.

- Using interpreters only in what hospitals decide is a ‘special occasion’ (Amanda) or ‘important conversation’ (Sally).
- Sally reiterates her stance: ‘No interpreter, no conversation.’

Trust

The absence of trust in healthcare systems and staff is raised by 12 participants (67%). When his wife, who has dual sensory loss and other impairments, is in hospital, William goes in every day ‘because the hospital does not take good care of her’. Trust in people, environments and situations are central to ontological security. Trust needs to be predictable to confer ontological security, with most participants describing unreliable trust.

Familiarity breeds trust. Linda says: ‘I felt better when I finally saw my own specialist because he was well aware of my situation … he sat very close, took my hand and drew a diagram and explained it all.’ Tom has little trust in public general hospitals, saying: ‘In mainstream hospitals, I know I would struggle, and I have, in terms of getting assistance, and needed help.’ Tess trusts the doctors and nurses who she knows well, because they give her ‘increased access to information and support’ but, when these staff are not available, Tess must rely on her support network for ‘information and orientation’. The experiences of the participants outlined throughout this chapter indicate that trust is not present at all levels, at all times.

Lachlan does not trust healthcare institutions or hospital staff; consequently, he avoids going at all costs:

> I don’t care if I get sick. I will just lie in my bed and let it take its toll … I don’t even go and see a doctor … not after what happened at hospital … I lost my eyesight there because of the doctor.

Rebecca also has no trust and is ‘grateful to leave’ the hospital environment, where she feels unsafe.

Proficiency

A significant component of trust in hospital is the proficiency of its staff. Proficiency is understood as the competency of staff at performing a job. The NSW Ministry of Health understands proficiency to be that staff ‘provide services to people with disability that are: inclusive, person-centred and accessible’ (2017, p. 1). To have ontological security, it is imperative that this proficiency be embedded at all levels; that is, proficiency is predictable from day-to-day, ward-to-ward, hospital-to-hospital. Most stories heard in this research are of exclusion, inaccessibility and decentring of the patient-participant’s care and communication needs.

Proficiency is raised explicitly in four interviews (22%) but is alluded to in 16. Linda notes that you never know ‘what you are going to get’ and experiences both proficient and non-proficient staff: ‘“You just ring the buzzer and I will come”,’ versus ‘“Can’t you wait?”’ The former was a ‘kind’ nurse; thus, proficiency becomes congruent with kindness; while lack of competency and understanding becomes aligned with ‘unkind’ or ‘mean’.

George and Ben are happy with the competency of staff: George felt ‘they tried’; one staff member could fingerspell and ‘that was wonderful … I was so overjoyed to be able to communicate with them’. Staff who are proficient in the simple manual alphabet can make a big difference in promoting inclusion. Tess notes that ‘casual staff are less proficient’ and less likely to know what is going on for her care, because ‘handover doesn’t seem to happen’. Sally experiences both proficiency and lack thereof. The physiotherapist, explains Sally, is ‘marvellous and they would book an interpreter for important conversations … we didn’t have an interpreter for every session but had them for the important times—new exercises or new plan’. In contrast, the doctor is recalcitrant, taking four weeks to finally book an interpreter to speak with Sally. Despite this, Sally found ‘staff helpful with directions and my safety’. After Ben requests it, staff ‘spoke slowly, clearly and facing me’. Competent staff enhance communication and inclusion, and confers dignity and predictability for participants.

Proficiency extends to the English language as well as healthcare skills. Barbara notes that print on palm or print on arm ‘was okay but some [staff] you couldn’t understand’, referencing the poor English spelling of some staff. Lachlan says: ‘Accents and English proficiency are important, so you need to avoid people without clear English.’ Plainly, this is not possible in a hospital, but such institutions have power when hiring to ensure communication competency.

Proficiency encompasses following through on promised actions, such as staff answering buzzers and helping when they say they will. Seven participants (Annie, Ava, Jane, Linda, Rebecca, Rose and William) comment on buzzer nonresponse and their ensuant distress: Will staff take too long to answer? Will they answer and be ‘cranky’ and ‘mean’ (Linda)? Or, will they solve the problem and ‘be kind’ (Rebecca)? Jane describes visiting a hospital while providing support to a friend. Even though she tells them ‘I don’t see or hear very well’ and staff promise to fetch her when her friend's operation is over, they leave her ‘waiting, waiting, waiting’ and never come to get her.

The unreliability of staff promotes a lack of trust and insecurity. As Linda says: ‘You never know what the experience is going to be like.’

Solutions focused

Ten participants (55%) describe attempting to solve problems or improve communication during hospital stays. All 18 participants have solutions and ideas for improving the status quo for patients with DBDSI and other disabilities. Their ideas are discussed in ‘The Wish List’ in **Chapter 11**. Many participants note that engaging in the present research is a contribution they can make to changing the realities of poor patient experiences. Lachlan states: ‘I reckon it’s about bloody time.’

Conclusion

Three overarching yet intertwined themes dominate the landscape of the participants' stories. Participants experience multiple difficulties with too few positives in the areas of access to information, communication, mobility and orientation. By not providing accessible formats, orientation, interpreters and consistent staff, hospitals are neglecting people with sensory disabilities. Exertions of power disfigure hospital experiences and leave PWDBDSI experiencing greater care disparities and increased risk of harm, neglect, abuse and distress. The hospital-institution exerts power, consciously and unconsciously, both in the services it provides and those it withholds from the participants—as demonstrated in this chapter. Ontological insecurity ensues.

Generally, a hospital admission is subject to uncertainty, but the participants suffer additional uncertainties with the unpredictability of staff proficiency and presence eroding trust. The participants are solutions-driven, however, both in the act of participating in this research and generating a constellation of solutions.

The overlaps and links between the major themes and their interwoven component subthemes demonstrate the strength and truth of the two emerging models. These are presented and examined in **chapters 12** and **13** (the discussion).

The findings of this research continue in **Chapter 11**. There are two sections: first, 'The Report Card' shows the quantification of participant experiences, using a patient-experience question set; and second, 'The Wish List' contains participant-led solutions to the inequities presented. The participants *want* to know what is going on, but they need support to do so. The 'not knowingness' that participants endure is not caused by their impairments, but by social, system and professional failures.

Chapter 11
Findings 4: The Report Card and the Wish List

Introduction

The preceding chapters examine the perspective of the patient-participants with DBDSI qualitatively, which is a challenging read. It lays bare the lack of care and communication experienced by most participants. One participant signs into the palm of an interpreter: ‘The staff at the hospital never talked to me at all, no one. No one at all … it is quite scary.’

The present chapter illustrates what the participant-patient experience looks like when using an established question set. The questions are based on 101 factors of hospital care, designed by Australian consumers of that care. While it appears that no PWDBDSI are consulted or represented in the focus groups or working parties, this question set nevertheless affords an opportunity to see how the hospital-institution performs for the participants in this research.

The present study participants not only tell their experiences of what happens when they go to hospital, which we can analyse thematically as well as quantify, they also talk of how to do better. Some of their solutions are common to PWD and are well documented in the literature and policies of local ministries of health. Although well documented, however, accommodations for PWD in hospitals do not appear present in practice (e.g., see National Disability Services 2014; Iacono et al. 2014). The participants also suggest specific solutions for patients with sensory losses. These are less well documented and, from the participants’ insights, rarely experienced in practice. It is important for patients’ health and wellbeing to feel cared for. As a focus group contributor for the AHPEQS observes: ‘When someone acknowledges us, or listens to us, or comforts us, or explains things to us, it’s so much better … we just feel better because someone has cared for us’ (AHPEQS 2017, p. 1). Thus, ‘The Wish List’ section that concludes this chapter aims to shepherd readers from collection and documentation in this thesis to implementation in all hospitals and care institutions.

Part 1: The Report Card

The performance of hospitals and staff from the perspective of the patient-participant is presented in this section.

The Australian and NSW governments explicitly support policies that promote parity of healthcare for all patients: ‘persons with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability’ (National Department of Social Development 2015, p. 50). In this research, the patient-participants’ hospital and care experiences are demonstrated using the same qualitative inductive thematic analysis, presented in the previous chapter. Key themes emerge of the participants ‘not knowing what is going on’, and of hospitals and staff members exercising power, conjoining to confer ontological insecurity. Recently, after coding but before completion of thematic extraction in this research, I became aware of an Australian patient-experience measure (PEM). It is likely that the data generated from this research could, in fact, be used to compile a ‘Report Card’ of the performance of hospitals when caring for participants with DBDSI. Mining the transcripts for detail draws a picture of the factors affecting the quality of patient experience.

Patient-reported experiences and outcome measures

Patient-reported experiences and outcome measures derive information about the experience of health services and delivery as described by the patients themselves, which preferences the patient’s standpoint, albeit within proscribed limits. This information can be used to monitor performance and drive improvements (Australian Institute of Health and Welfare [AIHW] 2018). Patient-reported experience data form an integral part of the AHPF. The ABS contributes to the AHPF and undertakes a yearly patient experience survey. The survey examines views on waiting times and access to health services, as well as patient–clinician communication. The NSW Department of Health conducts an annual NSW Population Health Survey to gauge patient perspectives on hospital experiences, rather than the hospitals providing those services. This is state-specific data, so the ACSQHC hopes to roll out a national survey and website to add to the conversations and knowledge about Australian health services, specifically through the eyes of those receiving that care.

For PWDBDSI, participation in any survey is limited by their communication methods and whether accessible formats are provided and easily available. My own experience with the NSW Department of Health survey (2016) is negative. The questionnaire is long, in very small print and DB is not accorded distinct disability status. Three letters requesting large-print forms went unanswered. My voice was silenced.

Because I only became aware of the AHPEQS during coding, I did not have specific questions and answers coinciding with the survey in the narrative inquiry interviews (the 101 factors and 12 questions can be accessed in **Appendix 10** and **11**, respectively). However, most interviews contain material that represent statements for the presence or absence of most of the 101 factors. Using the definitions for each factor, I re-examined each transcript with a coding assistant, counting where participant responses demonstrate the presence or absence of that factor. The definitions for the 101 factors are found in **Appendix 10**. By coding ‘yes’ or ‘no’ responses, the qualitative data obtained in this research are quantified and presented below. Crucially, this research uses the 2017 report’s version, which is not available in any accessible formats. From 2020, the AHPEQS is available in large-print format (AHPEQS 2020) but still not in braille or video Auslan.

As discussed previously, hierarchies and Likert scales are not generally accessible to all PWDBDSI (Roy 2019). Hence these results, which were generated from binary coding (yes/no), indicate only that a factor was present in the transcript, not its scale of magnitude. Absence, or a ‘no’ response, indicates only that the participant did not voice the concern, not that it has not occurred, because it may not have been specifically asked about. These results are a general barometer of how hospitals are performing but are not comparable to other results and reports using the hierarchical question set.

While people with deafness form part of the consultation group for the AHPEQS, it does not appear that PWDBDSI were targeted or included. This research, therefore, represents an addition to the national conversation on the experiences of these patient-participants with their care.

The points below outline factors affecting the quality of the patient experience, as detailed by the 18 participants with DBDSI. Some factors are not relevant to people with vision impairment, such as the question relating to cleanliness. If a transcript does not account for a factor, the number of participants for that factor is less than 18. This applies for the following factors:

- *My appointments and waits are well managed*. This factor seems to relate to outpatient clinics and appointments. Although waiting is something many participants note—for information, interpreters, care, responses to call buttons, assistance to the bathroom—only four participant-patients provide feedback on waits as intended in this question.
- *Good management of their hospital or otherwise*. No participants directly comment on this factor; however, the results of earlier factors demonstrate a lack of patient-centred care. Of the participants, 83% feel they are not treated as a human being, so it can be deduced that most hospitals in this study are not well managed, if they are not providing parity of care and access for all patients, with patients at the centre of informed, collaborative decision-making.

List 13. Factors affecting the quality of patient-participant experiences in hospitals

Interpersonal interactions

- I am heard = 6%
  I am not heard = 94%
- I am cared about = 11%
  I am not cared about = 89%
- I am informed = 44%
  I am not informed = 56%
- I am known = 11%
  I am not known = 89%
- I am treated as a human being = 17%
  I am not treated as a human being = 83%
- I understand what professionals say = 11%
  I do not understand what professionals say = 89%

Clinical quality interactions

- I can get the right care at the right time = 17%
  I cannot get the right care at the right time = 83%
- I experience high-quality and safe clinical care = 22%
  I do not experience high-quality and safe clinical care = 78%

Care delivery interactions

- I have confidence in the professionals treating me = 22%
  I do not have confidence in the professionals treating me = 78%
- I am discharged at the right time with the right plan = 50%
  I am not discharged at the right time with the right plan = 50%
- My personal care needs are attended to = 11%
  My personal care needs are not attended to = 89%
- My care is tailored to my needs = 22%
  My care is not tailored to my needs = 78%*
- My hospital is clean and welcoming**
- Different parts of my care are coordinated = 17%
  Different parts of my care are not coordinated = 83%
- I am treated equally no matter who I am = 22%
  I am not treated equally no matter who I am = 78%

Administrative interactions

- My hospital puts the need of patients first = 6%
  My hospital does not put the needs of patients first = 94%
- My hospital is well managed overall = 6%
  My hospital is not well managed overall = 94%
- My appointments and waits are well managed†
- My feedback is welcomed and acted upon (n=1) 25%
  My feedback is not welcomed and acted upon (n=3) 75%††
- My health records are well managed = 11%
  My health records are not well managed = 89%

Notes

* No participants (n=18) received consent forms in an accessible format.

** Factor not commented on.

† Factor not commented on. However, participants frequently noted waiting.

†† Only four participants gave feedback.

Adapted from: ACSQHC 2017; *Australian Hospital Patient Experience Question Set: Summary of development and testing*, ACSQHC, Sydney.

Participants with DBDSI are treated sub-optimally in Australian hospitals. They are unseen, unheard and unhappy. Almost all are unheard (94%) and feel uncared for (88%). Dehumanisation is experienced by 83%. These patients are not included in their own care if they do not know what is going on. More than three-quarters have no confidence they are receiving safe quality care, and 89% do not understand what their health professionals are saying. Only 22% feel they are treated equally. The following **Chapter 12: Deaf, blind and mute** explores why this might be so.

This Report Card is damning and indefensible. But what can be done? The participants have ideas, which are presented in Part 2: The Wish List, below.

Part 2: The Wish List

The preceding findings chapters and Part 1: Report Card, above, show an alarming decentring and neglect of patient care for participants with DBDSI. As part of positive framing—a move away from leaving the results as yet more vulnerabilities in a known marginalised minority group—this research takes a salutogenic approach. This is achieved by asking each participant how they might ameliorate the current wretched state of affairs in hospitals: 'What might improve hospital experiences for themselves and other PWDBDSI?' This indicates respect for the expert-knowers—the participants themselves. There is much evidence to show that the participants are solutions-oriented and strengths-focused during and following their hospital stays. Participants often try to mitigate the systemic and professional shortcomings of their experiences. Utilising support networks, wearing wristbands, bringing support workers/communication-guides with them and learning the layout where possible, together with small acts of resistance such as refusing to leave the nurses' station until informed or refusing a consultation until an interpreter is present, demonstrates this. These solutions are not enough, however, because the overall power imbalance is too great.

Each participant has a 'wish list'. These are aggregated and divided into three areas, according to who or what is responsible for enacting the recommendations: hospital-institution, professional or patient.

Each wish list is examined individually. Some suggestions fall into more than one category; for example, improving professional knowledge requires all three systems—patients to inform what knowledge gaps exist; professionals to undertake training to gain awareness and make meaningful change; and hospital-institutions to take responsibility for funding, providing and enforcing such training programs. To minimise repetition, most suggestions are discussed under a single heading with the understanding that funding is required from the system as well as input from the patient-expert-knowers.

Hospital-institution systems

Despite the law, international human rights conventions and Department of Health's own policies and publications, participants with DBDSI are not given the same care and communication as the sighted-hearing. The results of this research demonstrate these failures. Rose says hospitals should 'not treat people with deafblindness like cattle class'; George says that 'respect and responsibility should be part of the service'; and Emma says hospitals need to 'make an effort' to provide care and communication. The participants have practical suggestions for the way forward. These are grouped as follows:

- Changing the culture

- Changing the environment
- Funding what is needed
- Listening to PWDBDSI

Changing the culture

Rebecca speaks for all participants and patients when asserting that ‘no one should be allowed to be rough and brutal with any patient’. This includes what Tom calls the ‘the typical cliché ways of overcoming communication breakdown … Don’t push, shove, or yell louder’. The participants want an end to unwanted, forceful or negative touch. Restrictive practices, such as forceful medication or sedation of people who are disoriented due to sensory impairment, should be banned, say both Annie and Lachlan. Improved communication would help more and harm less.

A culture promoting good communication practices needs enforcing at all levels, and in all areas, of hospitals. Participants say more about communication improvements than anything else. This encompasses a wide range of improvements that are already covered by community expectations and legal and policy provisions, but which are not provided in practice.

Belinda, George, Rebecca and Sally suggest a daily briefing using the patient’s communication mode. Regular updates reduce the ‘not knowing what is going on’ issue for PWDBDSI, because sighted-hearing patients can see and hear information around them. There will be staff and cost implications, but hospitals must consider that communication with PWDBDSI ‘takes longer’ (Barbara, Belinda and George). It makes sense, says Annie, for hospitals to fund and staff ‘extra nurses’ if a deafblind person is admitted to a ward.

Emma suggests that ‘hospitals reduce waiting times in Accident and Emergency for deafblind people who need interpreter and communication support’. This means that support networks and interpreters are not squandered and forced to leave because their booked time expires. Emma also thinks that ‘ambulances should ring ahead to alert the hospital that an interpreter is needed’, ensuring efficient communication from the beginning of the hospital encounter. Belinda would like hospitals to ‘ensure staff are prepared when they know someone deafblind is coming into hospital’. Tess suggests that hospitals endeavour to ‘keep consistency of staff so staff know the patient well’ and follow up after discharge to ensure all is well and understood.

For those using tactile and sign languages, interpreter provisions and funding are of paramount concern. Interpreters are needed in all areas, whenever communicating with the patient. This means preadmission, emergency rooms, admissions, wards, daily briefings, theatre, recovery and for discharge, say Amanda, Annie, Ava, Barbara, Belinda, Emma, George, Rose and Sally. Interpreter bookings should be driven by patient need, as Barbara notes, ‘sometimes the hospital thinks one isn’t needed but they don’t think about the person lying in the bed’.

There are practical interpreter issues, too; participants would like them to be on time, with a guarantee that the interpreter shows up, say Rose and George. This means health departments need to work with booking services. Rose explains: 'Booking services leave it to the last minute, even if you have booked (your appointment) well in advance and then suddenly an interpreter is not available.' George wonders if there should be penalties for interpreters who don't show or who leave precipitously when engaged for hospital communication. Participants want interpreters 'to stay [for] the duration' says George, and 'not just [for] two minutes' as Amanda agrees.

For PWDBDSI, it is not enough to book just any interpreter. Hospitals must book the right interpreter because 'everyone communicates differently', say Amanda, Annie, George and Rose. George explains that 'the deafblind need an interpreter who is a good communication fit'. Rose suggests hospitals have an up-to-date and 'adequate list of interpreters and their specialities' to assist.

There are creative and innovative modes of getting virtual interpreters, but these are not useful for all PWDBDSI. Vision limitations may preclude using Skype interpreters or video Auslan, so it is 'not a solution for all' notes Rose. Rebecca points out that, if hospitals embrace using iPads or tablets, there could be 'Auslan channels on the iPad as well as on TV'. Tom and Ben say voice-to-text on tablets would help many.

Enhancing communication for participants means that hospitals should allow the aids and supports needed, where needed and when. Amanda, Ben and Tom want to wear hearing aids in operating theatres, where possible, and in recovery rooms always. Ava and Tess want staff to give patients time to put hearing aids on whenever you come to see patients who wear them.

Rebecca strongly advises hospitals to allow a support person in the recovery room. Allowing and funding a communication-guide or support worker to stay overnight makes all the difference, say both Annie and Rose. Hospitals need to recognise that the support network is 'there to support the patient', not to do the hospital's job for them, notes Emma.

The hospital's responsibility is to provide staff and ensure they do their jobs. Because this is not happening with predictability, it is not surprising that participants want to remediate current poor performances of hospitals and staff. All participants state that education is the means to change the status quo of poor care and deficient communication practices.

Hospitals need to provide training and awareness programs for everybody who works in the hospital, say participants (and echoed by interpreters, support workers and partners). Linda's partner notes that education and training is needed 'not just for the doctor and nurses—it's everyone: the allied staff, the food staff and cleaners'. Rebecca states succinctly, 'educate the whole lot', continuing that there should be training and orientation for every job in the hospital and for every health student. Of note, training should include the reminder of 'no MRI for people with cochlear implants', says Emma, and Ava wants education to ‘eliminate the idea that disability equals stupid.’

The research and participants demonstrate that guiding is an area of deficiency. Participants want training for all staff on how to guide—let PWDBDSI hold your elbow, say Linda, Tess and Tom. Hospitals also need to train staff to ask where you would like them to stand and to talk. Tom says it would be good to have a set of questions, starting with: ‘How exactly can I assist your deafblindness?’ Tess says hospitals need to ‘educate the educators’ as well. Sally thinks it would be great if ‘staff attend DB workshop programs where professionals get to experience what it is like in the deafblind worlds’.

With all this training and education, however, Sally reminds us of the problem ‘with turnover of staff in hospitals’; therefore, hospitals need to keep on training. ‘The hospital could make a video, but would staff watch it?’ Sally wonders. Health departments and hospitals could access many resources to help them perform their jobs to a reasonable standard. There is a communication book available from Deafblind Victoria and Melbourne council, Sally suggests.

Problems with communication run deeper than just a lack of awareness and education. PWDBDSI need communication in good, clear, spoken and written English. Nearly all participants struggle with accents and poor spelling. Hospitals, says Tom, should ‘insist on English proficiency for all staff’. Tess concurs. Tom illustrates this, saying: ‘I think definitely the English and skill set of the person clearly from another country [an anaesthetist] who clearly didn’t know what he was saying needs to be flagged big time. You can’t have people with bad communication skill sets, handling such an important role!’

Hospitals also need to promote better handover of communication information about patients with DBDSI, say participants: ward-to-ward; aged-care facility to hospital; and back again. This must include support workers, too, say Annie, Rebecca, Sally and Tess. Linda notes that hospitals could use wristbands to remind everyone that a patient has DB, DSI or single sensory impairment.

Support networks are important to PWDBDSI. Hospitals can help support patients by performing their own roles and responsibilities with predictability and proficiency. Jane, Rhonda and William would like hospitals to understand that PWDBDSI are also partners and carers, and that hospital environments and attitudes impact PWDBDSI even when not patients. Barbara suggests hospitals could ‘use volunteers to take deafblind people to appointments and hospital, as well as to visit patients’.

Critically, the prevailing laissez-faire attitude in hospitals regarding consent forms needs urgent change. All participants want admission papers and consent forms in accessible formats—hospitals are legally obliged to provide these. Rebecca says:

> The admissions clerk couldn't or wouldn't do a large-print consent form for me. I knew from being a health professional what was on it, but the principle to me was that I should have been able to read it.

Rhonda, a former nurse with DBDSI, feels there is a need for greater oversight and support of patients with DBDSI. She suggests that 'an allied health professional could act as liaison between hospital patients and staff'. This is akin to the nurse-navigator role, as used in the USA or New Zealand. These professionals act as a bridge for patients with complex conditions and/or disabilities to help them navigate the hospital system and environment.

Changing the environment

There are many changes that hospitals can make to comply with legislative and policy requirements and meet the needs of PWDBDSI for safe, predictable and secure environments. They are simple and achievable. 'Don't have obstacles around nurses' stations such as drip stands or trolleys,' says William. This helps both visitors and patients with sensory impairment/s. 'Be aware and reduce glare,' says Tom, because many PWDBDSI have sensitive retinas and/or cataracts. Emma speaks for those with night blindness when she pleads: 'Lights on all the time!'—this helps individuals orient themselves in low light or overnight.

Linda, Rose, Tess and William wish for 'more tactile markers' in and around hospitals. Specifically, Rose and Linda suggest tactile information at the toilet door with layout information and, in the toilets, letting you know where the soap is.

'Lifts should have a speaker saying, "Going up" or "Going down" like the London underground lift,' suggests William. Lifts should have a 'good volume and tell you what is on each floor,' he continues.

Participants feel that priority access to a single room should be given to patients with sensory impairments who indicate it would be helpful. 'I think having a room of my own would make hospital more comfortable, so I don't have to worry about people seeing me and having access to that bathroom, so I don't feel exposed,' says Annie.

The final request is Annie's: 'Better food?'

Funding what is needed

Article 21(a) of the CRPD states: 'Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost'. This positions funding what is needed for all people with disabilities to access information, communicate and mobilise is a human right. Hospitals and health departments, therefore, must fund support, access and training initiatives, which can range from a simple wristband to aid recognition and remind staff of a patient's sensory impairments, to technological aids for access and communication.

Several participants, who have hospital experiences during or after the research period, find wristbands useful. Amanda, Barbara, Lachlan, Rhonda and Sally want hospitals to support, streamline and fund identification wristbands, and Sally adds: ‘Make [them] available in smaller sizing.’

Access to information is a critical issue at the heart of this research. The participants want to know what is going on, what is going to happen and who is going to do what. More commonly, as Tom puts it, they remain ‘in the dark’ both literally and metaphorically. ‘Not knowing what is going on’ is frightening for participants with DBDSI.

The hospital-institution should provide alternative formats—very large-print, large-print, braille, audio—for information materials, forms, menus, admission papers, consent forms and discharge instructions, say Amanda, Annie, Ava, Barbara, Belinda, Ben, Emma, George, Jane, Lachlan, Linda, Rebecca, Rhonda, Rose, Sally, Tess, Tom and William (i.e. all participants). Tess also notes using hospital Wi-Fi to email braille material to PWDBDSI who use that format (and a braille computer).

Using assistive technologies is widely supported. ‘Use iPads or tablets for staff with strong accents (voice-to-text) and adjust size of text,’ says Ben. He also suggests using iPads or tablets to complete forms, because they allow for text size adjustment. Rebecca also notes using iPads to increase font sizes. Other tech devices with hospital-use potential, according to Ben, include amplified headphones and the Phonak Roger Pen™. Tom advocates for hospitals to engage with modern technology to help support and communicate with PWDBDSI; his ideas include providing ‘Bluetooth technology connected to devices’ and ‘microphones for distance to communicate, so the sound comes across clearly without having to speak louder’.

As previously mentioned, Emma, Rebecca and Rose advise using video Auslan services, if appropriate, but note that video Auslan is not possible for those with blindness or low vision.

Less directly related to hospital, but still important, Amanda says that health departments should liaise with the NDIS and NDIA to give more hours for interpreters. With this study showing the benefit of having support workers and communication-guides staying overnight, funding this arises as an issue. This needs negotiation between NDIA and hospitals, both public and private. Presently, the participants fund these stays out of their general core support, which prejudices the hours available after discharge significantly. A recent conversation with the NSW Ministry of Health yielded the little-known, barely publicised fact that a senior official can authorise urgent NDIS plan reviews and funding upgrades (Davison 2020, pers. comm., 7 October).

Listening to PWDBDSI

PWDBDSI cannot be listened to if their communication needs are not met. This research shows how much care, consideration and cost goes into meeting the communication needs of PWDBDSI. Ava suggests that ‘people with disabilities [should] be brought into hospitals to help teaching’. She and Tess do this already, but all hospitals need to do more to listen and act.

The participants want this research taken seriously; they want to effect change so that they can go to hospital with confidence, consistency and security.

Professionals

Linda says having proficient or caring staff is ‘a lucky dip’. Jane says: ‘They should do what they said they would.’ Consistency is important to ensure patient safety and security. Compliance with legal, ethical and occupational requirements should be monitored. Hospital-institutions are charged with providing a quality service, so they should do so. Tess says: ‘It is important that staff do their job as people with sensory impairments are extra vulnerable in hospital.’ Tom says staff should show ‘respect’ to PWDBDSI and Rebecca urges staff to ‘be kind to people with disabilities’. Realising these aspirations requires professional improvement in the following areas, according to the participants’ Wish List:

- Asking patients and reading notes
- Communicating better
- Orienting patients
- Updating and upskilling staff
- Using positive touch, kindness and introductions.

Asking patients and reading notes

This doctorate demonstrates that PWDBDSI are a vastly diverse group. Accordingly, there is no pro forma one-size-fits-all list of communication and accessibility instructions. Rebecca’s advice for staff: ‘Being informed is important. Ask and find out what the patient needs and then be consistent.’

Amanda, Ava, Linda, Rebecca, Sally and Tess all exhort staff to ‘read the notes’. As Sally says: ‘I don’t mind teaching people; however, I’m just sort of thinking, can you guys just read the notes?’

Communicating better

‘I would like staff to sort of make me feel welcome,’ says Annie. ‘I’d like the staff to do their job.’ Staff need to ‘explain the plan beforehand,’ says Emma. ‘Explain what is going on,’ says Tess. ‘Explain the daily plan,’ says William, so patients are ‘not left in the dark so to speak’. Explain the discharge instructions, says Jane, and when staff explain things or ask questions, ‘speak slowly, clearly and facing the patient,’ adds Ben. Tess agrees. Give us time to put our hearing aids on, say Ava and Tess. Ben, Emma and Tom say that staff need to ask where is best to stand. Use technology to help communication, such as iPads, iPhones and tablets with voice-to-text or adjustable font sizes, says Tom, Rebecca and Ben. ‘Use my braille teletyper,’ says Barbara. Use Bluetooth technology and microphones to enable clearer speech ‘without having to speak louder,’ says Tom. Staff can ‘try print on palm or arm’ or put ‘fingerspelling chart next to the bed’ so they can try, says Barbara, but spelling needs to be accurate with tactile methods, states George. If staff have proficient spoken and written English, say Tom and Tess, this enables communication with sensory impaired patients. Also, those with Auslan as their first language may not understand written English language structures and misspellings, says Rose. Misspelled tactile communication is equivalent to no communication.

‘Staff need to stop assuming an interpreter is not needed,’ insists Emma. If communication is proving difficult, staff should put a ‘special card beside the bed with the telephone number of someone who can be contacted to give or receive information,’ suggests Barbara. Emma agrees: ‘Staff need to put a communication board near the bed and use it.’ Linda says: ‘Write it above the bed “blind and deaf” or “deafblind” … Use wristbands to remind everyone’—William, Sally, Lachlan and Amanda agree.

There are many difficult spaces in hospital and staff should pay extra attention to communication in these spaces, says Ava. These include operating theatres, recovery rooms and handover. Better handovers are needed, say Ava, Linda, Rebecca, Rose, Sally and Tess. Rebecca is very firm that staff should ‘tell everyone at handover this patient is disabled, not a “difficult” patient’. Rhonda says: ‘Better communication is needed between all departments’; and Sally simply says staff should ‘talk to each other’.

Buzzers, or call buttons, deserve special attention. These devices communicate patient needs to staff. Patients with sensory impairments are more vulnerable in unfamiliar environments and need extra assistance to navigate the terrain. Please answer, Linda says, and don’t make patients feel they ‘are a problem’. Linda and Annie make two final suggestions for professionals communicating with PWDBDSI. ‘Talk to patient, not the partner/relative/friend/guide dog,’ says Linda. Include patients ‘in discussions, plans and reviews,’ says Annie.

Orienting patients

Hospitals are hostile places for PWDBDSI. Thus, orientation becomes critical. This includes the layout of the room, bed area, toilets, buzzer and the ward, say both Linda and Tess. Annie says help is needed ‘mobilising’, ‘going to the bathroom’ and ‘showering’. Do tell PWDBDSI ‘where food, drinks and medications are,’ says Tess. William reminds staff: ‘Don’t just tell us, show us.’ Staff need to take PWDBDSI for a walk to the lounge, because ‘if you are oriented, you can do it yourself’, as Linda points out. One thing guide dog owners, like Tess, want staff to do is ‘take the guide dog for a comfort break or walk’.

Staff need to use more consideration before moving patients with sensory impairments to other beds or wards, says Linda: ‘Staff might need to say actually “No, we shouldn’t move that patient, we should move another patient”.’ Annie says: ‘I think having a room of my own would make hospital more comfortable, so I don’t have to worry.’

Jane, William, Ava and Rhonda would like staff to understand that PWDBDSI are also visitors, carers, partners and friends—they may attend hospital in those capacities and still require orientation and guidance.

Finally, Rhonda and Rebecca want staff to refrain from telling the blind or vision-impaired patient to 'follow the yellow line'.

Updating and upskilling staff

As mentioned earlier, all participants recognise that staff need education and training to improve their service. In addition to the hospital-institution needing to fund upskilling and updating of awareness and communication training, all hospital staff need to undertake these trainings, not just doctors and nurses. Notably, staff need training on how to guide and interact without using negative touch.

Positive touch, kindness and introductions

This research demonstrates the prevalence and harm of negative touch. The participants want to be touched positively:

- 'ask before touching' (Tess)
- Touch to let you know they are there (Annie, Emma, Linda)
- 'tap on the shoulder' (Linda)
- 'Use firm but gentle touch' (Belinda)
- 'be gentle' with movement and touch (Rebecca, Rose)
- 'don't push, shove or talk louder' (Tom)
- Introduce yourself (Ava, Linda, Tess, Tom)

Patients

PWDBDSI can be better prepared for hospital, which will reduce some of the potential for pain and negative emotion points.

The wristbands given to the participants are patient-owned and controlled. They are cheap, safe and easy to use. There are 12 identities available from me or the Vision Australia shop; these now are funded under NDIS consumables. These wristbands are designed to enable recognition of patients with sensory impairment/s in hospitals, and to remind staff in all hospital areas, at all times, that the patient has sensory impairments and needs accommodations, adjustments, patience and time to ensure effective communication.

The tool is reported to improve hospital experiences, because staff take the time to properly communicate with, orient and care for the patient (Watharow 2018, 2019b). Anecdotally, the wristbands have also been useful on public transport, in airports, at the shops, engaging with the police, for sports and at the gym.

Here is what the participants say:

> Lachlan: Wristbands are a great help … I wear two rather than one because I think it is more eye-catching.

> Amanda: Four months ago, I was in hospital and it was having that band on my arm and can I tell you it was a Godsend. It was less stressful than what it had been in the past. Barbara says she waved her ‘bracelet and they got me an interpreter”.

PWDBDSI need to continue to campaign and agitate for improved access to and funding for assistive devices, for example, through NDIS plans. Lachlan has designed his own smart cane with a GPS attached to a white cane: ‘People kept falling over my cane, so I have attached a high-pitch beeping to alert people.’ ‘Carry emergency contacts’ with emergency information, says Belinda, keeping them on smartphones. Some good advice from Tess: take friends or family to hospital for support, advocacy and communication. Those with deteriorating senses may benefit from training in tactile language and haptics, suggest Linda and Rebecca, as well as for partners, they say. Take a deafblind manual alphabet chart to hospital, say Barbara, Sally, Belinda and George. Rose, Annie and Rebecca say that supports (family or communication guides/support workers) need to able to stay overnight in hospital.

Conclusion

Part 1 of this chapter presents the participants’ Report Card, based on their words and stories about what happened when they went to hospital. The result is a grim reading.

More than three-quarters of the participants do not feel they receive safe care and 89% do not understand their health professionals. ‘Not knowing what is going on’ and its distressing sequelae—as demonstrated in the previous chapter’s qualitative content, as well as quantitatively in The Report Card—is alive, present and incorrect in Australian hospitals.

The participants are a strengths-focused group, however, and deliver their Wish List—a suite of solutions that hospitals would be wise to consider implementing.

Attitudinal and cultural change is necessary. Funding is imperative. Consultation and co-creation with PWDBDSI is essential. In research, it is important to be salutogenic and illuminate ways forward, rather than finish on a population’s vulnerabilities and the healthcarers’ and institutions’ neglect.

However, it is not enough to take the data from **chapters 8, 9, 10** and **11**, and conclude that hospitals are deaf to the needs of PWDBDSI, blind to the dangers of the status quo and mute on the harm they are causing. It is necessary to establish how and why power is exercised by hospital-institutions and their workers. The research findings are illustrated in a model that illuminates the chain of consequences from the acts and omissions of hospital-institutions and professionals, which culminate in disempowered patients with DBDSI ‘not knowing what is going on’.

In **Chapter 12**, the focus shifts from power disparities to look instead at a model that promotes shared decision-making: centring PWDBDSI in their care, and creating an environment where trust and security flourish. In such a milieu, PWDBDSI will have better health and wellbeing outcomes (as well as patient experiences).

Chapter 12
Discussion 1: Deaf, blind and mute: How hospitals control knowledge, security and power

Introduction

In her 2020 memoir, *Dear Life*, Rachel Clarke writes of being a medical student and seeing the film *Wit* (2001), which is based on the Pulitzer prize-winning play by Margaret Edson (1999). In the film, Emma Thompson leads as the linguistics professor brutalised by the doctors she encounters during her ovarian cancer (mis)treatments. '*Wit* drew me up short. It compelled me to consider my future power as a doctor—my potential to dehumanise, distress and even hurt my patients' (Clarke 2020, pp.772, 4290).

This research study emphasises how doctors, nurses and hospitals wield power, reduce access to information and render insecure patients with sensory losses. These are not the fears Dr Clarke writes about, but frightening realities. This study identifies that Australian hospitals, and the staff who work in them, are deaf to patients with DBDSI; blind to their responsibilities under laws and policies; and mute on subsequent harm caused. The research thus far indicates (in)capabilities of sharing knowledge and power, where hospitals and staff wield power over ill or injured PWDBDSI. Consequently, these patients have their sense of security in themselves, others and the environment threatened—even assaulted.

This discussion chapter reflects on how these power relations unfold throughout small micro-events, not just big world order ones (Foucault 2012). Examining the practices of hospital-institutions and professionals at the patient-experience level generates knowledge about those power exertions. This study privileges the patient-participant perspective by utilising standpoint methodology. This research is bound to the participants and not the dominant health institutions, which is emphasised by theorists such as Smith-Chandler and Swart (2014), who demand that personal experiences and social structures of oppression are considered and then translated. Power imbalances (and the uncertainties of healthcare systems, hospital staff and environment) can impact the ontological security of an individual. The power exerted by hospital-institutions, exacerbated by a person not knowing what is going on, is a powerful silencer.

The previous chapters situate the data both in qualitative and quantitative formats. These demonstrate, with depth, breadth and saturation, how health professionals and hospital-institutions exert power via acts of commission and omission through data that reflect what was or was not done, when or where it happened, and who did what to whom. From there, I reflect on the role of ontological security and salutogenesis as a way of understanding the data collected, underpinned by theoretical understandings of the impact of not knowing what is happening.

Ontological security

It is necessary to work backwards to show what ontological security is and how it works (both generally and specifically for PWDBDSI), so that the impact of power disparities and lack of accessibility is clearly discerned. Security of the self—with social relations, experiences and the environment—is tightly interwoven with trustworthy information. Knowledge is controlled by the dominant hegemony (hospital-institutions and its professionals).

For the purposes of this study, ontological security is interpreted as the desired state of trust, reliability, predictability and information, which promotes the sense of 'knowing what is going on'. Within an analysis of the literature on ontological security, I explore the landmark work on the topic and how this is interpreted within vulnerable and marginalised groups. Vulnerability here is understood as situational such as in a hospitalisation.

In his book, *The Divided Self*, Laing (1965) first broached the sociological concept of ontological security within the context of people with mental illness. Laing reflects:

> … a man may have a sense of his presence in the world as a real, alive, whole, and, in a temporal sense, a continuous person. As such, he can live out into the world and meet others: a world and others experienced as equally real, alive, whole and continuous (1965, p. 39).

Calling this concept 'ontological security', he writes that from this central position, man could manage the 'hazards of life' (1965, p. 39). However, Laing's research concerns those with serious mental illness, for whom there is a partial or complete absence of ontological security. The consequences of an ontologically insecure position are 'greater anxieties and dangers' (1965, p. 67).

Giddens (1991) further expands ontological security in *Modernity and the Self*, identifying the confidence that most people have in the constancy and reliability of their self-identity, and the people and environment around them. Reliability, both cognitively and emotionally, is central to trust. In a health setting, ontological insecurity exists in clinical situations; for example, with certain head and neck cancers that result in communication difficulties (Crossley 2005), and in deafblind communities (Danermark & Möller 2008). The latter assert that reliable, constant and predictable relationships with people and their object-environments are crucial for ontological security. Writing of people with Usher syndrome, Ellis and Hodges (2013) note simply that ontological security is the 'sense of the reliability of persons and things' (p. 5120). PWDBDSI are vulnerable in stressful or unfamiliar situations, because reduced information creates uncertainty which, in turn, affects self-confidence because we with impaired or absent sight and hearing cannot trust what is seen and heard (Möller 2008). Several authors note that the degeneration of senses, as in Usher syndrome, is accompanied by difficulties in relationships with others and with an increasingly hostile environment (Hersh 2013a; Miner 1995; Schneider 2006; Wahlqvist et al. 2016). Acknowledging the impacts of ontological security, Hersh (2013a) writes of needing self-awareness, advocacy and efficacy in informed decision-making to address ontological security for deafblind people.

The link between ontological insecurity and increased risk of mental health problems is the basis of Laing’s (1965) work. This is continued by Giddens (1991), who discusses the consequences of the anxieties and fears that ontological insecurity generates. Miner (1997) makes this link, noting depression and suicidal ideation in persons with Usher syndrome, as do Heine and Browning (2004), who write that older people with DSI often feel ‘vulnerable, insecure and unconfident’ (p. 116).

Wahlqvist et al. (2016) note that not obtaining the support and help needed (9 of their 15 participants) and reduced social trust (8 of their 15 participants) is linked with ontological insecurity and its attendant psycho-emotional effects.

The relationship between individual psychological impact and ontological assault is further expressed by Danermark and Möller (2008). These researchers do not address the psychological impact from the ontological intrusions that hospitalisations can invoke, but it can be inferred, and this study confirms the relationship. While not referencing ontological states directly, Simcock (2017b) points out that PWDBDSI do not experience vulnerability as a constant, but rather as a situational state; this research decisively positions hospitalisation as a situational state of vulnerability. Note well, however: the ontological insecurities described in this work are **additional** to, not instead of, any uncertainties and anxieties related to the diseases, surgeries or injuries themselves. Where there is support, communication, information and removal of barriers, there is security and safety. Where these are absent, there is vulnerability, and the hospital becomes a hazard of life. All aspects of ontological security are diminished in acquired DBDSI, with the threat of constant change and adjustment to degenerating senses or losses (Danermark & Möller 2008; Ellis & Hodges 2013). This study demonstrates that these aspects are all assailed for PWDBDSI during a hospitalisation, if care and communication are not provided.

The decentring of patient care: part 1

By provoking ontological insecurity via the loss of trust, presence of distress and disorder, and prevailing sense of incoherence, I posit that patients with DBDSI experience a decentring of their hospital care. This research finds barriers, at all levels and in all spaces of hospitals, for nearly all the participants, which decentres and diminishes their participation in their own healthcare.

The presence of deeply embedded widespread service and attitudinal barriers restrict true participation (Möller 2008). The consequences for the participants are loss of trust, psycho-emotional distress, incoherence from missing information and diminished social confidence and certainty.

Loss of trust

In exploring sighted-hearing perspectives, Berry (2017) states:

> Trust especially matters in cases of serious illness because of the duration, intensity, and frequency of interactions with clinicians; the asymmetry and complexity of information; and the vulnerability and uncertainty that patients feel (p. 1377).

PWDBDSI have additional vulnerabilities and living realities, however, which this study reveals are ignored. Wahlqvist et al. (2016) demonstrate that, for Usher syndrome type 3, people experience ‘severe problems with health and social trust’ (p. 245). This means that accessibility, information, orientation and mobility restrictions need support and barrier removal to minimise their impact on the patient’s ontological security. For any patient, going to hospital can be an ontological threat, but ‘knowing what is going on’ and participating in one’s own care is enhanced for patients who can hear and see, and require no communication adjustments. When this study’s participants go to hospital, they experience situational vulnerabilities that test, threaten or assault their ontological security. Even for myself and the four participants with occupational healthcare experience and literacy, this knowledge is of little safeguard. We all experience hospital as a hazard.

There is a need for patients in hospitals to trust the healthcare system and its caregivers. Danermark and Möller (2008) identify that health providers need to acknowledge ‘that people who operate around and directly help persons with deafblindness are experienced at being trustworthy. This is not always the case’ (p. 121). Hospitals, staff, personal factors and the presence or absence of support networks determine how patients with DBDSI experience various therapeutic and clinical situations. It is not a binary of either/or, with the participants’ experiences showing that, within one admission, there are many situations with ontological consequences. However, as Linda expresses, it is a ‘lucky dip’ whether these are positive or negative for the individual at the time, with negative experiences predominant. Time is required to ameliorate uncertainties, build trust and exchange information; a process which can take twice (Möller 2008) or five times (Stoffel 2012) as long.

Psycho-emotional distress

Some literature suggests that there is an association between loss of ontological security factors and increased mental health risks for PWDBDSI (Bodsworth et al. 2011; Miner 1997; Wahlqvist et al. 2016). This risk of emotional and mental difficulties is greater for PWDBDSI than for the sighted-hearing population (Bodsworth et al. 2011; Wickham 2011). When experiencing situational vulnerabilities, such as hospitalisation, it is unsurprising that most of the present participants identify distress, panic, fear and anxiety as attendant emotional states. The emotional touchpoints described herein are predominantly negative, with sparse positives.

For those with sensory impairments, loss of predictability and trust in the very place where care, communication and compassion are expected and promised—by legislation, policies and ethics—has serious consequences. Given the abundance of negative participant experiences, it is more accurate to call it the ‘unlucky dip’. These consequences exacerbate practices of avoidance, non-compliance and delayed health help-seeking behaviours. Sutherland et al. (2017) note that the strong relationship to health and wellbeing outcomes is why experiences of trustworthy care is paramount.

Giddens (1991) discusses how anxiety is generated in situations with failures of ontological security—from free-floating general anxiety to anxieties ‘pinned to items, traits or situations’ (p. 44). Thus, the prospect of returning to hospital in the future provokes anxiety, which some participants describe explicitly. Tess checks Dr Google hoping to avoid a return; Lachlan ‘just lies there’ at home, refusing to return; and Rebecca ‘would have to be really crook’ to attend hospital again.

Möller (2008) references the decreasing participation and trust of PWDBDSI generally, because they are more likely to avoid a situation where they have had previous negative experiences, even if it is necessary, for example, a healthcare problem. This leads to further social and physical isolation and their attendant risks.

The participants’ narrative style, both what they say and how they express it performatively, reflects their lack of ontological security, in addition to what happened and how they felt. Minichiello, Aroni and Hays (2008) reiterate the work of Rice and Ezzy (1999), who identify three common plot themes that can assist researchers with their inquiry—these are narratives that focus on stability, regression or progression. Experientially, ontological insecurity is the lack of stability, which is seen in the instability of the narratives that participants shared with the researcher.

Missing information—the loss of the sense of coherence

Informed decision-making for PWDBDSI requires ‘information, good communication and good conditions for that information’ (Hersh 2013a). Absent, incomplete or unreliable information propagates a sense of incoherence and insecurity. This decentres patient care because patients need trustworthy information for parity of shared decision-making. Most participants feel that communication was done poorly or not at all which, in turn, contributed to the ‘chaos’ and ‘flooding in of anxiety’ that Giddens describes (1991, p. 36).

Danermark and Möller (2008) stress that communication, previously referenced as ‘knowing what is going on’, is critical to developing trust, participation and wellbeing for PWDBDSI. The theory of salutogenesis, as introduced by Antonovsky (1979), consolidates that trustworthy information is essential to enable people to ‘know what is going on’. Salutogenesis has as a core concept—the ‘sense of coherence’ (SOC), which is the ‘cognitive sense of information that is ordered, consistent, structured, and clear. The person scoring high on the SOC expects that stimuli they encounter in the future will be predictable, ordered, and explicit’ (Lindstrom & Eriksson 2005, p. 441).

Reliable information delivers a SOC of self, others and the world, which is also seen as essential to wellbeing and quality of life (Lindstrom & Eriksson 2005). The SOC is kin to ontological security, with the strong association between loss of coherence and anxiety and depression 'striking' (Lindstrom & Eriksson 2005, p. 441). A high SOC is related to optimism, good self-esteem and quality of life, and seeing challenges rather than burdens in life (Lindstrom & Eriksson 2005). Being a patient with DBDSI in hospital threatens their SOC, thus creating distress and decentring care. The SOC is not a personality trait or coping style but, rather, it reflects the person's 'capacity to respond to stressful situations' (Eriksson & Lindstrom 2005, p. 459). PWDBDSI do not lack capacity but need support to maintain their SOC, and thus retain ontological security. Maintaining their SOC requires patients with DBDSI to understand what happens around them, and to them, to manage the situation with support and to find meaning in those encounters. Resisting the loss of coherence requires support—be that material, in-person and/or knowledge supports. Hospitals and staff need to consider the patient with DBDSI and their attendant complexities and communication needs. This is difficult to achieve while exclusionary barriers are still deeply embedded in all interactions within a hospitalisation for PWDBDSI.

Diminished social recognition

Social recognition is acknowledging a person as a human being with needs and wishes (Danermark & Möller 2008). Honneth's (1995) theory of social recognition posits that it has three key elements:

1. Self-confidence (personal experience of security, communication and trust from others that helps self-development and awareness)
2. Self-respect (legal recognition and respect)
3. Self-esteem (social inclusion and value in society).

Without all three elements, one does not have full social recognition. Lack of recognition therefore challenges ontological security and trust in others.

The disturbed social relations and communication failures for most participants, seen in **chapters 8–11** (Findings 1–4) result in disrupted coherence and ontological insecurity. They do not receive the same level of care, respect and communication as the sighted-hearing population, self-confirming their lower status of social recognition. As with self-respect, the presence of legal safeguards is moot if they are not complied with or enforced. The net effect for the patient-participants is a battering of self-esteem, token self-respect and low social recognition—this decentres patient care by eroding their agency to confidently participate in decision-making about their own care. Simultaneously, there is an erosion of self-confidence and diminished ability to engage in maintaining or improving health. Unpredictable care fosters the participants' disempowerment and feelings of being disregarded.

This low social regard—and the lack of enforcement of legal, ethical and policy directives—see staff able to exercise their power to ignore basic care and communication imperatives. Thus, the link between power imbalances and ontological (in)security is strong, which is prominent in the present research because themes were developed and then appraised for wider meanings. In this study, participants paint an image of hospitals and staff doing what they do—and not do—because they can. No one appears to stop or check staff; no one except the participants themselves are educating staff otherwise, and they are doing so while ill or injured; as indicated, their complaints are rare and just as likely to be dismissed as upheld. Many of the subthemes fit across more than one of the domains of accessibility, power and ontological security—fortifying the connection between them in both theory and praxis.

The primacy of ontological insecurity in this research

The present research shows the linkages between access to information, power disparities and the resultant ontological insecurity, with most participants experiencing ontological assault and resulting insecurity. Annie is forcibly medicated, Tom is pushed, Rose is pulled along as if on a leash, four people hold Emma down and Lachlan lashes out when he does not understand what is happening around him.

Anxiety, trust, routines and social interactions are all tightly bound together (Giddens 1991); these are all compromised for the participants while in hospital. This is additional to the stress of the disease or injury that precipitates the hospitalisation and is additional to that imposed by daily life with a disability. In fact, no participant gives weight, time or storied space to the presenting-to-hospital problem.

Anxiety and distress is described by 83% of the participants, absence of trust by 67% and negative interactions with staff by 89%. Communication and ‘knowing what is going on’ are essential to building trust, security and wellbeing (Danermark & Möller 2008; Giddens 1991; Lindstrom & Eriksson 2005). According to the participants, there are too few supports and too many barriers. The lack of routine in hospital creates uncertainties—the environment is constantly shifting as patients are moved around and staff are ever-changing, with no information to anchor and reassure. Underpinning all of these failures is the fact that they exist because hospital-institutions and professionals have the power to provide or to ignore.

The decentring of patient care: part 2: power and disparities

The principal mediator of ontological security and ‘knowing what is going on’ is power parity. Disparity confers insecurity and ‘not knowing what is going on’. In this thesis, power is ‘understood as an individual’s or a group’s ability to act *in spite of* or *in response to* the power wielded over the individual or the group by others’ (Rolin 2009, p. 220, citing Allen 1989, p. 34; emphasis in original). Foucault (2012), and Giddens and Sutton (2017), assert that power is not simply between those in authority or not, but is multilayered and present in all levels of society.

The idea of power differences is enmeshed in how critical realism conceptualises society as stratified with multiple layers and influences (Burnett 2007; Danermark 2002). This organisation of social relations illuminates that more power is ceded to some of society's members, and less to others. Generally, PWDBDSI are less powerful because they have fewer means of communication, less access to information and more restrictions to mobility. They are more dependent on both others and society for providing support, remediation and barrier removal. These conditions confer a vulnerability for PWDBDSI in situations where support is not forthcoming. Safeguarding frameworks exist internationally, nationally and locally, which purportedly constrain the hospital and its staff from power exertions and service disparities.

Power parity in theory

In theory, the unfettered power of hospital-institutions over patients with disabilities is constrained by legal, ethical and government policy safeguards. In the *Convention on the Rights of Persons with Disabilities*, article 25 mandates:

> State Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability … and (State Parties must) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons (United Nations 2006).

In federal legislation, the *Disability Discrimination Act* 1992, while not referencing healthcare directly, states: 'It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to discriminate against another person on the ground of the other person's disability' (section 24).

The National Disability Strategy 2010–2020 is a federal policy that details Australia's government plan—in consultation with industry, families, carers and PWD—for the progressive implementation of the UN (2006) *Convention on the Rights of Persons with Disabilities*. This process reflects that PWD are their own experts and thus are best placed to provide input on issues that affect them and determine their priority. There are six core outcome areas, with each containing policy directives for the government. An overview of the relevant strategy to this research—health and wellbeing—follows:

- All health service providers, including hospitals, have the capabilities to meet the needs of PWD;
- Timely, comprehensive and effective prevention and early intervention by health services for PWD;
- Universal health reforms and initiative must address the needs of PWD, their families and carers;
- Factors fundamental to wellbeing and health status (such as choice and control, social participation and relationships) must be supported in government policy and program design;

- And, most significantly, service providers must **actively prevent abuse, harm, neglect and violence** [emphasis added] (from Health and Wellbeing, Human Rights Commission 2016, outcome area 6).

At the NSW state level, the *Disability Inclusion Act 2014* has several basic principles, some of which are relevant to this work. PWD have an inherent right to respect and dignity; the same right as other community members to make decisions that affect their lives; the right to be supported in making those decisions, if they want or require support; the right to live free from neglect, abuse and exploitation; the right to access information in an appropriate way for their disability and cultural background, which enables them to make informed choices; and the same right as other community members to pursue complaints (section 3).

The NSW Department of Health *Policy for Hospitalisation of People with Disability* 'sets out guiding principles for responding to needs of people with disability including inclusion, person-centred services, accessibility, communication, and reasonable adjustment' (Ministry of Health NSW 2017a).

These safeguarding frameworks demonstrate that, despite their existence within the provision of healthcare to PWD (including PWDBDSI), there is a lack of compliance in much of society. The present research's examination of the participants' experiences within hospitals finds serious and often wilful non-adherence in their interactions.

Power disparities in practice

The power that hospitals and health professionals wield over patients with DBDSI functions in many ways, and on many levels, to delimit the ontological security of those patients by decentring their care.

The lack of attention to conventions, legislation and policies means that power hierarchies pervade the healthcare system. Hierarchies are defined as 'a group of individuals ranked according to authority, capacity, or position' (Walton 2006, p. 229). Walton (2006) and Heath (2018) note that this results in the compromise of patient–healthcarer partnerships and outcomes. Walton (2006) refers to power hierarchies as the 'Berlin Wall of patient safety' (p. 229). The existence of power hierarchies and gradients does not align with ideas of patient-centred care (Heath 2018; Henderson 2003; Walton 2006) and shared decision-making (Berry et al. 2017). The decentring of patient care found in this research is due to health institutions and/or professionals exercising power over participants—such as withholding accessible services like interpreters, because the power to book and fund an interpreter in a public hospital resides with the staff and system.

Walton (2006) writes of the traditional doctor hierarchies, where older clinicians exert power over younger interns, residents and registrars to the detriment of patient care. This is coupled with the belief that all doctors have superior knowledge to patients (Walton 2006), which serves to delimit patient-centred care.

Those who hold knowledge hold the power

Foucault (2012) posits that power is gripped by those who hold and have knowledge. Thus, being in possession of knowledge enables professionals in hospitals to exert power and act as information gatekeepers (Foucault 2012; Henderson 1994, 2003). Sighted-hearing patients, who require no communication support, acquire what knowledge the professionals impart as well as what they glean from their senses; this means that patients with DBDSI are further limited by needing communication support and information. The participants demonstrate this when in the state of 'not knowing what is going on'; therefore, they feel powerless. Furthermore, it is not the impairment of sensory loss that is disempowering, but the hospital-institution and professionals who fail to provide the information and supports needed.

There are power gradients between nurses and patients, where knowledge is held by the former but not the latter. Henderson (2003) writes that contemporary nursing practice requires nurses to work in partnership with patients to achieve patient-centred care and optimal outcomes. In that study, however, most nurses were unwilling to cede power because they believe they know best and that patients do not have the knowledge to make medical decisions (Henderson 2003). In an earlier work, Henderson writes that nursing practices have the power 'to shape knowledge, and thereby dictate and limit the quality of the nurse–patient relationship' (1994, p. 935). Task orientation and time pressures also run counter to patient-centred care and communication; what is needed, therefore, is 'for nurses to share and give information to patients readily and to be open in their communication with them' (Henderson 2003, p. 501). The present research demonstrates that access to knowledge for shared decision-making (a parous state) does not occur for patient-participants with DBDSI.

The power exertions that the participants describe, which I classified, take many interconnected forms—exclusion through lack of access to information, loss of dignity, negative touch, neglect, abuse, fear, distress, loss of agency, dehumanisation/ depersonalisation and emotional labour. These exertions result in and from power disparities, with hospital-institution-professionals having the most power and patient-participants the least. The net effect is diminution of security and trust, and the decentring of care.

The power of negative touch

The nexus of power, and its influence on ontological security, is seen most forcefully in this research within the subtheme of unwanted, negative touch. Professionals practice, and hospital-institutions perpetuate serial and unnecessary assaults on persons and their ontological security. With patients who 'do not know what is going on' and cannot comply with inappropriately communicated instructions, staff feel able to grab, poke, shove, push, slam and pull with impunity.

When the hospital staff can touch you negatively and dehumanise you, deny interpreters and neglect your needs, disrespect and distress you, and even cause you harm, then you are not an equal citizen.

The role of living realities

Participants are not just disabled by power imbalances in hospital systems, but also when these combine with their living realities of life with DBDSI (less information generally, less mobility, less access and more vulnerability in specific situations, in tandem with more health and wellbeing risk factors). These risks and realities are well documented in **Chapter 5** and **Chapter 9**.

Patient-centred care: shifting the power

Power dynamics are at play in the relationship between the individual with DBDSI and the hospital-institution, and between the individual with DBDSI and other individuals (hospital staff, for example). This renders hospitals as disabling and hostile, one of 'the hazards of life' (Laing 1965). If being in hospital 'disables' PWD further, then it is oppressive. Oppressor-institutions are found in most theories and models of disability, notably, the social models, critical realism, critical disability theories and human rights social justice framings.

A power gradient exists in the uneven power between patient and clinician, which fosters 'not knowing what is going on'. Hostage bargaining syndrome (HBS) (Berry et al. 2017) is a phenomenon that regards patients as fearful and confused, attempting to negotiate health decisions from this parlous position with their 'captors'. HBS is a psychosocial dysfunction that exists as a result of uneven power balances in hospitals and may explain some of the dissonances, as well as the participants' ambiguous attempts to comply with what can be seen as staff-captor expectations. Linda describes not wanting to make 'the nurse angry', in case there were consequences such as 'being mean' or 'not coming'. Shared decision-making is diminished in the presence of fear, erosion of trust, and restricted and inadequate knowledge experienced in HBS (Berry et al. 2017). Heath (2018) also explains that power discrepancies adversely impact the partnership between patients and caregivers. This present research, too, confirms an erosion of trust that results from an uneven clinician–patient power balance, which promotes the 'not knowing what is going on' via restricting access to information.

The ways in which hospitals and healthcare systems exert power over patients are not limited to restricted information, erosion of trust and rights, but also include limiting access to (and trust in) evaluations and patient-satisfaction/experience surveys (Rolin 2009). Exclusion criteria and/or inaccessible formats act to silence some experiences (Berghs et al. 2016). The present research also finds that withholding accessible formats and interpreters results in disabling patients' participation in their own healthcare, as well as voiding complaint-making. HBS may also be seen in the absence of complaints—some participants (myself included) do not complain about care poverty because we have to keep attending these hospitals for our future care. 'Don't make a big fuss going to the top,' I tell myself, 'it will end badly.'

There are consequences for the lack of patient personal power in hospital care. Power parity allows patients to participate in and query their care. Absence of patients having personal power results in treatment failure and lack of compliance—it puts patients at risk (Berry et al. 2017; Heath 2018; Sutherland et al. 2017). The basic tenet of shared decision-making, and of patient-centred care, is that the patient and support networks are included in clinical decision-making and that they have clear opportunities to consent, clarify, query and complain. A climate of power parity is needed for patient-centred care. This study demonstrates that patient-participants with DBDSI are treated differently from sighted-hearing patients by routine exclusion and decentring from their care. No participant received a consent form that was accessible to them. Ava says she felt 'a bit left out'; while Rhonda says, 'I was not given the information of what was going to happen'; 89% of participants did not know what was going on or what the professionals had told them.

Small acts of resistance

Participants are not just tacitly complying with the status quo—they demonstrate small exertions of power during and after the events. All feel that engaging with this research is a contribution towards shifting power balances and gaining support for better communication and care in hospital. The NDIS enables Rose to have her communication-guide with her for the duration of her stay, although at the expense of her own day-to-day ongoing support needs. Rebecca 'sneaks' in her husband to increase her safety and security. William stands at the nurse's station until his questions are answered and he receives information. Sally does not tolerate any of the doctors' refusals to book an interpreter or rudeness in shouting into her cochlear implant. She states: 'No interpreter, no conversation.' She maintains this position for four weeks until one is booked. Weary of one-sided conversations she cannot understand, Amanda wears her wristband identifying her as DEAFBLIND; she waves it at staff and they 'go and read the notes'.

But not everyone is able to resist powerful clinical caregivers. Remember that these encounters occur when participants are ill or injured—sometimes very sick. They might not always have the emotional energy for educating the staff continuously and cyclically, or for challenging the status quo. Linda is too unwell over the weekend to defend herself against the carelessness of staff, but she is better able to once her surgeon returns, because he 'understands my situation' (referring to her DBDSI and attendant support needs). Acts of resistance do seem to elicit a positive mediative effect. They are linked to support networks as well—participants note their families, friends and support workers provide advocacy to push back against power exertions. The problem, however, is that support networks are not present at every hour, nor do all PWDBDSI have support available. Only one-third of participants have family, friends or a partner to mediate the hospital experience for some of the time.

The community-at-large is oblivious to these experiences, because the voice of the participants is stymied by the lack of accessibility and by psychological effects of fear, tacit acceptance and avoidance. When participants interact with the hospital system, the principal experience for most (89%) is poor care.

Concomitant communication gaps, power gradients and ontological insecurity in patients with DBDSI are both linked and causal. A more balanced power gradient should see better clinician–patient partnerships, shared decision-making and a greater level of attention to accessibility and patient wellbeing. This is seen in the single participant who recounts a positive hospital experience—feeling safe because staff were attentive to his communication needs without needing to be reminded by either his support network or wristband. The too-few positive experiences (2) are in private hospitals, mediated by the constant presence of support workers/communication guides funded by the NDIS (which drains their allocation of core support for future everyday needs, and means patients have to be well enough to battle bureaucracy for a review of their plan). Using the wristband (obtained via a support organisation or from the researcher) promotes access to information for the wearers by reminding staff to book interpreters and/or use alternative communication means.

Critical feedback and querying care

To give feedback or query care, patients require security, information and power parity. Patients, including older people and PWD, may feel intimidated or are hesitant to be labelled as 'difficult', so may not complain about or disclose poor experiences of care (Berry et al. 2017; Fisher et al. 2006; Heath 2018). This silencing is an effect of the power that hospital-institutions and their staff hold. By not providing accessible patient evaluation forms or communication support, hospital-institutions erect and maintain barriers to frank and shared decision-making, as well as complaint-making.

There is negligible research on complaint-making by PWDBDSI, and what the influencers and outcomes are. In a systematic review on older people and hospital discharge planning, the older patients' lack of personal power and lower status constrained their participation and complaint-making (Fisher et al. 2006). Bull and Kane (1996) studied older patients and hospital care, finding that only a small minority of patients complained of disrespectful staff attitudes, and that these patients were more likely to have received education beyond high school. Of the present participants who complained, three have education beyond high school and one does not. One reason for this may be because many PWDBDSI have fewer educational opportunities. This results in restricted world views from the general climate of decreased information and sensory input. Roy et al. (2018) discuss the need for researchers to understand this as part of better research practices; clearly, this is also a factor for hospitals and clinicians. The combination of a restricted world view and hermeneutic factors may conspire to silence patients. If patients are not aware of, or offered, accessible mechanisms for querying care or complaining, then they cannot communicate these experiences. Hospitals and professionals need to be aware of and provide all patients with the information they need to participate in, as well as query and critique, their care. This research also identifies dissonances between words (good) and experiences (poor), which likely impacts critical feedback as well as the capacity and comfort levels for querying care given in shared decision-making. There is much more work needed to clarify these opacities and promote climates where complaints can be heard and change actioned.

Silencing the storytellers

Presently, there is a selective mutism in the hospital-institution and community spaces around examining the experiences of patients with DBDSI. The hospital-institution effectively exerts power to silence these stories. Hospital-institutions also hold the power to rectify all these omissions of care and communication. In so doing, hospital-institutions would comply with legislation, policy and community imperatives.

That power hierarchies and gradients are alive and well is evidenced by Bell et al. (2018), who surveyed a total of 1175 patients and support networks. Of the participants (current and past ICU patients and families), 50% reported 'at least one barrier to voicing concerns' (Bell et al. 2018, p. 928), mostly due to fear about being seen as difficult or troublemakers. Participants also note that clinical teams appeared too busy to hear concerns, or that they themselves did not know how to voice complaints (Bell et al. 2018). These patients are not a group identifying as 'disabled', so this reflects the general difficulties of complaint-making, which are even more challenging for PWDBDSI.

Generally, the patient-participants in this research do not complain; part of the being-disabled deal is being held hostage to the fear of things getting worse, or in tacit acceptance of poor service. Half of the present participants also note how busy and time poor staff were, but it must be recognised that the supports required to communicate in hospital are the same supports required to voice complaints. Patients with no oral or spoken language may be silenced by the hospital's failure to provide an appropriate interpreter or forms in accessible formats. This physically restrains the patient from naming their experience. The patient-participants have few conversations complaining about the numerous and problematic healthcare experiences. Patients need power to be able to complain, as well as hermeneutic resources. There were human rights abuses evident in the patient-participant living realities (**Chapter 9**); none are able to master these burdens to create change without effective support.

Hospital patient-experience surveys are rarely, if ever, offered in accessible formats. If patients do not have interpreters for clinical care discussions, then they do not have them for evaluations or complaints. As well as inciting shame and fear, hospitals can exert power over participants when participants experience 'hermeneutic injustice' (Rolin 2009, p. 220). This is evident when patients do not have the language, label, confidence or communication support to describe what has happened to them. Being unable to understand or voice your experience makes protest impossible. This is relevant to many of the participants in this research, because English and its structures are a second language to some, others may not have spoken language at all, and most are unaware of their right to query aspects of their care. George describes how difficult he finds written English, witnessed after his last hospitalisation when he could only recognise ‘some words’ on his consent form (but not enough to make meaning)—he is now taking a course to improve his written English.

Mitigators of power

Ontological security is primarily mediated by ‘knowing what is going on’ and parity of power with health professionals and the hospital-institution. There are other mediators and mitigators, too, such as support networks and gender.

Support networks

The presence or absence of support networks is not a simple binary. The two participants who had round-the-clock support reported substantially better experiences on those occasions than without that support. For both Rose and Annie, the presence of a communication aide and physical helper ameliorates the failure of staff to do their jobs. The support person communicates on the participant’s behalf when required; communicates consent forms via sign language; requests alternative formats; imparts medical histories; cuts up food; alerts the presence of food, drink and medication; reassures; orients; accompanies them to the bathroom or toilet; guides; explains; voice interprets; tactile interprets; uses Auslan; and notes discharge instructions.

Other participants support mediated experiences incidentally because mediators are not present throughout the whole hospitalisation. Support helps to prevent risk (real or perceived), advocate and communicate. What support really does, however, is mitigate the failures of staff and systems. Rebecca describes ‘sneaking’ in her partner when communication failures threaten her ontological security. Her partner calls the attending medical officer to help with the situation, because Rebecca cannot do this herself. The hospital offers no other way to hear her fears and queries; others also describe this reality, where it is unpredictable whether an individual hospital allows a member of the support network to stay. In 2020, the novel coronavirus pandemic has exacerbated this unpredictability where, increasingly, visitor restrictions or prohibitions are the norm.

The presence of support mostly confers security and promotes advocacy and communication. A few participants note that family members do not always have the vocabulary of professional interpreters to explain medical matters. Amanda mentioned privacy concerns with family knowing ‘all your business’, and Jane’s friends were simply not available when she needed them at 2 am. This highlights the critical issue—support is incidental, not coincidental with need; this can only be rectified if support is present day and night. An alternative solution would be for all staff, on all shifts, to do their job of providing both communication and care. This includes calling for an interpreter when the patient needs one, not simply for staff-identified ‘special conversations’. Rebecca says, ‘I do wonder what people do when their partner or parent isn’t there? Or they don’t have anyone. Terrifying thought.’

Gender

The personal power of participants, or lack thereof, is likely to be gendered. Burgeoning research is indicating that women, women’s health and women’s health experiences are poorly understood, different to those of men and reflective of lower status and power (Dusenbery 2018; Dwass 2019; Norman 2018; Perez 2019). These authors, among others, demonstrate that women receive poorer, delayed or inappropriate treatment overall, when compared to men. Women with disabilities have lower status and power, and poorer experiences than able-bodied women; the *World Federation of the Deafblind World Report* (2018) indicates that women with DBDSI have the poorest experiences of all. In this research, women outnumber men (13 to 5), which may reflect impairment support usage patterns. The recruitment strategy did not seek to restrict anyone from participating, nor was there a quota based on gender. The single positive experience (without a constant support worker in attendance) is a male’s, but there is a lack of saturation and absence of hierarchy in experiences to determine ‘who had the worst time’—males or females. **Chapter 14** provides further details, in ‘Limitations and Paths for Future Engagement’.

Residential aged care

Residing in aged care is significantly disempowering, both generally and especially if inappropriately placed as a young person. This research does not specifically examine aged-care experiences but these are the most prominent border concern, where human rights abuses are noted (see **Chapter 9**). There are parallels between the care failures, neglect and abuse experienced within hospitals and aged-care residences, as described by participants with lived experience in both. Poor experiences are attributed to absent handover of medical and communication information between hospitals and residential facilities, and vice versa. Two participants mention the role of guardianship as eroding inclusion and personal power in both institution types. It seems that the absence of senses is equated with lack of capacity. Contrary to this is the fact that all participants are able to describe their experiences and wishes clearly, when given the correct personal communication support, as this research demonstrates.

The role of other mediators is unclear; this is discussed in **Chapter 14: Where to from here?**

The ‘(un)lucky dip’ model

The following model maps the participants’ social disadvantages, information inadequacies, situational vulnerabilities and power relationships, which are exposed through the participants’ critical insights in the present research. The ‘(un)lucky dip’ model illustrates what happens to PWDBDSI in hospital, and why.

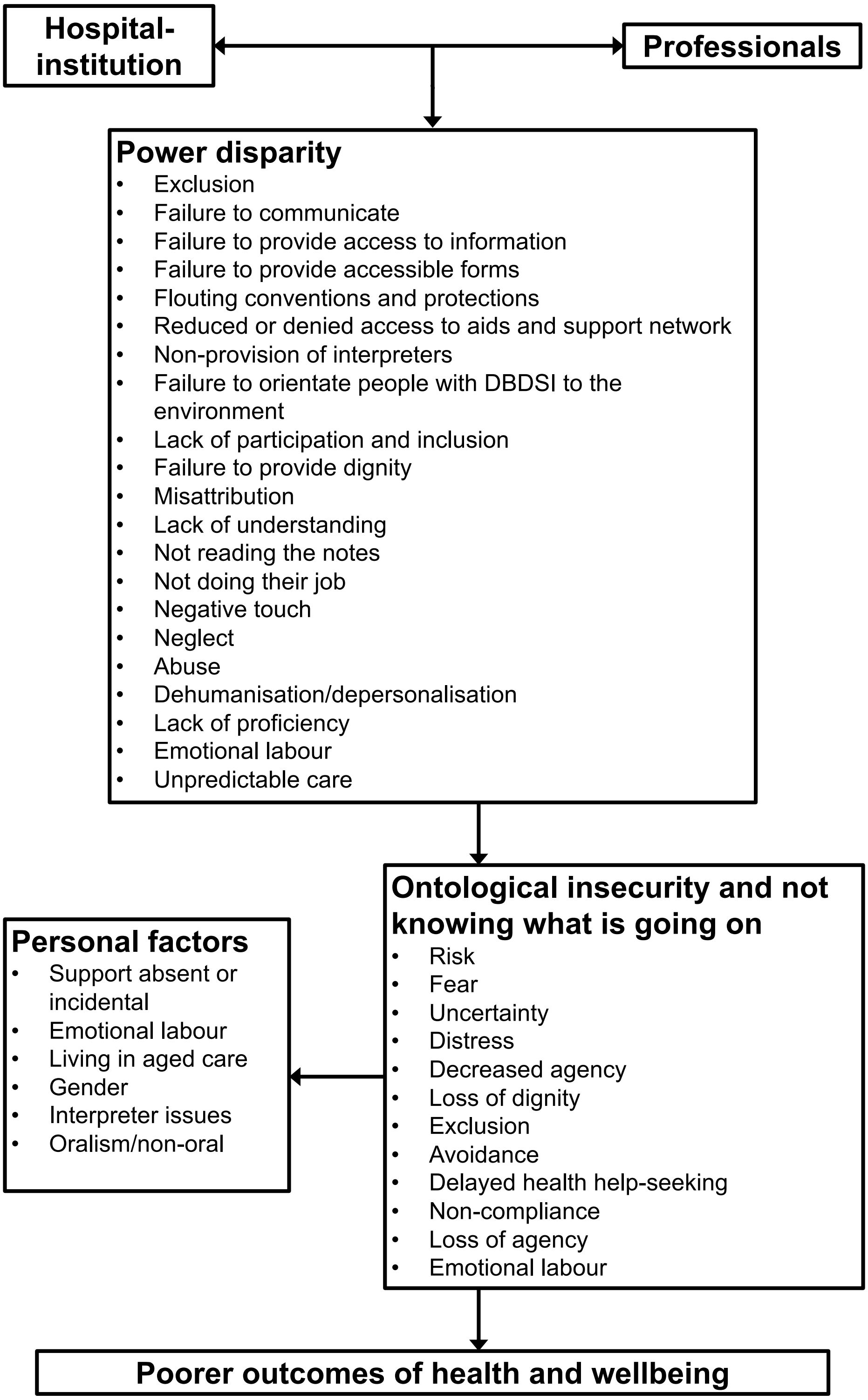


Figure 3. The (un)lucky dip model

NOTE: For those with screen readers, or who cannot access the model, a visual description is provided in **Appendix 13**.

Conclusion

This chapter examines the state of ‘not knowing what is going on’, power imbalances and ontological (in)security—specifically, how these are interrelated. It focuses on power discrepancies among hospitals, hospital staff and patients with DBDSI, and how these imbalances disrupt or deny the provision of equitable and patient-centred care. As is demonstrated in **Chapter 14**, ‘not knowing what is going on’ is a strong indicator of negative experiences, and ‘knowing what is going on’ safeguards ontological security. The patient-participants are resourceful, strengths-focused and solutions-oriented—they want change and have ideas on how to do this. Hospital-institutions and health professionals can provide communication, information and care, but may choose not to.

To improve the wellbeing of PWDBDSI in hospital, the way society and institutions are structured and organised needs examination. First, the patient-participants’ narrative space needs to be acknowledged as different, and resources applied to actually hear their voices. The exertion of power and the consequences of patients with DBDSI being silenced and erased when in hospital needs scrutiny. As Smith-Chandler and Swart (2014) maintain, the psychological sequelae of power dynamics need exploration, which is presented here through ontological security, because this captures many nuances of the lived experience of patients with DBDSI.

The findings demonstrate both a failure to provide care and a ‘care-less’ attitude to the plight of participants. Given the preponderance of negative patient experiences, the damning patient-experience Report Card (presented in **Chapter 11**) may be considered as more universal in the community than simply isolated to an individual few. Using a government derived and tested patient-experience measure, The Report Card shows a dire situation and demonstrates the extent of the work needed across most domains to ensure compliance going forwards. The findings chapters also establish a pattern of poor care, abuse and neglect for the participants. The ‘(un)lucky dip’ model shows how the overarching themes link via subtheme mediators, demonstrating the complex relationships that confer potential harm and risk to patients with DBDSI in Australian hospitals. The hospital hazards are not navigable if there is no information, predictability, proficiency, power parity or trust in the hospital system, environment and staff.

These obstacles occur despite existing ‘safeguards’. Ontological security is under threat every time a patient with DBDSI is hospitalised. Sadly, a hospital stay may even be experienced as an ontological assault. **Chapter 13: ‘The health system should look after us’**, which follows, identifies ways to turn healthcare’s oppressive features into positive and parous experiences for PWDBDSI, by examining the steps needed to move from ontological assault to confident and shared decision-making.

All this matters, as Lachlan says, ‘because the health system should look after you’.

Chapter 13
Discussion 2: ‘The health system should look after us’

Introduction

The National Disability Services (NDS) writes that ‘NSW is facing a reality where people with disability are being exposed to mistreatment and discrimination’ (2014, p. 3) This study concurs with that assertion, finding that the subpopulation of patient-participants with DBDSI are subject to care disparities and power exertions, including abuse and neglect, inaccessible formats, and hostile environments.

The participants in this study feel invisible in healthcare, spending days waiting in unfamiliar territory for unknown things to happen to them. Waiting for someone to tell them (in a method that works for them) what the day’s plans are, what their diagnosis is and what their treatment will be. They worry in the dark silence of hospital wards (which, for the sighted-hearing, are noise- and activity-filled spaces), not knowing what is going on; they are occupying a lonely place. For some, communication failures are worse than the diseases, procedures or operations themselves.

The participants note that PWDBDSI are often discharged still ignorant of what has happened to them, not knowing answers to the questions *where*, *when*, *how* and *why*. They tell their families, friends (including each other), support workers and interpreters what did and did not occur. Information about their experiences is not shared within the health system, however, if their experience is not reported as an adverse event or entered on an (inaccessible-to-them) patient-experience survey. Hospitals thus remain unaware of how they may be failing patients with DBDSI.

This study illuminates these issues to enhance awareness—mostly about the harms, but also the strengths of when hospital staff take the time to do things reflective of patient needs. Participants eagerly tell their stories as a way to co-create how the system can do better.

The previous chapter identifies situational vulnerabilities, institutional and professional failures, and power exertions, resulting in ontological insecurities for patient-participants. This chapter takes a salutogenic perspective to demonstrate how the participants’ Wish List can be harnessed into change for good. This affirmative ‘looking after us’ model has consequences for future policy, planning and practice. The chapter then discusses ‘the climate of inaction and indifference’—highlighting the seemingly perpetual failure of systems and institutions to embrace care improvements for PWD generally and PWDBDSI specifically.

In the wake of the novel coronavirus pandemic, an opportunity has arisen to work towards wider inclusion of PWD in their healthcare. The pandemic has exposed the rampant ableism and barriers for PWD in hospital and society, created new barriers with the lockdown responses, and exposed the shortcomings of some public health measures. At the same time, a microclimate is developing; this research is enhancing the conversation across governmental and non-governmental organisations to fan the winds of change. This is a call to action: patient care and experiences must improve.

Salutogenesis

This research pivots not simply on identifying systematic and professional failures but, rather, on how to effect change for the participants (and myself) to receive, participate in and benefit from their healthcare. As Minichiello, Aroni and Hays (2008) stress: ‘According to the ideals of participatory research, the primary beneficiaries of research should be the participants because they have played a significant role in “doing” the research (co-researching) as well as providing the data for it’ (p. 7).

Care and communication improvements would benefit all patients, with or without disability. Better healthcare and communication experiences generate better health outcomes, and better health outcomes mean economic savings. Thus, the participant-led solutions potentially have wider social benefits for all. It is possible to pivot to address care needs. Forgotten your reading glasses? Large-print forms to the rescue. Having an eye operation and temporarily vision impaired? Hospitals are aware and can help you. Undiagnosed impairment is common, such as hearing loss in older age; if staff are more cognisant and accommodating, they will detect and support more readily. Because mask-wearing disables lipreaders, staff can quickly turn to pen and paper, speech-to-text or smartphone flashcards.

The thematic richness and truthfulness of the participants’ and researcher’s co-constructed findings demonstrates that there is substantial work to remediate and ameliorate how people experience care. The risk of doing nothing is to perpetuate human rights abuses, discrimination and care neglect.

In the previous **Chapter 12**, I broach the idea that salutogenesis—in particular, the SOC—links to ontological security for patients with DBDSI. Danermark and Möller (2008), and Simcock (2017b), support a salutogenic approach that focuses on solutions, potentiality and capabilities, rather than globalising vulnerabilities. Simcock (2017b) also notes that, at present, salutogenic approaches are largely absent from the literature on DB. Roy, McVilly and Crisp (2018) remind researchers that better research practice with this population means positive framings that benefit participants, while respecting their knowledge and contributions. Using a salutogenic framework, therefore, can position the participants’ Wish List onto paths to ontological security and better health outcomes for PWDBDSI (and other patients in hospital), as well as safeguarding compliance and economic savings.

As cited in Lindstrom and Eriksson (2005), Antonovsky’s original definition situates salutogenesis as:

> … a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement (p. 441).

Put more simply, salutogenesis is two-handed: first, the orientation to problem-solving; and second, the harnessing of resources and capabilities to achieve solutions (Lindstrom & Eriksson 2005). The combination of being solutions-oriented and having capability form part of the SOC. Another core element is the requirement of trustworthy information to assess situations, problem-solve and harness resources.

The lessened stimuli and increased communication, accessibility and mobility needs of PWDBDSI impact their personal resources for problem-solving, thus limiting their ability to have confidence in their life and interactions. Information provided in inaccessible formats, or not provided at all, reduces coherence and diminishes capacity. Society should provide the commensurate support needed to attain or regain trust and coherence.

The salutogenic approach asserts that health exists on a continuum between disease (illness) and ease (wellness). It is more important to resource health-promoting factors than focus on risks, illness or disease. The capacity to promote wellness refers to:

> … a combination of peoples' ability to assess and understand the situation they were in, to find a meaning to move in a health promoting direction, also having the capacity to do so—that is, comprehensibility, meaningfulness, and the manageability, to use Antonovsky's own terms (Lindstrom & Eriksson 2005, p. 440).

This means that patients with DBDSI who possess trustworthy information have trust in their clinical caregivers; if given supports and respect, they are in a better position to move towards health-promoting outcomes. Thus, it is incumbent on society, hospital-institutions and clinicians to provide respect, resources, and trustworthy information and care.

Whereas previous chapters of this thesis identify the status quo and its problems, and present a model delineating some causal mechanisms and mediators, this chapter regards factors that promote health and wellbeing. In the following section, I outline the conceptual 'looking after us' model and show what patients with DBDSI require. This can then be harnessed to build capacity and provide solutions to the situations described in **chapters 8–11**, the research findings, as well as those in the broader discussion. These solutions will help PWDBDSI achieve participatory rights and parity in their healthcare, alongside better health and wellbeing outcomes.

Looking after us: A conceptual model

The following sections detail a model of affirmative framing, using the participants' Wish List and positive experiences. This model includes societal, institutional and professional factors, as well as individual considerations.

Societal factors

Upholding and enforcing conventions, federal law, state law and putting policy into actual practice.

Hospital-institution and health professional factors

- Compliance with safeguards and conventions
- Compliance with policies and practices
- Provision of accessible-to-the-individual consent forms
- Provision of accessible formats, communication and information
- Positive touch
- Kindness
- Provision of orientation and mobility
- Funding for what is needed: staff and equipment
- Harnessing of new technologies such as virtual reality to help explain the experience of being a patient with DBDSI in hospital
- Non-discriminatory care
- Provision of interpreters whenever the patient wants one
- Proficient, predictable care and trustworthy care
- Up-to-date and informed staff (e.g. staff reading the notes)
- Patients asked what they need
- Collaboration with support network
- A safer and more accessible environment
- Navigators, dedicated staff who support patients with disability, chronic disease and other complexities

Personal factors

- Patient-led care team that embraces support networks
- NDIS and aged care funding for interpreters when needed in healthcare and hospital
- NDIS and aged care funding for all assistive technology needs
- Wristbands that identify the patient and remind staff wherever the patient goes
- Social haptics training and dissemination: touch signals that reassure and signify important hospital events
- Patients' contact and health information available to clinical caregivers
- Patient passports
- Going-to-hospital kits

These factors lead on to the patient's security and situational awareness; in effect, the ability of the patient with DBDSI to know what is going on and participate fully in their care. This means outcomes of:

- Promotion of the SOC and its central dependence on reliable information
- Patients’ ability to query, question and complain
- Patients included in their care
- Shared decision-making
- Patient-centred care
- Patients’ dignity and respect valued
- Informed consent
- Trust
- Compliance with treatment and management plans
- Patients’ confident health help-seeking behaviours

All these power-equilibrating and ontological security–promoting factors align to ensure better patient experiences, and better health and wellbeing outcomes.

The ‘looking after us’ model

Sighted-hearing people expect to be looked after in hospital, as one of their top priorities (Australian Commission on Safety and Quality in Health Care 2017; Cunnett 2010; Roberts et al. 2011). Both internationally and locally for any patient cared for, this model is critical in delivering positive experiences and achieving better outcomes. While the phrase ‘looking after us’ may sound paternalistic and overprotective if used in everyday situations of wellness, in this discussion and model, the concept relates to situations of illness or injury when in a place of supposed care. It references that care should be provided with shared decision-making and power parity.

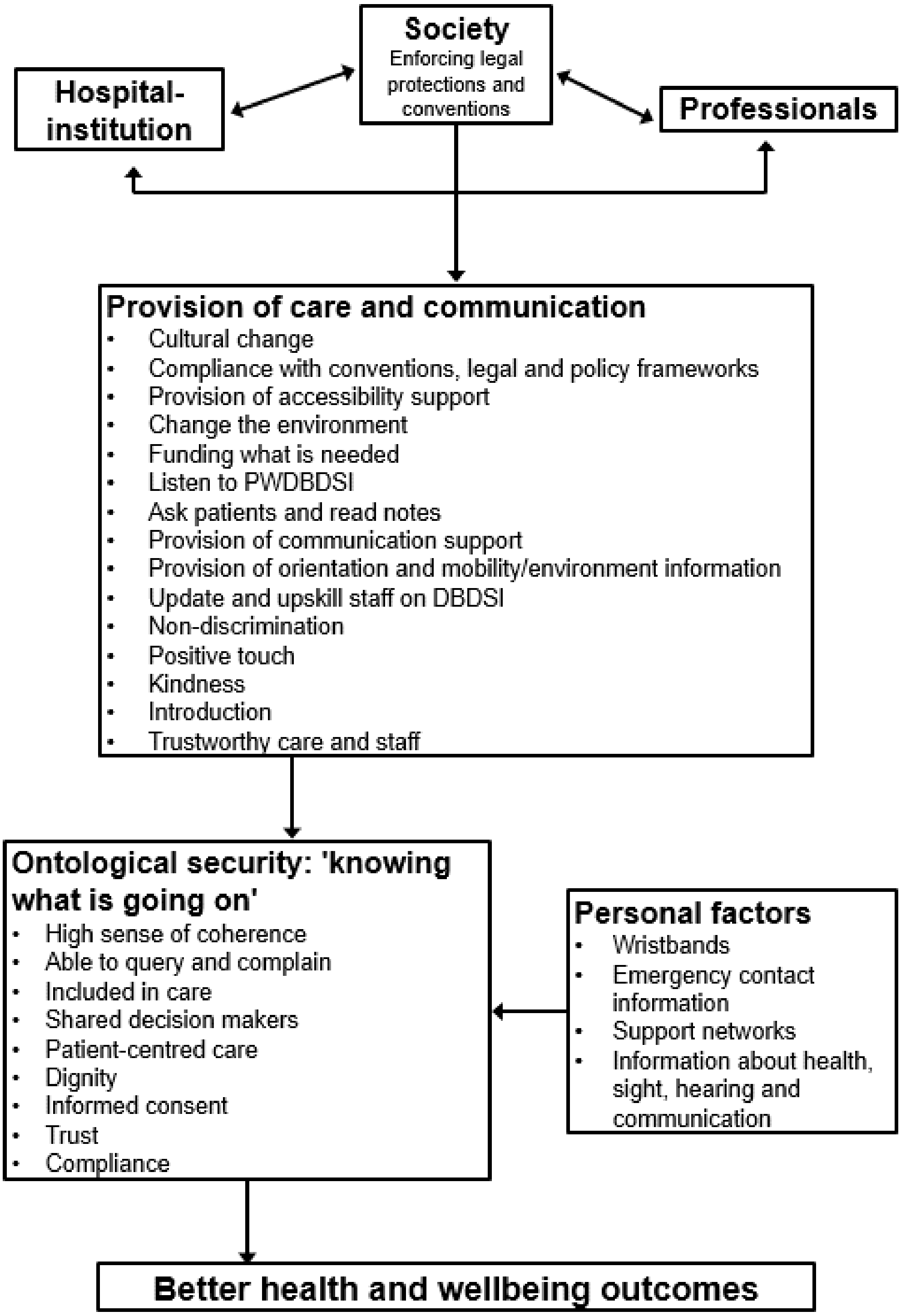


Figure 4. The ‘looking after us’ model

NOTE: For those with screen readers or who cannot access the model, a visual description is provided in **Appendix 14**.

Implications for present and future policy, planning and practice

The ‘looking after us’ model means that what is needed—and the implications for present and future policy, planning and practice—is considered. Changing the status quo of poor experiences for patients with DBDSI is important; as Sutherland et al. (2017) note, ‘experiences of care matter. They matter not only because healthcare providers should aim to meet patients’ expectations about how they want to be treated but also because, to a great extent, healthcare experiences shape outcomes of care’ (p. 17). Additionally, better health and wellbeing outcomes save money—as well documented by the NDS (2014).

Being known

This study’s findings are not entirely new: White (2014) makes recommendations pertaining to hospitals that fundamentally mean knowing the person-specific needs of deafblind–dual sensory impaired patients. All staff must have basic deafblind knowledge and training; they should take steps to identify deafblind patients, including older people, who may not yet know they have a combined sensory deficit; and there need to be systems in place that make an individual and their needs known to all healthcare staff (White 2014).

The Spanish-language study of Fernández-Valderas, Macías-Seda and Gil-García (2017) identified a range of architectural modifications needed, as well as access to information, professional development and use of technologies. Their participants wanted the staff to know them. Takahashi (2019) stresses that PWDBDSI like continuity of care, that is, for professionals to ‘know them’ and ‘know deafblindness’.

The participants of this study have spoken, signed and written. They, too, want to be known, heard, seen, listened to, understood, and treated with dignity and equity. Instead, they receive predominately disparate, discriminatory and distressing care. Yet, from their expert-knower positions, the participants are energising transformation. Now, it is up to hospital-institutions and society to listen, heed, fund and enable change.

A striated society has layers that include personal resources, both internal and external, as well as a person’s social and material environment. To tackle inequities in how PWDBDSI are treated in hospital, therefore, requires the following dimensions (based on Vehmas and Watson [2014]):

1. Personal resources (internal)
2. External resources
3. Hospital and health structures resources.

Personal resources

Participants and their support networks have demonstrated that they are willing, and are already doing much, to mitigate poor performance and lack of proficiency in the staff they encounter—and they are prepared to do more. Suggestions from the participants include being prepared with kits, signs, wristbands, contact lists and health information on smartphones, as well as inpatient passports. Healthcare haptics are a growing international system of touch signals; these originated in Finland through the work of Lahtinen (2008) and Lahtinen, Palmer and Tuomaala (2016), which Able Australia has taken up locally.

Hospital preparedness

Patients can prepare themselves for hospital by gathering information in one place, wearing wristbands that identify their communication needs and having a patient passport. These can all integrate into a going-to-hospital kit that reflects individual needs, identities and choices. Patients with DBDSI may need support and funding to collect and curate the individual components of their kits, so it’s vital that health departments organise their provision.

Contact and health information

By having all the information—regarding health, history, disability, contact information for support network and communication partners, communication needs, and devices used—readily available in hard copy, or on smartphones or tablets, patients can assure themselves that health staff can easily access accurate information. In Denmark, the Association for the Deafblind provides its members with personalised cards, stipulating their communication requirements and needs. These are placed by their hospital beds in case of emergency, alerting providers to their needs.

Wristbands: identifying and reminding

Wristbands represent one way that patients can continuously identify, highlight and remind staff of their sensory impairments wherever they go. As stated previously, the wristbands are the result of my quest to find a patient-controlled, cheap, portable and affordable solution; they promote recognition of the presence of sensory losses and inform and remind staff wherever the patient goes. If this initiative is nationally adopted and funded, all those who need and choose to flag a communication, accessibility or mobility issue could do so in practice. These wristbands can also extend to other disabilities, conditions and identity choices of patients; as well as other situations such as travelling, shopping and encounters with the police.

Some participants have already used wristbands with good effect. It should be noted that these are honoraria for participants—I handed out wristbands at our initial meetings, well before the interviews, and two participants were able to use them during unexpected hospitalisations. Three further participants contacted me after the interviews to tell me of their wristband experiences: ‘I just waved it at them (the staff) and they got me an interpreter,’ says one. Wristbands are also available from impairment support organisations and the Vision Australia online shop—the NDIS consumables budget can be used to acquire them. It must be noted that there may be bias in their reported usage, because participants may seek to endorse the bands to please me. However, user data as reported at conferences in 2018 and 2019 (Watharow 2018, 2019b) demonstrated acceptance and utility by patients with different sensory impairments and communication modes. I myself wore a band in 2019 and 2020, which improved my experiences because I received more effort from staff to meet my communication needs. This was critical during lockdown (April 2020) when support was restricted, as well as when away from the wards such as in X-ray, theatre and recovery. In May Sense UK requested bands to support their clients during the first and second waves of COVID-19 and these were sent and found useful (Emma Boswell 2020, pers. comm., 14 April; Lahtinen & Palmer 2020).

Prior to this research, I established that the wristbands are acceptable, comfortable and useful to separate groups of people with hearing loss, low vision or DSI (Watharow 2018, 2019c).

The care and communication passport

While not mooted directly by the participants, the spirit of collecting all relevant information and communication support in one place is present in individual recommendations. There are many examples of aggregating important patient information, such as Mackenzie's (2014) design for children with CHARGE syndrome and other complex disabilities; this idea is translatable to adults with DBDSI.

The patient produces a care and communication passport in collaboration with people involved in their care (family, partners, support workers, healthcare professionals and interpreters). This means that external and hospital–health system resources must support the PWDBDSI's personal resources.

The patient's care and communication passport resides with them and contains information on medical issues and history, with additional details regarding sensory loss/es, residuals and communication devices; information on other impairments and needs (e.g. personal care and feeding); information on communication and languages used (e.g. Auslan, tactile and/or hand-over-hand signing); information on any idiosyncratic communication language, signs or touch signals; copy of the deafblind alphabet if relevant; list of ways to calm patient (particularly important if the patient is nonverbal); information on equipment and assistive devices used (including photos and operating instructions); current health issues; allergies; emergency contacts; and social haptics or touch signals used on the body to convey information.

A care and communication passport can potentially be used by patients with rare syndromes, complex disabilities, intellectual disability and dementia—both with and without sensory loss.

With COVID-19 restrictions and/or prohibitions on visitors to hospitals, such a collaborative document represents one destination for all patient chosen important support information. This has potential to enable better experiences and reduce patient risk.

Healthcare touch, signals and haptics

As far back as 1996, knowing a few touch signs, such as the deafblind manual alphabet, was noted as improving patient experiences and communication. The participant in Mascia and Silver (1996) reported a strong positive touch and emotion point when the anaesthetist could fingerspell for her.

The use of informal, idiosyncratic on-body symbols is described by two participants, Annie and her support worker use touch symbols when in hospital, as do Rebecca and her husband.

These have a formal counterpart in social haptics. These are touch signals on the back or upper arm, which are generally used to convey information about the environment, emotions and events.

Haptics can also be used as a quick messaging system to convey emergency and health information. Haptices (touch signals), as developed by Lahtinen (2008) for health cover the following:

- Yes/no
- Start/finish
- Stay calm
- Is everything OK?
- Nurse/doctor
- Injection
- Pain
- Blood pressure
- Time
- Wait, don’t move

Further information is available in **Appendix 15:** *Using haptices in health care settings* (Lahtinen, Palmer & Tuomaala 2016).

In Australia, Able Australia currently teaches this system of social haptices to workers and clients. It would be feasible to disseminate more widely, and for more groups of patients such as those with disabilities, cognitive impairments or communication disorders. Again, with the pandemic increasing isolation in hospitals (psychical as well as social) touch signal systems could be beneficial for staff–patient communication. The haptices in use can be included in passports and kits.

Going-to-hospital kits

While a few organisations provide members with a uniform hospital kit, there is no consistent, system-approved version. Better Hearing Australia, Canberra have a low-cost kit that addresses hearing loss; it also contains a range of wristbands and cards to display on the bedside containing practical advice for staff. At a series of webinars presented by Deafblind International during COVID-19, Lahtinen and Palmer (2020) talked about their work with tactile kits, ready-to-go with a sticker on the front door to tell paramedics where to find the kit (they suggest on the refrigerator).

Hospital preparedness is well served with individuals building their own kits. Individuals can incorporate the above patient resources (information, wristband and patient passport) into a personalised kit. PWDBDSI can also include fingerspelling charts, and instructions for their devices and aids.

There is a lack of continuity, funding and research into the best items for different sensory, physical and intellectual impairments; national uptake and distribution of kits is prudent, so their effectiveness can be evaluated. Within a universal design, all PWD could build their own going-to-hospital kits from a range of components and options to suit the individual. These would provide greater support for staff seeking information during COVID-19 restrictions and enhance security for patients to know their information and support needs have been communicated.

External resources

Patient capabilities can be enhanced if they have the necessary external resources for participation and inclusion.

Interpreters

For many participants, no interpreter equals no communication. Availability of interpreters is both an international and local issue (World Federation of the Deafblind 2018). Several issues are contemporaneously driving interpreter availability for healthcare work in Australia, including not enough spaces at TAFE for learning sign and tactile languages; too few qualified teachers of sign and tactile languages; and the acute-on-chronic shortage of interpreters driven by the NDIS, enabling many PWDBDSI to improve their social participation with paid hours per week (House of Representatives Standing Committee on Health, Aged Care and Sport 2017). Shortfalls of interpreters also exist in rural and remote regions, thus exacerbating their already vast divide with urban centres. This means that, even before addressing hospitals' failures to provide interpreters when needed, the supply arm needs strategies and funding for the long-term demands.

Participants in this study note that staff not only need to learn when to book an appropriate interpreter, but also how to use interpreters, while maintaining respect for the patient as the principal narrator and centre of the care team.

Harnessing technology for accessibility

There's a need to make funds available from the government to both PWDBDSI and their treating hospitals to:

- Purchase technology
- Train support staff and PWDBDSI
- Train staff in hospitals.

In particular, tablets offer a wide variety of communication support applications and multiple modalities. These can improve access to information and provide a range of accessible formats, thus improving the patient experience.

Again, hospital systems need to form partnerships to ensure that their computer systems can print out large- and extra-large-print forms for those who need them, on demand. Adding a braille printer/reader makes braille forms easy to provide. 3D printers may also offer modes of tactile communication, though this role is understudied. These ideas do not have substantial extra costs; they merely put increased accessibility into practice with existing systems to give patients what they need. While policies and legal requirements exist concerning accessible formats, they have not been transferred into practice.

Support networks

Critical to a PWDBDSI's coping, daily living and participation strategies are support networks. Hospitals need to consistently welcome support networks, when and where patients want them, because they promote personal capability and inclusion. Support people should be able to reside overnight in hospitals to help provide communication, access and orientation support. As this research demonstrates, at present, the practice of allowing support people to remain when needed is not embedded at all levels or hospitals, or for all patients. This generates uncertainty and contributes to ontological insecurity. This is particularly heightened during the present COVID-19 crisis, because visitors to hospitals are severely restricted. While this has been recognised at a policy-making level locally, there is a current minimum 24-hour turnaround time from when support is requested until it is approved (Ministry of Health 2020a). As Jane's journey (Chapter 7) illustrates, a lot can happen in 24 hours, causing pain and negative emotion that delimits good experiences. The state and federal departments of health need to have a clear, unambiguous policy that is enforced for all hospitals in the state and country, with an immediate response in real time for approving the presence of a support network member.

The NDIS and aged care resources

For those who have plans, increased costs for hospital preparedness items, such as wristbands or kits, can be claimed via the NDIS consumable's funding. A change required is that funding additional interpreter assistance for hospital use should *NOT* be taken out of core NDIS funding but, instead, is ancillary and can be utilised at short notice—for example, in an unplanned or emergency hospital admission. Presently, in the private hospital system, patients bring their own interpreter or communication-guide with them. This is funded by themselves or the NDIS, meaning an out-of-pocket expense or reduced hours of available core support, simply because hospitals are not doing their job to fund access to information and communication. While there is a mechanism in place for the NSW Department of Health to 'fast track' an NDIS plan review, neither I nor the participants have benefited or, indeed, have even known about this.

For older citizens, they remain poorly served and poorly resourced. This has been noted by the NSW Ministry of Health (Community of Practice for Disability, working group for admission to discharge [COVID-10] and plain English working group meetings) and is under scrutiny by two Royal Commissions (ageing and disability). Much more is needed to give older

PWDBDSI choices in accommodation, support for daily living and technology devices and training for communication. As the greatest victims of COVID-19 morbidity and mortality, the care and communication inequities are being laid bare.

Systemic resources: health and hospital structures

The lion's share of improving patient experiences rests with hospital-institutions and the professionals who work there. This is a task of Sisyphean proportions. Each patient with sensory impairment is different: diverse impairments, varying residuals and individualised communication preferences. A good start can be made with the capacity and resources that hospitals already possess:

- Accessible forms and papers can be provided with current infrastructure
- Educating staff on their legal and ethical obligations to provide respectful care can be achieved within the present professional development and orientation obligations
- Streamlining booking of interpreters for daily attendance to provide updates, plans and answer queries.

When patients know what is going on, staff will find less 'need' to push, shove, drag and pull. Restrictive practices would be unnecessary and could be banned. These achievable starts come at minimal cost. There are benefits to the wider system when good communication is practiced, such as cost savings from reduced readmissions, improved compliance and decreased adverse events (Slade et al. 2015).

Raising awareness

This work demonstrates low levels of awareness and problematic staff attitudes in hospitals, which are a global issue (World Federation of the Deafblind 2018). A recent initiative to combat these occurred in Mexico, through a training course to support interactions between nurses and patients with DB (World Federation of the Deafblind 2018). Student nurses were offered training workshops on basic communication systems; these were made ongoing due to their success (World Federation of the Deafblind 2018). Information kits on DB have been useful in Sweden, when the government distributed them to health providers. In addition, the Swedish government organised a DB 'team' to provide support on health, rehabilitation and social inclusion (World Federation of the Deafblind 2018). Despite this, there is little evidence in Australian hospitals of a commitment either to increase knowledge or change attitudes at any level.

Somehow, we must make the leap from repeated resource and policy directives into actual practice. In 2014, The NSW Department of Health denoted PWD as a priority group in health policy and outlined expected standards of knowledge and care for hospital staff. Furthermore, disability expertise, education and awareness introduced to hospitals and all health services, must address both:

- Hospital-wide staff training and awareness.

- Leadership and specialised disability support in hospitals (National Disability Services 2014, p. 4).

Despite the rhetoric, little was done. At the structural level, so much more needs doing to ensure hospitals and staff know what is needed by PWD, including PWDBDSI.

Governments and departments of health can promote wellbeing and inclusion by funding, training and upskilling staff at all levels, across the healthcare system. This entails:

- Orientation for all new staff
- Proficiency-testing language and disability-awareness skills
- Links to accessibility standards
- Links to accreditation
- Assigned dedicated educators
- Provision of adequate training for healthcare staff, both on the causes of DB and specific communication requirements of persons with DB
- Involvement of PWDBDSI as training consultants, co-creators and presenters.

Looking at the bigger picture, there is no reason why training and awareness modules should not be inclusive of many disabilities. Finally, and most importantly, hospitals and staff must not, except in an emergency, carry out any procedure on a PWDBDSI without the procedure being fully explained to them in clear and accessible way (White 2014). This would reduce many of the unacceptable incidences of negative touch experienced by this study's participants.

Nurse-navigators

The nurse-navigator role has seen success in New Zealand and in some US children's hospitals (Carter et al. 2018; Newman 2017). One participant with a health background mentions this role. Nurse-navigators have benefits for and beyond PWDBDSI, because they support patients and families from preadmission to discharge. They also support patients with complex needs through educating staff, liaising with care teams, organising follow-up on discharge, and booking supports and interpreters. Nurse-navigators decrease the burden on PWD and their support networks to educate staff, because this is now shared. Patient complaints, queries and critiques of care can be addressed to or solicited by nurse-navigators, giving patients a direct voice.

Admissions and handovers

Nursing admission checklists need to ensure communication plans exist for those who need or request them. This will make handovers more effective and can reduce the personal burden of educating staff every single shift about one's communication needs.

Continuity of care

Providing continuity of care in social relations promotes ontological security for PWDBDSI (Möller & Danermark 2008). This means, where possible, the same staff caring for the PWDBDSI and meticulous handovers to provide the information needed for oncoming staff members. This will promote trust in and reliability of healthcare personnel. Participants who had known and trusted consultants overseeing their care had better experiences. The practice of allocating the on-call specialist to emergency admissions robs PWD, particularly those with multiple or complex disabilities (such as DBDSI), of continuity of care and means they need to begin again with lengthy explanations. This all occurs when the patient with disability is acutely unwell or injured. Having a team leader clinician for patients with complex needs would ensure knowledge about individual needs and histories are curated in one place. Other staff members would be educated, which would decrease the burden on the patient and offer new insights to discharge planning (for example, Jane wouldn't have been sent home to cope with a new impairment alone, if someone had considered the impact of her DB and immobilised arm on her ability to self-care). The electronic record system is not an effective custodian of this information, as demonstrated by participants noting that staff don't read the notes.

Status enhancement: attitudinal change and respect

Existing legislation and policies emphasise the importance of respect. However, respect is an opaque entity that varies across countries, cultures, groups and individuals. Sutherland et al. (2017) note:

> … it is mostly enacted in clinical interactions, according to people's expectations and cultural norms, and consistent and diligent effort on the part of doctors is required. While clinicians strive to provide the same level of care to all their patients—giving equal treatment for equal need—when it comes to respect and other interactions, equal care may not be enough (p. 17).

Respect for difference is an important attitude to imbue, again across all staff at all levels in hospitals and institutions. Yet, respect for differences is not needed if a philosophy of 'culture is inclusion' exists, as advanced by Avery (2018), or if difference is respected as normative. Shildrick (2020) remarks that critical theories, including critical disability theories, attempt to advocate for eliminating difference as a sub-optimal version of normal.

Compliance promotes status enhancement. Hospitals need to do more to comply with legislation and human rights conventions. This confers status by increasing the legal recognition of the rights of PWD. Improving the patient experience is a low-status activity in hospitals and health departments (Robert et al. 2011) which needs to change. Society needs to audit, rectify and enforce the recognition and respect of patients with disabilities.

The climate of inaction and indifference

Paradies (2018) notes that putting research and ideas into action necessitates navigating 'complex and entangled social, political and affective contexts' (p. 125, citing Neale & Vincent 2017). This state of affairs is clearly evident in Australian society and its hospitals.

A great number of writings—strategic plans, policy documents, position statements, guidances, white papers, briefing documents and so forth—proscribe universally equitable and safe healthcare with better health outcomes for patients with disabilities; but these simply don't translate into practice beyond bureaucratic fantasyland. In 2014, the NDS acknowledged this situation and advised strategies for enacting real change. PWD aged 35 to 64 (roughly the same age distribution as this study's participants) have the highest health cost and burden of any person in NSW (National Disability Services NSW 2014). In 2017, Dr Kim Sutherland of the NSW Department of Health, Bureau of Health Information, wrote that 'capturing and amplifying the voices of people with disability will help to deliver better health outcomes for patients' (Bureau of Health Information 2017, p. 2). From the experiences of this research's 18 participants—and from my experiences as clinician and patient—it is difficult to see how the NSW Department of Health proposes to deliver these 'better health outcomes' when its own hospitals and professionals do not give the participants the necessary information, nor access to communication, to be heard and be partners in their own care. Rather, the system in its current form mutes patient voices and excludes patient experience, as evidenced in the findings of this work. And yet, the cost-saving benefits if these changes were implemented would be significant because, 'at present, NSW Health is spending more than it should on the health and hospitalisation of PWD due to longer hospital stays, poorer outcomes, and repeated, unnecessary admissions' (NDS NSW 2014, p. 3). This climactic apathy is evident elsewhere, with Ellis, Keenan and Hodges (2015) noting that, while their study derived extensive practice guidelines for hospitals treating people with Usher and other rare syndromes, the great difficulty is how to enforce and ensure compliance.

There is thus much work to do to resist this weather pattern for present and future policy, planning, and actioning. We are confronted with ongoing evidence that, in 2018, 2019 and 2020, little appears to have progressed for patients with disability and DBDSI. Clearly, we are in a holding pattern, in a climate of inaction and indifference.

Our healthcare systems cannot learn from their failures if they ignore them. Patient-experience data and research occupy lowly status and there is muted uptake of recommendations in hospital management. Robert et al. (2011) write on the translation into practice of patient-experience outcomes in the UK: 'Provider organisations use a variety of different methods and approaches to capture patients' experiences, but they make relatively little use of the information to improve quality' (p. 3). Robert et al. (2011) also find poor links between the arm of the organisation that collects patient-experience information and suggestions, and the arm providing staff training and professional development. As this research demonstrates, the two need uniting so that the former informs the latter. Furthermore, there are poor, likely non-existent, links between patient-led suggestions for improvement and the training of healthcare students at universities and vocational colleges (Robert et al. 2011).

Following this study of the experiences of patients with DBDSI, the key task now facing us is how to act upon this new knowledge, along with the plethora of existing edicts calling for improvements—and how to transmit these into practical change for better patient experiences.

Dramatically, in March 2020, the challenges of the novel coronavirus exposed the fault lines and inequities in society, both here in Australia and globally.

Opportunity out of adversity: The corona pivot

My doctoral journey began on 17 January 2017, and the last six months (from March 2020) have seen the COVID-19 pandemic erupting in Australia. The impact and experience of this pandemic on PWD are only just coming into view and are not yet documented or researched. Despite the absence of peer-reviewed evidence, the observations that follow must be acknowledged.

Among the most vulnerable people in a public health emergency are those with reduced access to information and mobility limitations, as well as those with other impairments and diseases. Providing care and information to situationally vulnerable members of our society are essential public services. This research specifically notes the societal and hospital-institutional deficits in providing information to participants with DBDSI in ordinary times. Information allows PWDBDSI to make sense of what is going on, to safeguard their health and comply with good public health practices. The COVID-19 crisis highlights the importance of this research for informing policy and practice, reminding me that, invariably, public health information is transmitted in ways that privilege the sighted-hearing over the single impaired and PWDBDSI. Berghs et al. (2016) note that so much more needs to be done to include PWD in public healthcare and research generally; these gaps in public health messaging are also demonstrated in **Chapter 5: Externalising the literature**. Accordingly, it is critical to ensure that all public health emergency messaging is available in plain English in multiple formats, and that those who depend on tactile communication methods are included.

As well as the provision of critical messaging, the COVID-19 crisis has put a 'spotlight on individuals with disability in hospitals' (NSW Ministry of Health 2020). The following discussion is based on aggregating personal/family experience; anecdotal case examples from PWD and PWDBDSI communities; participation in Community of Practice meetings, which inform NSW Ministry of Health COVID-19 responses; engagement with the week-long international seminars in COVID-19 and DB chaired by Deafblind International (22–26 June 2020); discussions with key informants from Deafblind NSW, the Deaf Society and the Council of Physical Disabilities; and information from media reports and the two Australian Royal Commissions (into aged care and disability). Thus far, there is negligible academic reportage on the lived experience of PWDBDSI during the pandemic, apart from a report into the disability support workforce

(University of Melbourne Disability and Health Unit 2020) is disability homogenous. There are multiple media and anecdotal reports about the difficulties that PWD and PWDBDSI are experiencing in the current public health emergency.

Data gaps

Very limited data are available at national and state levels due to a lack of definition and absence of pathways to capture experiences and incidence, compounding COVID-19 morbidity and mortality data for PWD (Anthony Lark 2020, pers. comm., 29 October).

As of October 2020, there were no NSW data (Sarah Morton 2020, pers. comm., 28 October). Data are most compromised by the lack of accepted indicators for disability. By 21 August 2020, media reported that 75 PWD were COVID-19 positive in Victoria (using NDIS client status to define PWD, a flawed method that does not capture the population's full extent); eight died (ABC News 2020). These numbers have been impossible to verify. Yet indisputably, those in residential disability services and residential aged care—arguably the most disabled and disadvantaged group, are disproportionally represented in mortality data. The absence of data means that services, resource allocation and public health safeguarding are compromised, suboptimal and disparate.

Following the reopening of public submissions to the Royal Commissions on ageing and disability, concerns were raised about the disparities and impact of infection, restrictions and the safeguarding concerns around people with vulnerabilities.

PWDBDSI: Few opportunities, many disparities

At the outset of the crisis, Armitage and Nellums (2020) write with prescience:

> COVID-19 mitigation strategies must be inclusive of PLWD [people living with disability] to ensure they maintain respect for 'dignity, human rights and fundamental freedoms' and avoid widening existing disparities. This necessitates accelerating efforts to include these groups in preparedness and response planning, and requires diligence, creativity, and innovative thinking, to preserve our commitment to UHC [universal health cover], and ensure people living with disabilities are not forgotten (p. 257).

The pre-eminent questions for PWDBDSI are: What do they need to cope? How do they receive information? How will they manage in hospital with reduced support and universal face mask–wearing?

Opportunities

The pandemic response has led to new ways of doing things that benefit some people with impairments. There is some creative problem-solving: rather than admitting all PWD to hospital, the Alfred Hospital Melbourne, in conjunction with Deakin University, is trialling a home-monitoring program called CovidCare. This is a remote, intelligent monitoring and triage system, which analyses patient data remotely from oximeters and thermometers. If the patient's oxygenation drops or temperature rises, an ambulance is called to transport them to the nearest hospital (Alfred Hospital 22 July 2020).

The loss of some socially constructed barriers reduces the burden for some PWD, such as removing difficult commutes with the new work-from-home provisions. Online shopping and home deliveries reduce daily difficulties for some PWD; however, it must be noted that PWD's priority access to home deliveries relies on the NDIS disseminating access codes, which is patchy because the NDIS does not always communicate in suitable formats for individuals. For those 'in the know', the NDIS-funded iPads for use in telepractice consultations; again, piecemeal messaging to target populations means that this information is not universally available.

Telepractice is a boon to many PWD, because it reduces the need for travelling support and long waits in consulting rooms. For others however, especially PWDBDSI, telepractice creates another socially constructed barrier.

Disparities, difficulties and the closed-door approach

Sighted-hearing ways of doing things are especially prominent in COVID-19 times, with PWDBDSI falling through policy and service cracks due to attitudinal and social barriers. Some PWDBDSI are unable to access the telepractices of the socially distant new normal. Being tactile-centric is not compatible with the virtual world, thus vulnerable PWDBDSI are denied services and support because they need face-to-face or tactile communication.

There is a digital divide—not all PWD have access to communication technology devices, have internet access or are proficient users. The latter may include the older age group with sensory impairments, as previously identified by Australia's 2017 Senate Inquiry. Interpreters (at the time of writing) do not have infection control protocols and training, nor do they have planned access and training in using personal protective equipment (PPE). In NSW, a home visitor protocol was not released until August 2020, meaning that some services providing home visitation simply stopped from March 2020. Overzealous interpretation of government guidances also saw many impairment support organisations cease home visits and face-to-face service provision.

When advising organisations to include PWDBDSI in their care by communicating in the preferred-by-the-individual method, it is important to consider what it involves. Some individuals require visitation, extra precautions for the reduction of social distancing to enable communication (e.g. tactile languages with an interpreter) as well as clear and calm messaging in alternative formats.

Universal mask-wearing in hospital and other spaces has created a communication barrier for lipreaders and those who use facial cues. The insistence of completing forms online to minimise face-to-face interaction and less 'hands-on' reassurance is a barrier to many PWD, including PWDBDSI.

These examples demonstrate how the current COVID-19 crisis exacerbates PWD's communication difficulties, in many circumstances creating new difficulties in hospitals and other social encounters. Patients with DBDSI report not knowing what is going on and feeling frightened and scared in hospital. There are reports of patients with DBDSI denied visitors or supports (including interpreters, communication partners, support workers and family) (Deafblind International 22–26 June 2020). The global shift to telepractice, with its concurrent abolition of personal contact, is effectively pushing some PWD (and some isolated older people) off a digital-divide cliff.

More than ever, PWDBDSI need to be prepared for hospital visits with kits, wristbands and health/contact information ready and accessible. The high rate of multiple disabilities justifies various organisations working together on hospital preparedness kits.

Anecdotally, there is talk in the media and among mental health colleagues of the sharp rise in anxiety and distress symptoms for PWD due to COVID-19. This seems related to mixed or uncertain messaging and fearfulness for the future, alongside an undercurrent in public media reports that the loss of 'some lives' is unavoidable and acceptable. International reports from countries heavily impacted by ICU admissions and stressed hospital systems, makes some PWD fear that they will be denied services on the basis of disability—essentially, they feel they have perceived lower status and value (Deafblind International 22–26 June 2020). Thus, it is critically important that PWDBDSI receive trustworthy information in accessible-to-them formats from impairment support organisations; NSW Department of Health; NDIS; local, state and federal governments; and media outlets.

Disability workforce

The invisible casualties in this pandemic have been disability support workers. In many jurisdictions, they have not been classified as 'essential workers' (so do not have access to travel permits, border crossing permits, community recognition of client need); designated 'healthcare workers' (so cannot access priority processing of COVID-19 results); or considered as a group needing infection control upskilling or PPE access and training (University of Melbourne Disability and Health Unit 2020).

Border closures isolated some PWD living in border communities from their over-the-border-living support worker—because permits are not given to supposedly non-essential workers. There are anecdotal reports of these workers being denied access to their clients in hospitals, to the detriment of their clients' care and communication.

The lesson going forward is that those who work with PWD are performing an essential public service and need inclusion in definitions of 'essential' and 'necessary'. Support workers also need access to PWD in hospitals to provide necessary support.

Ableism, ageism, racism and disablism

The public debate around health threats versus economic cost is seeing subtle (and not so subtle) messaging about eugenics, discriminatory beliefs and practices. Anecdotally, many communities (including PWD) are expressing concern that focusing on the economics of COVID-19 restrictions makes the wellbeing and lives of those most at risk from COVID-19 secondary. Of special concern is that older people have increasing numbers of impairments. At highest risk are people in aged care, including those ageing with DBDSI, ageing into DBDSI and younger PWDBDSI inappropriately placed in residential aged care (due to society's failure to create alternative accommodations). First Peoples with and without disability are also at greater risk from COVID-19. Racism underlies some of the economy-over-health arguments in the mainstream media. The potential for the loss of lives, elders, communities and culture through uncontrolled viral rampage is profound and devastating.

Discussions about how the cost of a few unfortunate deaths (in aged care and in at-risk community groups) is preferable to widespread economic turmoil reiterate to PWD and older people how lowly their status is. As outlined in **Chapter 12**, social recognition and respect are requisites for ontological security, stability and self-esteem. Disabled lives matter. Older lives matter. Black lives matter.

In an op-ed for *The Sydney Morning Herald* on 31 August 2020, Stephen Bartholomeusz, the senior business writer, argued that the health versus economy trade-off is a fallacious position to take. There is financial fallout from putting economic survival first (Bartholomeusz 2020). Even without lockdown and other health protective restrictions, large sectors of the community change their behaviours during a crisis: staying home instead of going out, spending less, not travelling abroad, choosing home-based entertainment and food delivery, avoiding large sporting and entertainment events, favouring work-from-home options and online learning, avoiding public transport, and so on. Then there is the cost of strain, stress and/or actual collapse of healthcare systems, as seen in some countries during the first wave. So, measures that knowingly consign some groups to greater risk of infection will not be successful economically in any event and are contrary to respect of human rights of all (Bartholomeusz 2020).

PWDBDSI are raising concerns that they might be denied care, especially critical care, on the basis of having a disability (Deafblind International 2020). With the data gaps at this time, it is hard to know if this is an anticipatory concern or one based on actual events and decisions.

However, the media report both overt and covert ageism, racism and disablism. Dan Patrick, a Republican politician from Texas, USA, told Fox News that 'grandparents' should be content to sacrifice themselves for their country. Patrick said: 'My message—let's get back to work, let's get back to living, let's be smart about it, and those of us who are 70-plus, we'll take care of ourselves' (cited in Beckett 2020).

In Australia, the *Australian Financial Review* ran an article with the headline 'Lives matter, but at what cost?' The author writes:

> Many seniors have had time to enjoy careers, children and grandchildren. My father is 68 and insists he's had a good run … Some seniors like him would not put their own life above the livelihoods of their children and grandchildren, if the economic and social costs become too great (Kehoe 2020).

Politician Tony Abbott denounced the coronavirus response as a 'health dictatorship' and argued that we should consider the economic impact of lockdowns and start talking about 'the level of deaths we might have to live with' (Wintour 2020). In the UK, Dominic Cummings, chief advisor to Prime Minister Boris Johnson, stated 'if some pensioners die, too bad' (Williamson 2020).

These opinions unsettle me personally and especially as a social and health researcher. These overt and covert messages—often violently held opinions—are at odds with placing value on all lives. It creates and perpetuates fear and anxiety for PWD, because 'letting the virus rip' will decimate the vulnerable wherever they are found. Thus, the pandemic is entwining with social justice movements fighting inequity and disparity for people of older age and/or with disability and/or from First Peoples communities and/or people of colour and/or people of diverse genders.

Furthermore, to give a real-life perspective, a death by COVID-19 is not pleasant or peaceful, and it occurs in hospital and care systems that are isolating, devoid of the loved ones and support that surround a death from other causes in other times. We are right to fear being devalued as currency might and being thrown off the COVID-cliff face.

Lived experience stories can counter the eugenic and socially unjust notions of prosperity and status quo over people's lives. Dr Charon, the founder of narrative medicine and faculty member at Columbia University, writes:

> Telling and listening to stories is a necessary prelude to action. When done in bad faith, storytelling spreads lies and widens polarizations. But when done in good faith, narrative work accelerates justice by generating connection, challenging bias, animating conscience and changing minds (Charon 2020).

Contributions of this research

This research is in action in 2020. During this crisis, I have brought my expert-knowledge on PWDBDSI and hospitals to two impairment support organisations, as well as the NSW Department of Health. Already, this research is helping to inform policy, planning and practice in a public health emergency. The following illustrates steps taken thus far:

- Representation on NSW Ministry of Health committees advising the NSW Government COVID-19 responses, namely, the Community of Practice for Disability, working group for admission to discharge (COVID-19), and plain English working group.

- Wristbands provided to multiple organisations across Australia and to Vision Australia.
- Wristbands couriered to Sense UK for use with PWDBDSI.
- Presentation to the Disability Community of Practice (NSW Ministry of Health) on the communication experiences of PWD as part of their meeting: Consumers, communication and COVID-19 (27 May 2020).
- Communication with Deafblind NSW, Vision Australia, Guide Dogs NSW and Better Hearing to identify gaps in service, where their clients are missing out on public health messaging, resources and support.
- Contribution to guidance surrounding mental illness, specifically 'The management of acute behaviours in hospital emergency departments' (Watharow 2020a).
- Contribution to guidances for residential group homes (NSW Ministry of Health 2020a).
- Contribution to accessible and plain English versions of public health messaging for COVID-19, specifically: what COVID-19 is, how to get tested, how to self-isolate, going to hospital and how to support PWD during this crisis (NSW Ministry of Health 2020b).
- Liaison with the Council of Physical Disabilities on hospital preparedness and going-to-hospital kits.
- Seeding of funding discussions with impairment support organisations for older Australians and those with physical, sensory and/or intellectual disabilities to create a widely available, consistent, recognisable approach to hospital preparedness (e.g. wristbands, passports, kits and technology). This is a resource that, while universal, is customisable to individual identity, needs and choices. Disability is not a homogenous category—we need a uniform approach that is customisable to be person-specific.
- Presentation by invitation to the Royal Commissioners on the impact of COVID-19 on 10 July 2020.
- Liaison with and supply to Sense UK of wristbands.
- Supply wristbands to local and interstate impairment support organisations and individuals.

In summary, work is in progress to support PWDBDSI communities during this catastrophe, using both the recommendations of this research to problem-solve and the researcher (me) to engage in community action. What I envision as ideal is that the pandemic creates opportunities for lasting change beyond the crisis: those of improved care and communication for all PWD, including PWDBDSI.

Conclusion

Structural, professional and systematic solutions are needed so that patients know what is going on, can participate in care and are cared for. For PWD, however, hospitals are described as 'disabling, uncoordinated, inadequate and inequitable' (NDS NSW 2014, p. 3); the participants with DBDSI concur, as evidenced in this study.

This chapter looks forward, beyond risks and vulnerabilities, to positive framings and solutions created by the participants—the expert-knowers. The salutogenic ‘looking after us’ model is presented, giving a visual representation of how the solutions are linked to hospital-institutions and professionals doing their jobs, power parity and ontological security. These in turn are strongly connected to better experiences and better health and wellbeing outcomes.

The NSW Department of Health and hospitals need to listen harder and do what is needed to escape the prevailing climate of indifference and inaction.

The hospital and healthcare systems of NSW and Australia have been put to a grim test at the time of writing this thesis. The COVID-19 onslaught has made two divergent outcomes: exposed ableisms and disparities in healthcare for PWD generally, and especially for PWDBDSI; and conversely, started a conversation in the cabinet, ministry, media and community about its impact on PWD in hospitals, residential aged care, group homes and the community.

The process of this research has seen me evolve into an expert-knower-researcher, who can contribute during these challenges of the COVID-19 pandemic. This research is important in informing those tasked with providing trusted information and support of the needs and rights of PWDBDSI. Conversations are happening, small translations into practice are evolving, proving that matters under discussion are more likely to be actioned than when they are hidden or ignored.

The following **Chapter 14** concludes this research journey, examining the strengths and weaknesses of the present study, as well as the implications for future research. The research questions are answered, yet lacunae remain in our knowledge of what happens when PWDBDSI go to hospital. I reiterate, both here and there, the magnitude of the policy and practice changes required, not only to comply with legal statute and community expectations, but also to provide healthcare and communication to PWDBDSI. These all work to promote ontological security as the outcome—achievable when hospital-institutions, professionals and personal strengths of PWDBDSI align.

Chapter 14
Where to from here?

Deafblindness and dual sensory impairment are characterised by gaps: in understanding and awareness, literature, data, and services.
—Jesper Dammeyer (2014)

Introduction

The events unfolding in Australia since March 2020 show the fault lines in how society prioritises and practises supporting PWD. Like in this research, the concurrent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is hearing different versions of the same stories. The COVID-19 pandemic has perpetuated and exacerbated existing inequities, and created new ones that further isolate and disadvantage PWD, including PWDBDSI. At least, at last, however, there is recognition—a conversation beginning to take place in Skype meetings, virtual partnerships, and communities of practice and collaboration. Just as this document is revised and prepared for submission, this new knowledge is needed to underpin new guidances, paradigms, protocols and briefings.

And yet … and yet. The clouds of inaction and indifference hover overhead. These are days, weeks and months of opportunities; time to have the disparities of clinical care and communication demarcated, underlined and bolded. My voice is solicited. That is new. Even small changes with little cost can make a big change for the better, I argue. Accessible materials are largely achievable with existing resources: change the font size on admission papers, consent forms, patient literature and discharge information; use smartphones, iPads and computers; adapt and adjust what already exists; and broadcast to all who work in the hospital system that we expect our staff to be respectful and accommodating. Do this so that all patients will *know* what is going on. We (society as well as the researcher) will continue to ask PWDBDSI (in the ways best suited to the individual) what is actually happening so that *we* will always know what is going on, too.

In many ways, this thesis is about words—what they mean, how they are used, and how they change with usage and over time. The words 'complexities' and 'heterogeneities' describe the intricacies and shifting boundaries of living and researching with sensory losses. This thesis is also about the words unsought, lacunae in the literature and words ignored: the CRPD, legal statutes and policy directives. Countering these are the words spoken, signed and written by participants about what happens to them when they go to hospital. Even then, there are words that remain unsaid, and what this silence might mean. There are words that are dissonant from experiences—cracks as it were—and these cracks tell a story, too. Then there is the act of mine, of putting my experiences and those of the participants into academic-storied word form, so that others can access these mighty words demanding change. Even now, when I will not ever be able to read this thesis, these words have traction and impetus. They prove imperative. They are timely in these times of the novel coronavirus.

This research encompasses the Australian context of the primary question: what are the experiences in hospital of patients with DBDSI?

Secondary questions include:

- Are hospitals doing enough for patients with DBDSI?
- How can patients proactively bolster their own defences against negative hospital experiences?
- What changes are needed at societal, hospital-institution and professional levels to improve their experiences, and thus promote better health and wellbeing outcomes?

In answer to these questions, the experiences of patients with DBDSI in Australian hospitals are predominately negative. To reiterate, 89% of participants say that access to information is a concern; 89% feel distressed by their hospital experiences; 78% disclose neglect; 78% describe dehumanising incidents; 61% feel a lack of inclusion and participation in their care; and 61% suffer a loss of dignity. This research provides an analysis of what is and is not happening in hospitals that creates the climate of ontological insecurity for patients with DBDSI. The first omission is not providing accessible information, from the admission paperwork to the legally important consent forms to discharge instructions. Rarely, if ever, are individuals provided with them in their preferred format/s. The next omission is that of communication, with clinicians failing to book interpreters or communicate with patients in the individual's preferred method; failing to recognise and remove barriers to good communication, such as poor English or accents; failing to resolve environmental difficulties, for example, too much glare or too little lighting; failing to face patients and talk clearly and slowly; and failing to ask patients what they need for good communication. All this creates the milieu of 'not knowing what is going on'.

It is not just accessibility and communication that are deficit, it is power parity, too. The exertion of power by hospital-institutions, health professionals and other hospital staff over the patient-participants confers ontological insecurity, and poorer health and wellbeing outcomes. Power exertions see staff abusing, neglecting, ignoring, assaulting, dehumanising, disenfranchising, excluding, side-lining, disrespecting, discriminating and providing manifestly disparate care to PWDBDSI. These are seen in the themes and subthemes of the participants' collected narratives. Quantifying these is possible with the AHPEQS. This provides a damning patient Report Card—reminding the reader that 94% feel unheard by hospital staff; 89% do not understand what health professionals say; 83% feel hospital staff do not treat them as human beings; 89% say staff do not attend to their personal care needs; 77% say the hospital does not treat them equally 'no matter who I am'; and finally, 94% say the hospital does not put their needs first. This makes a mockery of the much-vaunted patient-centred principles of Australian hospitals. This Report Card effectively demonstrates that hospitals are not doing enough to provide care and communication, and promote positive patient experiences that are linked to better outcomes.

Having established the parlous state of care of PWDBDSI in hospitals from the expert-knower testimony of 18 participants, the research looks forward to enabling better patient experiences. The 'looking after us' model shows how power parity—from society to hospital to professionals to patients—results in generating security and safety for patients, which engenders the best health outcomes. This salutogenic framing is merged with The Wish List—generated by amalgamating all the participants' suggestions as to improvements they would like (and need) to see. This includes actions that patients can take, as well as what society and governments must do, and what hospitals and healthcare professionals must enact.

Making these changes requires a top-down approach to embed, at all levels, better understanding and support of PWD generally and PWDBDSI specifically. This requires society to promote and enforce legal and ethical safeguards, ensuring parity in power, access to information and individual person-centred care. In turn, this approach requires hospital-institutions to comply with statutes and policies, and to promote inclusive practices. As this research demonstrates, the implications for policy, planning and practice are titanic, as introduced in the previous chapter. There is a seemingly insurmountable barrier to progressing change, however: the climate of indifference and inaction. This is in spite of the manifest failures in the face of patient suffering, and the stories and suggestions from expert-knowers voiced in this research.

We need now to ask if this research is generalisable, or if it is simply an island of poor experiences that happened to an unlucky few PWDBDSI.

Saturation and generalisability

Thematic analysis of the 18 participants' transcripts evolved to a point where a similar constellation of ideas and categories kept recurring, and no new themes were being derived. This accords with theoretical saturation, as described by Vasileiou et al. (2018) and Holton (2011). Saturation means 'the point at which no further dimensions, nuances, or insights of issues are identified' (Vasileiou et al. 2018, p. 3). In qualitative interviewing, various magic numbers are suggested as ideal for obtaining theoretical richness united with the prospect of saturation—that is, no new data, themes or categories. Vasileiou et al. (2018) posit that this may require 16–24 interviews', while Bernard (2013) suggests 10–20.

In the present research, while it is tempting to say that the small sample size of 18 does not encompass all possible variations of impairments and living realities, given the vast heterogeneity of the population whose experiences are under study, themes remain persistent. Under such circumstances, the likelihood of the results as a true indication of what occurs in hospitals is very high. Confirmation of this is a matter for future study. But ignoring this study, or wanting further research and replication without enacting change is a power play in and of itself.

The review of patient-experience literature by Roberts et al. (2011) ‘highlights the importance of relational aspects of care to patients’. By this, they mean:

- Good information provision
- Having confidence in health professionals
- Awareness and understanding of specific health conditions
- The right treatment from the right staff at the right time
- Continuity of care
- Being treated as a person
- Partnerships with professionals (Roberts et al. 2011, p. 9).

The present study’s participant-led resource, ‘The Wish List’, dovetails with these broad objectives, showing that patients, able-bodied or not, have similar desired outcomes from their hospital experiences.

Strengths of this research

This research’s strengths include engaging with narrative medicine doctrines, attentive listening to stories told, reflecting back on what is heard and seen, and affiliating in partnerships to impel action towards social justice (Charon et al. 2017, p. 8). I give all participants all the communication choices and controls that are missing in action in hospitals. I elicit and engage with the stories of hospital experiences, and show how and why these occur in the ‘(un)lucky dip’ model. This research charts a passage towards remediation and restitution; the salutogenic ‘looking after us’ model demonstrates this commitment to promoting health and wellbeing. The research questions, primary and secondary, are answered.

While acknowledging that PWDBDSI are a vastly heterogeneous population, this research manages to capture some diversity, nonetheless. Participants from congenital DB, acquired DBDSI, Usher syndrome, over 65s, younger deafblind, ageing with DBDSI and ageing into DBDSI groups are represented. Some are living in aged care (inappropriately and appropriately) and others live in the community. There is one veteran, and more women than men.

The research also yields commonalities in experiences, with saturation in the data and themes inducted. Negative experiences predominate. Neglect is common. Not knowing what is going on is frequent. Not receiving accessible information and consent forms is universal.

A key asset is how my own disabilities and support needs shape and influence this work. The multiple lenses add layers and confer insights that strengthen the data derived from the research. Both my clinician role and lived experiences as a patient and person with disabilities demonstrate the systematic disparities of care and their consequences. Having acknowledged this, it is still important to maintain distance—these might be my experiences, but they cannot be considered as illustrative of the status quo unless so demonstrated by the participants' stories. The research participants' individual experiences contextualise the data set of my own experiences. While observations of the absence of care and caring that I faced in hospital are responsible for initiating the research, the anecdotal accounts of others are the impetus for action. This results in giving back some power to the people, with the wristbands project and this doctoral study. As an insider, I also know how important it is to document the realities of hospital experiences for PWDBDSI, to give heft to the urgent need for change.

It is not just the patient-participants who experience 'not knowing what is going on', but also the hospital-institutions, professionals and community-at-large. This research is thus a clarion call for care, communication and change. There is no doubting that the participants' problematic experiences, and my own, exist and are remediable.

Surveying the lived experiences of PWDBDSI in hospitals using narrative inquiry has not previously been undertaken from the standpoint of PWDBDSI—the knowledge gaps are startling and significant. I was anxious about the research space becoming contaminated by my disabilities and the people I need to support me. The reality is that, as a group, PWDBDSI welcome the sameness and are accustomed to their life spaces being filled with the human, technical and animal assistance on which they depend. We are accustomed to touch, alternative formats, assistive devices and people as conduits of information. The support and accommodations that the research given to the participants (i.e. whatever they needed) is in stark contrast to that given by hospitals and health professionals (i.e. unpredictable and too-often absent). The NSW Department of Health's own patient-experience evaluation forms are not universally accessible, so this research has a strong position to generate knowledge on how things really are.

The principal strength of this work, therefore, is to enable and privilege the voices of participants with DBDSI. This required additional resources, extended time and creation of a different safe narrative space, so that the participants' voices were supported and valued as expert-knowers. There was consultation, engagement and co-creation via impairment support organisations and support groups. This is an immersive and educational process—as a student researcher, I had much to learn because my life experiences are at once the same (loss of senses) and diverse (with differences of language and in life-course trajectories).

This research and I are independent of the prevailing health hegemony, and I embrace a standpoint methodology. My clinician background serves to aid understanding, not only of how things in hospitals work but also how they should be done better. The cross-faculty collaboration with supervision from both Arts and Social Sciences, and Health and Disability is also a strength. This ensures that the dominant discourse in health does not prevail to silence or trivialise the participants' and my experiences.

Another strength of the research is that ‘it happened’. The support of the University of Technology Sydney and my dedicated accessibility assistance team were instrumental in finding ways few have found before. I am supported by a more-than-adequate funding model from the university, and by a principal supervisor who anchored the work’s authenticity and urgency. Without access there is no research, no communication support and no conversation about what happens in hospitals to PWDBDSI. The work of my Head Accessibility Assistant, and the students who work with her and myself to ‘make it happen’, cannot be overemphasised. These ‘by-products’ of the research process have themselves created new knowledge and understandings of what students with DBDSI can do, when ably supported by society and higher education institutions.

Limitations and paths for future engagement

The following discussion considers the weaknesses of this work: sample size and composition; urban bias; and the lack of real-time data. It also considers age, culture and other factors that affect the research findings. I then suggest paths for future engagement.

Sample size

While the sample size is relatively small and may not be representative of all PWDBDSI or all subgroups, the saturation of poor care experiences for 89% of participants makes it exceedingly likely that other subpopulations also experience disparities. What is unknown is to what degree. This is an area for future research.

Sample composition

There are significant limitations regarding the generalisability of some findings, because several population groups are either not represented at all, or only in small numbers.

The research participants were initially recruited through the auspices of impairment support organisations. However, membership in these impairment support organisations does not necessarily represent all PWDBDSI. Many factors can influence engagement with impairment support organisations, such as not knowing these services exist or not being eligible to receive support. A South African report found that those who are more financially secure or in employment ‘tended not to join DPOs (Disabled Peoples Organisations)’ (National Department of Social Development [South Africa] 2015, p. 21).

Engaging with impairment support organisations based in the city limited the recruitment reach to rural and remote regions. Dyke (2013) estimates that one-third of PWDBDSI live in rural and remote regions. While this research included one rural participant who travelled to attend an interview, specifically targeting this group was beyond the funding available. The research does not capture other significant populations, either at all or in representative numbers. Principally, these are:

1. Infants, children and adolescents, whose experiences were not canvassed at all due to exclusion criteria requiring participants to be over 18 years. Issues of funding and consent necessitated their exclusion. This should be rectified with separate, targeted research in future.
2. As stated in **Chapter 1: Complexities**, older Australians with DBDSI form a group with large numbers of people who 'don't see very well or hear very much'. This research has four people over 65 years: two are ageing with DB and two are ageing into DSI. The community has growing numbers of people with co-occurring hearing and vision loss. This group can include up to 30% of those over 80 years; these are disparate individuals who seem poorly served by impairment support organisations and health services, which offer segregated specialities dealing with either vision or hearing loss, not both. Because recruitment was from impairment support organisations and via word-of-mouth, future research needs specific and different recruitment strategies to include more older Australians.
3. Aboriginal and Torres Strait Islander Australians are not represented at all in the present group. This is not intentional. These communities are important groups to investigate sensitively and urgently. When combined with disability, racial discrimination, structural racism, and endemic and embedded experiences of inequality are a double disadvantage. Avery (2018) discusses the experiences of First Peoples' encounters with healthcare—exemplified through examples of misattribution and misdiagnosis, and the impact of dissonance. This research is not able to amplify Avery's observations because no participant identified as belonging to Aboriginal or Torres Strait Islander communities. That there is a lack of respect in how First Peoples are treated in hospitals is evident from the research of Sutherland et al. (2017).
4. Disparities in healthcare exist for Australia's First Peoples generally and in hospital care experiences specifically (Sutherland et al. 2017). Little is known about the differences and gaps for Indigenous Australians with the double disadvantage of a disability. Sutherland et al. (2017) outline findings from a Bureau of Information report, pertaining to the delivery of respectful care. This report urges doctors to exert greater diligence to provide respectful care that meets the patients' expectations because, to 'a great extent, health experiences shape outcomes of care' (Sutherland et al. 2017. p. 17). Full co-creation and leadership from the First Peoples Disability Network and First Peoples community leaders are necessary for trustworthy and culturally appropriate engagement, ensuring the delivery of research outcomes that encompass multiple multigenerational disadvantages and harness the capabilities of Indigenous individuals and communities. Such research must be rooted firmly in the standpoint of First Peoples with disability and should support community-driven solutions (for more information, see Avery 2018).
5. Those with DBDSI and cognitive impairment lack representation. Participants in the present research are all cognitively intact, so their

lived experiences do not reflect those of people with sensory and intellectual disability, for example, those with dementia. Anecdotally, these groups are poorly represented, poorly studied and poorly served by hospitals, so should be a focus for future investigation.

Data density

In this work, unhappily, there is more data on negative experiences than space to detail. Thus, there are gaps in explanations, as well as quantitative and qualitative data omissions, such as cross-tabulations examining potential mediators. These bear exploration and dissemination in the post-doctoral setting. As the weight and volume of participant stories grew, my own contribution via the creative component diminished by design—giving preference to the participants. Hence, the creative nonfiction component is limited to the positioning of my own origin story in the opening preface of this thesis, 'A Note to the Reader', and the participant portraits in **Chapter 7: The patient journey**. While necessarily limited by word count, the latter chapter brings the participants into the reader's sphere and reminds all of us that this doctorate is about people, for whom there is a call to action to provide better support in hospitals.

Non-hierarchising of experiences

With the good advice from Roy (2018, 2019a, 2019b) and hearing from people with DB in February 2017 at a World Café event on participation in research, this study does not utilise Likert scales and other hierarchies because they are not accessible for many PWDBDSI. Consequently, it is not possible to formally hierarchise the participants' experiences into an ascending order of atrocities. This is also noted in **Chapter 11: The Report Card and The Wish List**, in which the AHPEQS is applied to transcripts in a binary mode. This limits the comparability and generalisability of this research to reports and results that utilise hierarchies and Likert scales. It might be possible to include these measures in future research, through using more accessible formats (not just large print) and with considerable unpacking of questions and concepts, to trial with PWDBDSI to obtain comparable results between different population groups. However, I do not believe that it is necessary to hierarchise the pain and negative emotion points experienced by patients with DBDSI to know that the persistence and pervasiveness of negative patient experiences demands action.

Dissonance

A further confounder in this research is the dissonance between words and experiences, discussed previously in **Chapter 8: Performing narrative inquiry.** This means that not all what participants have to say is entirely reliable; underestimating the scale and frequency of negative events is likely. Dissonance is not seen in positive experiences at all; however, it is possible that this may be seen with a larger sample size.

Oralism

Intuitively, I have a sense as the interviews progress that being nonverbal and depending upon sign language and a communication partner confers the greatest risk of more negative experiences. Patient-participants with no oral language are less able to alert clinicians around them to aspects of their experience and health. At present, many clinicians are too ignorant or busy to exert the extra care required to instil confidence and trust. Remember George, who had only his wiggling toes to communicate with staff during his 'awake' surgery; Annie, who was sedated at night rather than communicated with and oriented to her surrounds; Barbara, who was confined to bed in an endless waiting fugue; and Emma, who could not tell anybody she was suffocating. The sounds and movements that Jane made in the recovery room when she awoke, not knowing what was going on, were interpreted as aggression and 'that's not allowed in this hospital'. It seems to me, as the researcher in this study, that having no spoken language confers an extra blanket of vulnerability and risk. This research does not untangle these complexities enough, nor are there numbers to make confident assertions. As an urgent priority, future research and indeed practice, should focus on groups with a lack of oral language. These patients are the most unable to participate and thus future policy, planning and practice must ensure provision of specialised and individual communication support—both often and whenever needed. Spoken language appears to mediate experiences in hospitals; its absence confers risk. The presence of spoken language enables Linda and Ava to garner support from other patients to assist in calling for help; Sally to say 'No interpreter. No conversation'; and William to stand, saying 'I'm not moving until someone tells me what is going on'. However, this research cannot quantify or put these experiences into a hierarchy. The majority of the participants describe so many negative experiences, and even the positive experiences that 11% report contain more than one instance of failure to provide care or communication.

Hostage bargaining syndrome

As discussed previously, HBS may operate for patients with DBDSI in similar ways to the sighted-hearing population. Further research is needed to ascertain the role, if any, and the magnitude of its effect.

Mediators

More work is needed to elucidate other mediators of poor hospital communication and care experiences, as well as those who promote positive engagements with hospitals. The role of factors including age, gender, oralism, culture, impairment type, and the presence or absence of residual senses needs examination. The small participant numbers involved in the various subcategories of this research population make it difficult to generalise, because so much is not yet known. Using statistical software to explore cross-tabulations of potential mediators could be undertaken in the post-doctoral space. The role of support networks in mediating hospital experiences also warrants further exploration; this research does not target support networks explicitly, and participants likely have more to say on the matter. This research suggests that the round-the-clock presence of interpreter-guide support (partner, communication-guide and/or support worker) promotes awareness of what is going on, trust and security. Support networks also mediate experiences by mitigating the failures of staff and institutions to do their jobs. Private hospitals and specialised eye and/or ear hospitals seem more accommodating to the needs of patients with DBDSI. That these institutions provide better care to all cannot be generalised with confidence, however, because the numbers are very small (two in each category). The capacity of different hospital types to provide communication and care needs a deeper examination in future studies.

Research methodology

There are several limitations in the research methodology. For instance, I had a late-onset realisation regarding mixed methods because, initially, this study was designed as a qualitative inquiry. During coding, the opportunity arose to quantify some of the qualitative data with an existing patient-experience measure. I decided to engage with this question set to add breadth to the depth of the narrative inquiry results. This likely means that the research omits to canvas the quantitative questions fully, because it is the researcher mining the transcripts for answers, not the participants. Regarding balance, however, the question set is not accessible in its current form to most participants.

After eight interviews, I also realised that a topic was *not* discussed. The participants are silent regarding complaining about healthcare experiences. As a result, for the remaining interviews, I added a specific question to explore complaints. The previous interviewees were contacted again and asked if they had ever complained. None had, but again, as a potential mediator of experiences and as a consequence of poor experiences, the role and complexities of making complaints need examination. The present research gains some insights from asking this question, but not enough to be considered a full exploration.

In Ellis, Keenan and Hodges (2015), the difficult spaces of outpatient hospitals are identified as making the appointment, getting the referral, making contact with the clinic, travelling to the clinic, at the hospital, in the clinic, during the consultation and after the clinic. Ellis, Keenan and Hodges (2015) record their attempts to walk with the patients by accompanying them on some hospital clinic visits to note in situ what transpires, rather than solely basing their research on patient and carer recollections. This allows the study to:

> … gain as real a sense as possible of the patient experience, of the individual difficulties faced by some participants during their hospital visits, and of their needs as sensory impaired people within the hospital environment, and how these were addressed (Ellis, Keenan & Hodges 2015, p. 51).

While not targeting PWD or PWDBDSI directly, Slade et al. (2015) embedded researchers into hospital emergency wards to record real-time communication encounters; nevertheless, this provides a startling glimpse into the realities of communication encounters (averaged in the hundreds per inpatient stay) for sighted-hearing patients. The present study lacks the real-time imperative, but I remain convinced that pursuing further research in the face of the damning evidence now at hand means preferencing research power over real-time solutions.

Post-discharge space

Another limitation is that this study does not investigate the post-discharge space. One participant alludes to difficulties on returning home with an additional impairment; another talks about being moved into aged care, without consultation, while awaiting home modifications. Other participants talk about avoiding future hospitalisation(s) and an inability to comply with post-discharge instructions. Because the post-discharge space is where many consequences of poor experiences play out, close study is warranted to pain and emotion points. What is apparent is that 'not knowing what is going on' does not simply end at the exit from the ward; it impacts on compliance, avoidance and future health help-seeking behaviour. This is an area for future research because, clearly, discharge without cognisance of the specialised and changing needs of people with sensory impairments confers added risk.

Insider complications

The consumer-researcher conundrum exists. My experience likely clouds my perspective on occasion, but I am clear that it does not impair my insight. Action is needed to address serious care disparities. My obligations as medical practitioner versus *objectivity as researcher* conflicted on a few occasions. I am firm, however, in believing that what is best for the participant trumps any consideration of *objective* research. Critical realism, social relational theories and standpoint methodologies also reject the insidious invisible power of the *neutral* or *scientific researcher* position. I obtained help for participants who needed it through facilitating engagement with a professional (not connected to the research) and abiding by patient confidentiality regulations. Accordingly, clinical histories are not discussed in any detail in this thesis or its documentation. There are insights to gain from how PWDBDSI are or are not able to access primary healthcare, but those are for another time and another study.

Staff attitudes

While staff attitudes towards patients with DBDSI are not part of the study, they are very evident from the participant experiences on the receiving end. One study that explores nursing staff attitudes towards caring for deaf patients demonstrates discriminatory care (Ljubicic, Zubcic & Sare 2017). Exploring how staff feel would determine how pervasive discriminatory attitudes are and what is needed to ameliorate them. Sutherland et al. (2017) also find that staff attitudes play a significant role in the delivery of respectful care, as discussed earlier. In particular, doctors as clinicians and team leaders need vigilance in their interactions with patients to ensure effective communication, and in aiding compliance to ensure successful outcomes (Sutherland et al. 2017). The present study's results demonstrate that failures are embedded at all levels of the healthcare system and that staff attitudes remain a prominent participant concern.

Carer perspectives

Whilst some participants had caregivers present in interviews, their contributions are not solicited but volunteered. Carers bear witness to healthcare inadequacies and are often additionally burdened by these. This particular gap is being addressed by Dunsmore in her doctoral study (Dunsmore et al. 2020).

Omissions

There may be inadvertent omissions in this research, which limit its extent and depth. By its very nature and pervasiveness, the disability of the researcher reduces information and awareness of cues. While an enormous and skilled safety net was created to catch any misconceptions, misreading or misrepresentations, it is always possible that some may have escaped notice. A great many of the tools of research are inaccessible for this researcher: information management applications, referencing software, statistical packages such as NVivo and especially track changes. Even cut/copy and paste proved disastrous at times. My team and I have done all we could with what limited senses I have left (even those diminished over the doctoral journey, meaning that adjustments were needed unpredictably).

Trauma

The present study does not provide insights into the duration and depth of any trauma or distress the participants experienced. This study does not utilise a tool measuring trauma. Certainly, participants mention psychological distress as a result of hospital experiences, but this is not measured. In future, this could be accomplished by using a PTSD instrument, for example, PTSD Checklists or Clinically Administered PTSD Scales (CAPS-5). The presence of PTSD indicators would strengthen the current research findings. Any instrument used to measure PTSD, however, needs validation for a population with sensory impairment/s. For this to happen, Likert and other hierarchical scales need to be removed and questions unpacked with PWDBDSI and interpreters.

The present study also does not engage in discussion on any trauma and distress of the researcher. Space is limited but these few observations I will make. Being mired in the horrific experiences of others while simultaneously being triggered by these, alongside navigating tremulously my own declining senses, is dark and complex. Working in the narrative inquiry space and witnessing the experiences is an act of utility. For a person with deafblindness and its accompanying wrecking ball effects on life, being useful and contributing to society is not a naff overworked trope but elemental to survival.

Being invisible and visible, segueing in and out of the participants perspectives made me preference their data over mine, their/our complexities over brevity—seeking to give space to the earlier chapters rather than token paragraphs on quick definitions and theory summaries. From the beginning, I made sure to keep connecting to a psychologist because this has been a turbulent journey.

Direction for future research

Future research directions are, to a large extent, shaped by the present work's limitations in scope, funding and reach. A great many are referenced explicitly in the 'Limitations' section above. The large lacunae in current knowledge and research about the healthcare experiences of marginalised, hard-to-reach populations also dictate these directions, which include:

1. Investigate the gendered influences that prevail in our medical system. There are more female participants, which may reflect the different ways each gender uses impairment support. As to whether gender influences care and communication, based on current social and health research, the answer is 'yes'. The present study, however, is unable to determine whether men or women experience care disparities over and above those of their disability. As to whether the hospital workers' gender influences care and communication failures—this is also not established. Further post-doctoral work is intended to engage with gender, using more sophisticated statistical analysis.
2. Produce and use a healthcare 'passport'. Researching and developing digital and hard copies of a care and communication passport (as described in the previous chapter) is vital, so that crucial information about an individual patient's impairment and communication requirements is readily available for staff in hospital. This represents a cheap and effective contribution to helping staff know what is going on and what patients need. There are many models and versions locally and internationally, but a consistent and streamlined health information passport would ameliorate some of the difficulties that patients and staff face.
3. Simcock (2017b) writes: 'Future studies of the lived experience of vulnerability among this population should explore coping, resilience and the potential of positive outcomes when one is vulnerable' (p. 813). I concur.
4. Conduct ongoing research into better research practices and the power dynamics of research, to ensure that future participants are true co-creators whose expert knowledge is validated.
5. Audit the accessibility provisions in hospitals and formulate minimum standards for legal, policy and practical compliance. The practice of inaccessible consent forms needs termination. The impairment support organisation Sense UK undertook an accessibility survey of health services, titled *Equal access to healthcare*; in Australia, such a survey would provide a valuable starting point to guide the development, implementation and enforcement of accessibility standards (see also, NHS Accessible Information Standard).
6. Further explore 'what "good" looks like' and 'what PWDBDSI mean when they use "good" to describe an experience'. Cunnett (2010) describes a good hospital experience as 'one that has solid leadership and effective management with teams that work well together and focus their work on the whole patient journey … preserving dignity and providing basic care outcomes' (p. 37). This research has demonstrated that there are difficulties in

> understanding what ‘good’ means, because there are many instances of dissonance between the participants’ words and their actual experiences. A greater understanding of these dissonances is critical because we cannot rely on patient evaluation surveys to show how things really are.

Research in DBDSI is a nascent field. Any additional research interest is welcome.

Hospitals, you have a problem!

The ‘(un)lucky dip’ model presents a challenge to society, hospitals and professionals to ameliorate the current climate of inaction and indifference, which spawns poor patient experiences for PWDBDSI in Australia. The salutogenic ‘looking after us’ model is a vital corollary—using problem-solving and available resources, as participants designate, to provide quality care and communication in an environment of power parity, knowing what is going on and ontological security. The presence of these promote better health and wellbeing outcomes for PWDBDSI; for the full suite of solutions, see **Chapter 13: ‘The health system should look after us’**.

There is unknown generalisability to populations and subpopulations of PWDBDSI; this study’s strength is that it reflects the experiences of 18 participants with a range of impairments, histories and living realities. As noted, this research began from my experience as a clinician and patient. So much more work needs doing to turn around the negative Report Card and to deliver care and communication to PWDBDSI. This work is about the ways forward, despite the flaws and in light of the assets of this thesis. From inception to finale, the research journey delivers many pieces of new knowledge to add to the armamentarium of what we know about the experiences of patients with DBDSI and how we know these, from the words of the participants themselves. Not only do we have a voicing of the previously unheard, but we have solutions-focused participants who, as expert-knowers, have illuminated the path ahead. This work is not the beginning of the end, it is the end of the beginning. Future researchers will do and understand more, and more pressure will be brought to bear upon hospitals and professionals to do their jobs, providing care and communication to PWDBDSI.

Conclusion

PWD, including those with DBDSI, have the right to parous hospital care. They/we have poor health and wellbeing outcomes, and are more at risk of adverse events and negative experiences than sighted-hearing people. There exists a climate of inaction and indifference around the hospital experience stories of patients with DBDSI, as outlined in this doctorate. Innovation and motivation are needed to get policymakers, professionals and management to act upon these findings and translate them into practical change. This will yield both better outcomes for health and wellbeing, and bring benefits to the health sector. Presently, PWD stay longer, present more often and have poor outcomes. This research shows that they have poor experiences and seek to avoid future contact and admissions. In effect, the Department of Health and hospitals need to listen harder and do what is needed.

This research is a key opportunity for improving the areas of hospital care and communication. So here we are. Somehow, we have to make the leap from repeated resource and policy directives into actual practice.

In the screenplay *Still Alice*, a film about a linguistics professor who is losing her memory and competence due to early-onset Alzheimer's disease, Alice says:

> … please do not think that I am suffering. I am not suffering. I am struggling. Struggling to be a part of things, to stay connected to who I once was. So, live in the moment, I tell myself, it's really all I can do, live in the moment and not beat myself up too much for mastering the art of losing.

In many ways, all ways perhaps, this doctoral voyage has been a way of connecting, of tethering me to meaningful occupation—of still being useful. Struggling, for sure, but not suffering (unless admitted to a hospital). I'm living in the moment and making life less difficult for others, through this work and advocacy.

In this journey, I have been mastering the art of a different kind of losing; that of the two communication senses. It is hard enough to navigate the shrinking inwards of life with Usher syndrome, without adding hostile hospitals, with their quick-sanded communication death trap of not knowing what is going on. Nowhere else have I felt such extremes of emotion: the high of being a clinician, yet far outweighed by the unbearable agonies of being a patient with DBDSI. To be a patient with DBDSI is, from this study and my own experience, to be subjected to the power of others in the forms of denied accessibility and whole information; and to suffer through the increased risk of neglect, abuse, dehumanisation, and unwanted, unpleasant, unnecessary touch.

Negative touch is a central power-broking experience for most participants, arising out of staff not able or bothered to communicate their intention. These are assaults on people, their ontological security and rights. It is so much more than not knowing what is going on. When hospital staff can touch you negatively and dehumanise you, deny interpreters and neglect your needs, disrespect and distress you, and even cause you harm, then you are not an equal citizen. You are oppressed, subject to the power exertions of others.

This doctoral study is about disseminating what is going on and providing a suite of solutions. McCann (2020) writes about the Israeli–Palestinian conflict, divide and disaster in his creative nonfiction Booker-nominated work, *Apeirogon*. His words resonate here:

> Power already knows the truth. It tries to hide it. So you have to speak out against power. And I began, back then, to understand the duty we have to try to understand what’s going on. Once you know what’s going on then you begin to think: What can we do about it? (McCann 2020, p. 224/470).

Appendices

Appendix 1: Australian health system overview

Abridged from Australian Institute of Health and Welfare 2020, Health system overview*, viewed 10 February 2021, <https://www.aihw.gov.au/reports/australias-health/health-system-overview>.*

A key role of the Australian health system is to provide safe, effective, accessible and appropriate treatment and other services. Australia's health system is a complex mix of service providers and other health professionals from a range of organisations—from federal and state and territory governments, as well as the non-government sector. Collectively, they work to meet the physical and mental healthcare needs of Australians. Australians admitted to public hospitals are guaranteed access to fee-free treatment as public patients.

The heath system is funded by Australian and state and territory governments as well as non-government funders such as private health insurers and individuals. Funding is managed through intergovernmental agreements between federal and state and territory governments.

Who is responsible for the health system?

The Australian federal and state and territory governments broadly share responsibility for funding, operating, managing and regulating the health system. The private for-profit and not-for-profit sectors also play roles in operating public and private hospitals, pharmacies and medical practices.

A variety of organisations support health services:

- Health departments are responsible for policy and service planning.
- Research and statistical organisations collect and publish information on the health system's performance, health conditions and issues.
- Universities and health services train health professionals.
- Consumer and advocacy groups participate in public debates on policies and regulation.
- Voluntary and community organisations provide support directly to individuals through fundraising and health advocacy programs.

Role of government

Federal government

- Develops national health policy
- Funds medical services through Medicare and medicines through the Pharmaceutical Benefits Scheme
- Provides funds to states and territories for public hospital services
- Funds population-specific services

- Funds research
- Regulates medicines
- Supports access to and regulates private health insurance

State and territory governments
- Fund and manage public hospitals
- Regulate and license private hospitals
- Deliver community-based and preventative services

Local governments
- Deliver community- and home-based health and support services
- Provide environmental health services
- Deliver public health activities

All levels of government share the responsibility of educating and training health professionals, regulating the health workforce, improving the safety and quality of health care, and funding programs and services.

Available services include health promotion and disease prevention programs, primary health care, specialist care and hospital care.

Medicare

Underpinning Australia’s health system is Medicare, a universal health insurance scheme. Medicare pays rebates for medical services by private practitioners in the community, and ensures Australians can access free hospital services in public hospitals and a range of prescription pharmaceuticals. The Australian government funds Medicare through taxation revenue.

Medicare is currently available to Australian and New Zealand citizens, permanent residents in Australia, and people from countries with reciprocal agreements.

Private health insurance

Some medical and allied health services are not subsidised through Medicare; for example, ambulance and dental services. Private health insurance is an option for people to manage these costs, avoid waiting lists in the public system, and choose one’s own doctor.

Appendix 2: Terminology of papers used for this thesis

List 15. Terminology of papers used for thesis

Term = Number of papers using term

- **deafblind = 39**
  - Arndt 2005, 2010, 2011; Bodsworth et al. 2013; Bodsworth, Clare & Simblett 2011; Dammeyer 2010, 2012, 2013, 2014; Bourquin 2007; Danermark & Moller 2008; Dean et al. 2017; Department of Health 1995; Dyke 2013; Fernandez-Valdera, Macias-Seda, Gil-Garcia 2017; Flemming & Damen 2014; Gullacksen et al. 2011; Hersh 2013; House of Representative, Standing Committee on Health, Aged Care & Sport 2017; Jones 2001; Larsen & Damen 2014; Miner and Feldman 1998; Möller 2003; Möller 2005, 2008; Ozioko & Hersh 2015; Prain et al. 2012; Prain, McVilly & Ramcharan 2012; Schneider 2006; Sense UK 2016; Senses Australia 2018; Simcock 2017a, 2017b; Soper 2006; Swann 2010; Todd 2001; Wittich et al. 2012, 2013; World Federation of the Deafblind 2018
- **deaf-blind = 13**
  - Blumsack 2009; Boughman, Vernon & Shaver 1983; Dalby et al. 2009; Dammeyer & Hendar 2013; Ellis & Hodges 2013; Fellinger et al. 2009; Marks 1998; Mascia & Silver 1996 McDonnall et al. 2017; Miner 1995; Parker, Davidson & Banda 2007; Sanford School of Medicine, Center for Disabilities n.d.; Swanson 2007
- **Deafblind = 2**
  - Care & Support for Deafblind Children and Adults Policy Guidance 2014; Roy, McVilly & Crisp 2018
- **DeafBlind = 1**
  - Wolsey 2017
- **dual sensory loss = 11**
  - Blumsack 2009; Brennan & Bally 2007; Capella-McDonnall 2005; Department of Health 1995; Dyke 2013; Fletcher & Guthrie 2013; Fletcher & Guthrie 2013; Guthrie et al. 2016; Heine & Browning 2002, 2004, 2015
- **dual sensory impairment = 8**
  - Crews & Campbell 2004; McDonnall et al. 2016; Saunders and Echt 2007, 2011; Schneider, Gopinath, & McMahon 2012; McMahon et al. 2017; Viljanen et al. 2014; Wittich et al. 2012

Appendix 3: Research readings

Table 1. Literature review

Author, year and title	Type of knowledge*	Medium and purpose	Deafblind population	Scorecard**
1. Alexander & Alper (2014) **Not fade away: A memoir of senses lost and found**	User knowledge	Memoir Purpose is to share experiences of living with Usher Syndrome.	N = 1 Usher 3 syndrome	T: Y A/NR: Y MP: Y U: Y C: Y S: N/A
	Description: Now in her late 30s, Alexander discusses life and occasional misadventures with Usher 3. After a difficult decade and a terrible accident (fell out of bedroom window) she finds happiness, a new career and gets both tactile language and a cochlear implant. Much reflection.		Limitations: Single person	
2. Ellis, Keenan and Hodges (2015) **The experiences of people with rare syndromes and sensory impairments in hospitals and clinics**	Research knowledge	Impairment support organisation report Consultation with carers and users Purpose: assess the experience of patients with DBDSI outpatient clinics in hospitals in the UK and general guidelines.	N = 52 Mix of Usher and rare syndromes: Alstrom, Bardet-Biedl, CHARGE, Stickler Syndrome, Wolfram. Ages from 14 months to 85 years	T: Y A/NR: Y MP: Y U: Y C: Y S: Y
	Description: Patient interviews, environmental audits, and accompanied visits to outpatient clinics to examine: • What are the hospital outpatient and clinical experience of this group with rare syndromes and impairment? • What practical guidelines can be derived from these to improve access, communication and mobility issues?		Limitations: This study pertains to outpatient experience, not inpatient. There is still relevance to the present study because accessibility and experience at the entry point to hospital is assessed. Study confined to England. Study derives extensive practice guidelines but acknowledges the greatest difficulty is how to enforce and ensure compliance.	

	Study noted lack of existing guidelines and hospitals’ failure to enforce those that are already in place. Note: the term ‘hospital’ is used to mean outpatient hospital-based clinics not inpatient experiences. Three sets of guidelines derived from the study: (1) Good practice in the environment, (2) Good practice by staff and (3) Good practice in clinical situations.			
3. Chambers (2012) **Words in my hands: a teacher, a deaf-blind man, an unforgettable journey**	Practitioner knowledge (observation of hospital experiences of client) and carer/support person knowledge	Memoir and dissemination of tacit practitioner experience with 84-year-old client.	N = 1 Has Usher syndrome (detailed observation of impairments and living realities)	T: Y A/NR: Y MP: Y U: Y C: Y S: N/A
	Description: Author’s recollections as an American sign-language teacher, who supports and teaches sign language to Bert, an 84-year-old man with DB. She chronicles the living realities and complexities for individuals and their families. Bert has a number of accidents, requiring hospitalisation and extensive rehabilitation, and the author details her observations of these, the communication failures and solutions.		Limitations: Second-hand observations and recollections.	
4. Fernandez-Valderas, Macias-Seda, & Gil-Garcia (2017) **Experiences of deafblind people about health care** **[Experiencias de las personas**	Research knowledge Clinical research paper in Spanish. Translated 2017 by translator employed by researcher	Peer-reviewed journal article Purpose is to consult with users to identify issues with accessibility, communication and mobility for PWDB	N = 8, females = 4, males = 4 7 from a deafblind day-care centre; 1 from a care home for the deafblind. 2 have congenital deafblindness; 6 were born deaf and gradually became blind.	T: Y A/NR: Y MP: Y U: Y C: Y S: Y (peer-reviewed)

sordociegas sobre la atención sanitaria]	Description: Phenomenological study, semi-structured interviews. Primarily on architectural barriers and difficulties accessing information in healthcare centres in 3 local regions in Spain. Findings: • Architectural modifications needed, e.g. improved lighting, increased number of ramps and lifts, handrails, tactiles, improved signage. • Access to information, e.g. nurses need to learn sign language and use of braille technology; need more interpreters, staff training on deafblindness; improved use of technology such as mobiles, pictogram or tablets. DB wait longer when no interpreter. Lack of privacy. Participants like continuity of care, for professionals to know them. • Participants 'are satisfied' with healthcare. • PWDBDSI want professionals to know them.		Limitations: Difficulty of conducting interviews—interpreter required 'the lack of health of literature on the health care of this group' Seems to relate only to healthcare clinic settings, not hospital. Focus on environmental factors and interpreter need, rather than how participants felt about their experiences. Also, some translation issues, e.g. the word 'positivity' is used when 'paucity' fits the context.	
5. Huddle et al. (2016) **Association between dual sensory impairment, hospitalisation, and burden of disease**	Research knowledge	*Journal of American Geriatrics Society*—peer-reviewed Quantitative/ Measuring costs and testing associations between sensory impairments and hospitalisations, using burden of disease indices.	N = 1669, with 291 DSI adults over 70. Community-dwelling, civilian population. DSI based on objective hearing loss, subjective report of vision impairment and self-report of hospitalisations, number of days (based on two cycles of the US National Health and Nutrition Navigation Survey [NHANES]).	T: Y A/NR: Y MP: Y U: Y C: Y S: Y (peer-reviewed)
	Description: Statistical examination demonstrating		Limitations: No lived experience.	

	an association between DSI, hospitalisation and burden of disease. This increased compared to those with no sensory impairments.		Self-reporting, therefore likely under-diagnosing DSI. Longitudinal study needed to examine relationships prospectively.	
6. Mascia & Silver (1996) **Cochlear implant for an adult who is deaf-blind: a case study**	Research knowledge	Journal article Purpose is to demonstrate the benefit of CI to older persons not just children.	N = 1 Female ageing with DB (in USA)	T: Y A/NR: Y MP: Y U: Y C: Y S: Y
	Description: Hospitalisation for CI in which braille consent form was requested but not received. A positive enabler of her experience was that anaesthetist could finger-spell. Details anxieties beforehand regarding impact of CI and the operative experience.		Limitations: Older study, single case; but larger cohort studies now available that confirm findings.	
7. Revell (2006) **Take my hand: the extraordinary story of a girl named Janis**	Carer knowledge Lived experience (mother of PWDBDSI)	Memoir of parent Purpose is to celebrate the life of a daughter with DBDSI, and the systemic healthcare and hospital failures that resulted in her death.	N = 1 Female Multiple diagnoses of DB given over time, but never given a clear cause.	T: Y (very emotional) A/NR: Y (varies as author describes what happens in final chapters) MP: Y U: Y C: Y S: N/A
	Description: Tragic story of the life of girl with DB. Story is told via a series of largely preventable medical misadventures and misattributions in her 30s, which lead to her death.		Limitations: Observed experience. Single case.	
8. Sense UK (2016) **Equal access to healthcare: the importance of accessible**	Policy /community knowledge	Grey literature Impairment support organisation's commissioned report to provide oversight and	N/A	T: Y A/NR: Y MP: Y U: Y C: Y S: Y

healthcare services for people who are deafblind		monitoring, and examine compliance		
	Description: Demonstrates that health services fail PWDB, who face issues such as communication failures, lack of informed consent and delayed help-seeking because of traumatic experiences.		Limitations: No lived experiences. Biggest issue is inability of society to enforce accessibility legislation in healthcare settings.	
9. Soper (2006) **Deafblind people's experiences of cochlear implantation**	Research knowledge	Peer-reviewed journal article Purpose is to evaluate CI program effectiveness for PWDBDSI.	Participants recruited from national impairment support organisation in the UK N = 5 (all male, DB with CI) P1: RP causing blindness, deafblindness indicative of USH2. P2: Mumps and rod cone dystrophy. P3: Meningitis. P4: Born deaf, suspects USH1 is cause of DB. P5: Born blind and deaf in one ear, eventually lost hearing in other ear, cause unknown.	T: Y A/NR: Y MP: Y U: Y C: Y S: Y
	Description: Semi-structured interviews establish experiences of CI in three areas: access, information and mobility. Research was conducted with five individuals known to the national charity, Deafblind UK, and explores participants' feelings about individual problems encountered prior to implantation, the experience of CI surgery in hospital, and the outcome.		Limitations: No women. Participants not recruited from general population of PWDBDSI	

	Improved communication and quality of life is greatest for those with post-lingual deafness.			
10. Stoffel (2012) **‘Bad medicine’, in Deaf-blind reality: living the life**	User knowledge	Book chapter Purpose is to demonstrate living realities for PWDBDSI across a range of domains and life stages.	N = 7 All female: 5 from USA, 1 from UK and 1 from NZ. One over 65 (NZ: 71), all others under 65 (UK: 52; US: 35, 38, 53, 57, 63).	T: Y (difficult to assess because multiple narrators) A/NR: Y (variable) MP: Y (has lived experiences) U: Y (part of series of chapters on living with DB) C: Y S: N/A
	Description: Chapter on lived experiences of PWDB titled ‘Bad Medicine’. Chronicles the negative impact of ignorant, unsympathetic healthcare staff on PWDBDSI.		Limitations: No men. Emphasis on under 65s (only one participant over 65). Impairment information not available for most. No reflection on the meanings of the experiences and solution.	
11. Takahashi (2019) **Accessibility for people with deafblindness when getting medical services**	Research knowledge	Conference oral presentation Purpose is to demonstrate there is a problem with healthcare for PWDB.	N = 47, female = 24, male = 23 All participants need help filling out survey.	T: Y A/NR: Y MP: Y U: Y C: Y (a live transcription was used) S: Y
	Description: Survey of PWDB and parents of children with DB in Japan. Explored the following areas: looking for a suitable hospital, reception, consultation, examination, treatment and hospitalisation. Consultation by survey with users and carers. Findings: • We need a hospital that is experienced in deafblindness.		Limitations: Impairment information not given. No evaluation of results because aim is to ‘demonstrate problems exist’.	

	• Staff need to communicate better—louder, slowly, through touch or sign language; do not restrain patients; explain more clearly; be patient; and we want staff to understand us.			
12. Todd (2001) **‘Keep in touch’ in *Nursing Standard***	Practitioner knowledge	Article in weekly magazine for nurses Purpose is to summarise impairment support organisation literature and provide practitioner tips.	N = 0 Generalised information from survey conducted in 2001 by Deafblind UK and Sense UK	T: Y A/NR: Y MP: Y (report of a report, very brief) U: N C: N S: N
	Description: Practitioner perspective, dissemination of results from 2001 *Who Cares?* survey of people with deafblindness and their healthcare experiences. Outpatient: More likely to have someone with PWDB. Inpatient: Staff need to know how to communicate. Tips: (1) Talk to patient, not interpreter; (2) Be patient. Survey of 2500 PWDB in 2001—382 responses provide information on how they fared, accusing health services (including hospitals). Many negative experiences. Findings: Problems hearing name when called out in clinic; most bad experiences are avoidable. Solutions focus: Communication strategy for different combinations and degrees of loss.		Limitations: Limited distillation from a research report. Negligible participant information. No definitions, no references.	
13. White (2014) **What does good care look like for a deafblind person?**	Policy and community knowledge	Report to the Care Quality Commission. Purpose: plain English guide on how to provide good care in a range of settings:	N = 8 (7 adults and 1 child) Case studies to illustrate report by Sense UK to the Care Quality Commission in 2014 by Sarah	T: Y A/NR: Y MP: Y U: Y C: Y S: Y

		community, residential care, health services and hospitals.	White, Sense UK's Hearing Policy Officer.	
	Description: Among the recommendations, those pertaining to hospitals are: • Ensure all professionals have basic deafblind awareness training. • Take steps to identify their deafblind patients, including older people who may not yet recognise they have a combined sensory deficit. Support them to access the help they need to lead full and active lives. • Put in place systems that alert all healthcare staff to an individual's communication and access requirements. For hospital inpatients, this should include a sign above the patient's bed highlighting their needs, as well as information about communication and sensory needs being shared during handover. • Medical records should include information about how PWDB communicate (moon, braille, large-print, audiotape, etc) and services should ensure that PWDB are contacted in a format that is accessible. • Understand systems and requirements for booking appropriate communication support (interpreters) and commit to doing so. Be flexible with agencies and communication professionals used—communication needs can be person-specific. Make decisions in partnership with the individual. • Except in an emergency, no procedure should be carried out on a PWDB without it being fully explained to them in clear and accessible way. • Ensure professionals are aware of legal requirements for reasonable adjustment and put these in place to support the PWDB.		Limitations: Patient vignettes for illustrative purposes, not contextualised lived experience material.	

	• Provide signposting information for where additional support can be accessed, and ensure staff are aware of their duty to support PWDB. • Have information available in accessible formats for all patients, e.g. braille, audio, large-print, moon, etc. • Have communication boxes available to support staff’s work, including hearing-aid batteries and tubing, signage on needs above beds, objects of reference, communication cards (Block/DB manual alphabet), etc.; on children’s wards, include sensory toys (pp. 11–12).	

Notes

* Knowledge types use Pawson et al.’s (2003) classification: organisational, practitioner, user, research or policy/community knowledge.

** Scorecard uses Pawson et al. (2003) (Yes or No [Y/N]; includes comment as relevant).

Abbreviations: A/NR: accuracy/narrator reliability, C: comprehensibility, CI: cochlear implantation, DB: deafblind, DSI: dual sensory impairment, MP: meets purpose, N: number, N/A: not applicable, NHANES: National Health and Nutrition Navigation Survey, P: participant, PWDB: people with deafblindness, RP: retinitis pigmentosa, S: specificity, T: transparency, U: utility, UK: United Kingdom, USA: United States of America, USH1: Usher Syndrome type 1.

Appendix 4: Visual description of literature search flowchart

The literature review flowchart has three strands that connect at the bottom. The first level of the boxes details how information was gathered, and the second level contains the number of relevant articles retrieved. These three strands join together in a box at the bottom, which details all items included in the literature review.

The top left-hand box says ‘Database searches in 2017, 2019 (EBSCO, ProQuest, PubMed, Scopus). Exclusion criteria applied: 1990–2017; 1990–2019; NOT child, children, youth, education, behaviour. n = 1546.’ This flows to boxes with ‘Duplicates removed and exclusion criteria applied’ then ‘Abstract (n = 2)’. This then flows to ‘Literature after screening by reading abstract (n = 1)’, which breaks off to ‘Records excluded as unable to access (n = 1)’ and flows down to ‘Items: Fernández-Valderas, Marcías-Seda & Gil-Garcia (2017)’.

The top middle box says ‘Material located in research process 2017–2020’. This flows down to ‘n = 5’ then to ‘Items: Alexander & Alper (2014); Huddle et al. (2016); Mascia and Silver (1996); Soper (2006); Takahashi (2019)’.

The top right-hand box says ‘Wider social care literature search (grey) conducted in 2017–2020 of material 1990–2020. Identified through other sources (hand searches, online organisations, news media). Exclusion criteria applied.’ This flows to ‘n = 7’ then ‘Items: Chambers (2012); Ellis, Keenan & Hodges (2015); Revell (2006); Sense UK (2016); Stoffel (2012); Todd (2001); White (2014)’.

The three strands join and lead to the final box, which says:

Items included in the review, 2020, n = 13

- Research knowledge, n = 6 (Ellis, Keenan & Hodges 2015; Fernández-Caldera, Marcías-Seda & Gil-Garcia 2017; Huddle et al. 2016; Mascia & Silver 1996; Soper 2006; Takahashi 2019)
- User and carer knowledge, n = 4 (Alexander & Alper 2014; Chambers 2012; Revell 2006; Stoffel 2012)
- Policy/community knowledge, n = 2 (Sense UK 2016; White 2014)
- Practitioner knowledge, n = 1 (Todd 2001)
- Organisational knowledge, n = 0.

Appendix 5: Interview guide

What is it like having a dual sensory impairment or deafblindness and going to hospital?

This is confidential and anonymous. Your name will be removed after your interview.

Name:		Age:
Gender:	Male / Female / Non-Binary	Postcode:

Information about your Impairments

☐ Hearing impairment or loss

☐ Vision impairment or loss

☐ Deafblind

☐ Other (please describe)

Education

What year did you leave school?

☐ Year 9 or below

☐ Year 10

☐ Year 11

☐ Year 12

Have you been to TAFE? Yes / No

Have you been to University? Yes / No

Communication

What do you use now to communicate? Please list as many as you can:

What is your preferred method of communication with others?

Tell me what it is like being in hospital

Did you feel the staff at the hospital understood your communication needs?
Yes / No

Any further comments?

Did you understand what was happening to you at all times?
Yes / No

Any further comments?

Did you understand what the plan was for treating you?
Yes / No

Any further comments?

Did you feel anxious or upset as a result of communication difficulties while in hospital? Yes / No

Any further comments?

Please tick any of the particular places in the hospital where you experiences communication difficulties.

☐ Preadmission forms/clinic

☐ Accident and Emergency

☐ Admissions

☐ Transfer to the ward

☐ On the ward

☐ Operating theatre

☐ Recovery room

☐ Return to the ward

☐ During procedures

☐ Ward rounds (by doctors)

☐ Therapy treatments (e.g. Physiotherapy, diabetes education)

☐ Discharge

Did you have an interpreter whenever you needed one?
Yes / No / Don’t use

Any further comments?

Can you think of ways to improve communication in hospital?

Have you ever made a complaint?
Yes / No

Who did you make a complaint to?

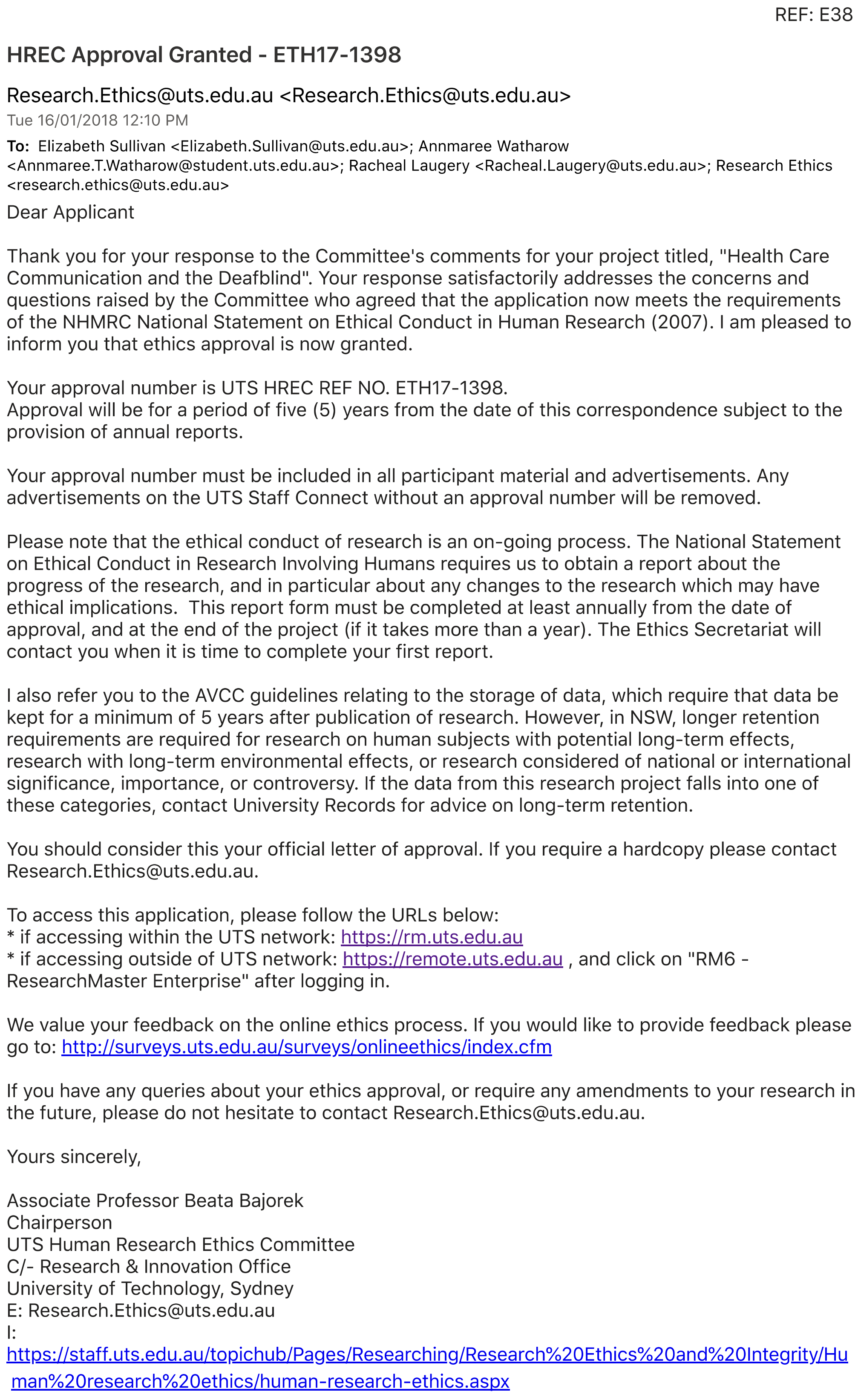
What was the outcome of your complaint?

Can you tell me about your deafblindness? When it started and how it happened.

What is your hearing like now?

What is your vision like now?

Appendix 6: Ethics approval



REF: E38

HREC Approval Granted - ETH17-1398

Research.Ethics@uts.edu.au <Research.Ethics@uts.edu.au>
Tue 16/01/2018 12:10 PM
To: Elizabeth Sullivan <Elizabeth.Sullivan@uts.edu.au>; Annmaree Watharow <Annmaree.T.Watharow@student.uts.edu.au>; Racheal Laugery <Racheal.Laugery@uts.edu.au>; Research Ethics <research.ethics@uts.edu.au>

Dear Applicant

Thank you for your response to the Committee's comments for your project titled, "Health Care Communication and the Deafblind". Your response satisfactorily addresses the concerns and questions raised by the Committee who agreed that the application now meets the requirements of the NHMRC National Statement on Ethical Conduct in Human Research (2007). I am pleased to inform you that ethics approval is now granted.

Your approval number is UTS HREC REF NO. ETH17-1398.
Approval will be for a period of five (5) years from the date of this correspondence subject to the provision of annual reports.

Your approval number must be included in all participant material and advertisements. Any advertisements on the UTS Staff Connect without an approval number will be removed.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually from the date of approval, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://remote.uts.edu.au , and click on "RM6 - ResearchMaster Enterprise" after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Associate Professor Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au
I:
https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/human-research-ethics.aspx

Ref: E41

HREC Approval Granted - ETH18-2488

Research.Ethics@uts.edu.au <Research.Ethics@uts.edu.au>
Thu 14/06/2018 6:23 PM
To: Annmaree Watharow <Annmaree.T.Watharow@student.uts.edu.au>; Sarah Wayland <Sarah.Wayland@uts.edu.au>; alana@thesignsoflife.com.au <alana@thesignsoflife.com.au>; Research Ethics <research.ethics@uts.edu.au>

Dear Applicant

UTS HREC REF NO. ETH18-2488

The UTS Human Research Ethics Expedited Review Committee reviewed your amendment application for your project titled, "Health Care Communication and the Deafblind", and agreed that the amendments meet the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that the Committee has approved your request to amend the protocol as follows:

"1. Interviews will now be recorded through iMovie. There will be a live transcription on the day, and once they have been coded they will be destroyed. Until that time they will be kept in a locked filing cabinet in a locked office. Dr Wayland will be doing the co-coding with the student.

2. The interview questions have changed slightly, for example, instead of asking Yes/No we are now asking Yes/No/Somewhat. We have also added a section for more detail about the deafblindness/hearing losses as a result of difficulties when canvassing the literature when details of participants' impairments have not been recorded or have been recorded with minimal detail. This makes comparison difficult.

3. Regarding one of the interview questions, we were advised for the ease of tactile interpreting, to separate the words anxious and upset to unpack them in two separate questions (also they are two very different emotional states for the deafblind). We haven also modified the question 'comments' to engage the participants, e.g. 'can you please explain in more detail?'

4. There will also be a research assistant (Ms. Alana Roy) as a backup in case my disabilities impact on my performance as an interviewer. Alana will assist will field notes and analysis discussion after the interviews. To ensure consistency in the data collection and interviewer guide has been put together. The proposed research assistant is well credentialed to undertake the task."

You should consider this your official letter of approval. If you require a hardcopy please contact the Research Ethics Officer (Research.Ethics@uts.edu.au).

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au , and click on " RM6 – Production " after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you wish to make any further changes to your research, please contact the Research Ethics Officer in the Research and Innovation Office, Ms Racheal Laugery on 02 9514 9772.

In the meantime I take this opportunity to wish you well with the remainder of your research.

Yours sincerely,

Associate Professor Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office

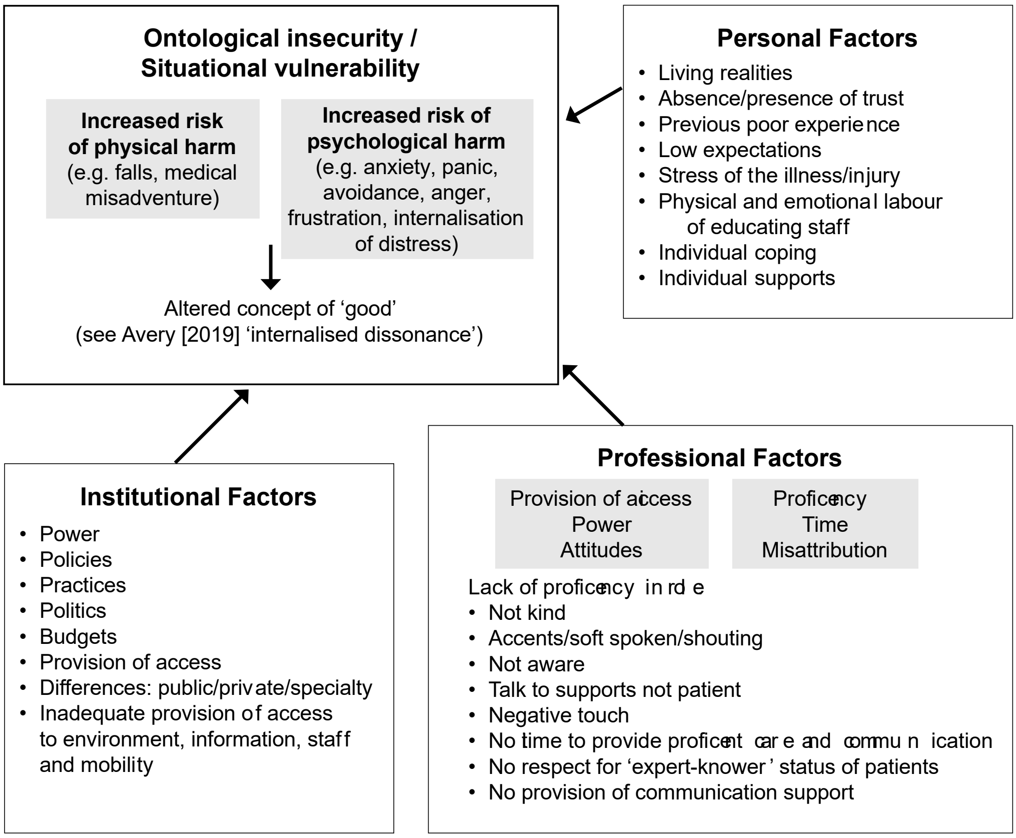
University of Technology, Sydney
E: Research.Ethics@uts.edu.au
I:
https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/human-research-ethics.aspx

Appendix 7: List of concepts derived from first rounds of transcript analysis

- Accessibility
- Equality of opportunity
- Intersectionality
- Participation and inclusion
- Non-discrimination
- Dignity
- Living realities
- Performative aspects
- Border concerns
- Power imbalances
- Wishlist
- What happens next?
- Educating others
- Support/advocacy
- Strengths/solutions focused
- Proficiency
- Touch
- Interpreter issues
- Ageing with deafblindness
- Dual sensory impairments (ageing)
- Trust
- Uncertainty
- Stigma
- Isolation
- Neglect
- Distress
- Agency
- Dehumanisation/depersonalisation
- Tacit compliance
- Emotional labour
- Abuse
- Fear

Appendix 8: Mind map

‘the health system should look after you’—Lachlan



Ontological insecurity / Situational vulnerability

Increased risk of physical harm (e.g. falls, medical misadventure)

Increased risk of psychological harm (e.g. anxiety, panic, avoidance, anger, frustration, internalisation of distress)

Altered concept of ‘good’ (see Avery [2019] ‘internalised dissonance’)

Personal Factors

- Living realities
- Absence/presence of trust
- Previous poor experience
- Low expectations
- Stress of the illness/injury
- Physical and emotional labour of educating staff
- Individual coping
- Individual supports

Institutional Factors

- Power
- Policies
- Practices
- Politics
- Budgets
- Provision of access
- Differences: public/private/specialty
- Inadequate provision of access to environment, information, staff and mobility

Professional Factors

Provision of access
Power
Attitudes

Proficiency
Time
Misattribution

Lack of proficiency in role
- Not kind
- Accents/soft spoken/shouting
- Not aware
- Talk to supports not patient
- Negative touch
- No time to provide proficient care and communication
- No respect for ‘expert-knower’ status of patients
- No provision of communication support

Appendix 9: Participants

Table 2. Participant demographics

Factor	Number	Percentage
Number of participants	18	100%
Age		
Under 65	14	78%
Over 65	4	22%
Gender		
Male	5	28%
Female	13	72%
Other	0	0%
Location		
Urban	15	83%
Regional	1	6%
Rural	2	11%
Remote	0	0%
Interstate	3	17%
Identities[2]		
Aboriginal and Torres Strait Islander	0	0%
Deafblind	7	39%
deafblind	5	28%
deaf and blind	1	6%
Usher Syndrome	2	11%
Dual sensory impairment	4	22%
Blind with hearing loss	1	6%
Low vision	1	6%
Low vision with severe hearing impairment	1	6%

---

[2] Note, these add to more than 18 because multiple identities were occupied.

Blind	1	6%
Blind with severe hearing impairment	1	6%
deaf with low vision	1	6%
Hearing and sight loss	1	6%
Living situation		
Single	10	56%
Partner	4	22%
Family	1	6%
Group home	0	0%
Aged care	4	22%
School education type		
Specialist: Deaf, deafblind or blind schooling	5	28%
Other	1	6%
Mainstream	8	44%
Combination	3	17%
Highest education level achieved		
Pre-school certificate	5	28%
School certificate	1	6%
Higher School Certificate	1	6%
TAFE	6	33%
Undergraduate	3	17%
Postgraduate	2	11%
Occupation		
Studying	0	0%
Working	1	6%
Volunteer	1	6%
Retired	3	17%

Not employed	13	72%
Healthcare background/work		
Yes	4	22%
No	14	78%
First language		
English (oral)	12	67%
Auslan	4	22%
Tactile	0	0%
Idiosyncratic language	1	6%
Fingerspelling	1	6%
Present language		
Same as first	7	39%
English (oral)	7	39%
Restricted-frame Auslan	4	22%
Hand-over-hand	2	11%
Braille	4	22%
Auslan	1	6%
Tactile signing	1	6%
Print on palm	1	6%
Fingerspelling	1	6%
Verbalism		
Nonverbal	4	22%
Verbal	14	78%

Appendix 10: AHPEQS: Development and testing

Table 3. 101 factors affecting the quality of patient experience

Factor	Definition
Care delivery factors	
1. Access	
1A. Timely access	Being able to access care or treatment at the right time
1B. Expertise access	Being able to see a professional with the right knowledge and skills
1C. Treatment-care access	Being able to access the right treatment and care for illness/condition
1D. System navigation	Finding it easy to find out what health services are available locally
1E. Barriers to access	Assistance with overcoming access barriers (e.g. cost; transport)
2. Discharge	
2A. Timely discharge	Being discharged when patient feels ready
2B. Discharge home situation	Staff taking patient's home situation into account when making discharge decisions
2C. Post-discharge support	Staff ensuring that any required support is arranged for after patient's discharge
2D. Discharge warning	Knowing as early as possible when discharge will be
3. Environment	
3A. Welcoming environment	The hospital or health service feeling welcoming
3B. Quiet environment	The room or ward being quiet
3C. Privacy provision	The room or ward offering enough privacy
3D. Disability design	The hospital or health service being designed appropriately for people with a disability
3E. Equipment functioning	Equipment and facilities in the hospital being in good working order
3F. Comfortable environment	The room or ward being comfortable
4. Food and personal hygiene	
4A. Accessing meals	Being able to physically access the food and drink provided, or being offered assistance to do so

4B. Appetising food	Food being pleasant to eat
4C. Dietary needs	Food being appropriate to patient’s dietary needs
4D. Toilet help	Being able to get prompt help with toilet needs if required
4E. Keeping clean	Getting help with keeping clean when needed
5. Organisation of different parts of care	
5A. Written overall plan	Having a written plan showing the steps involved in care and treatment
5B. Staff share info	Different staff or services involved in patient’s care communicating with one another about this care
5C. Care co-ordination	Having one person or team co-ordinating all the different parts of a patient’s care
5D. Continuity of relationship	Being able to see the same staff for treatment and care over time
6. Care tailored to needs	
6A. Responsiveness and flexibility	Staff being flexible in their approach in response to patient’s needs and preferences
6B. Whole person approach	Staff take ‘whole of life’ needs into account (e.g. social, psychological, work and quality of life needs)
6C. Comorbidities	Staff taking other health conditions or illnesses into account (other than the reason for admission)
7. Consistency in quality of care	
7A. Geographical consistency	Being able to get the same quality of care in regional/rural/remote health services as in city health services
7B. Day of week consistency	Being able to get the same quality of care in weekday services and weekend services in hospital
7C. Time of day consistency	Being able to get the same quality of care in daytime and in night time services in hospital
7D. Sector consistency	Being able to get the same quality of care in private and public health services
7E. Clinical quality consistency	Patient being able to get the same quality of care no matter who they are
Clinical practice factors	

8. Clinical treatment	
8A. Care-treatment addressed problem	Patient feeling that the problem they attended service for has been properly addressed
8B. Waiting in pain	Not waiting unnecessarily long for pain relief
8C. Appropriateness of pain relief	Receiving appropriate pain relief
8D. Iatrogenic harm	Not experiencing physical or psychological harm as a result of treatment or care
8E. Error or unsafe practice	Not experiencing any unsafe practices or mistakes in the processes of care and treatment
8F. Medication management	Medicines being managed safely
9. Clinical knowledge and skills	
9A. Staff clinical knowledge	Patient feeling that staff have good knowledge of illness/condition
9B. Staff clinical skills	Patient finding that staff have good clinical skills (e.g. surgery; needle insertion)
9C. Trust in professionals	Patient having confidence in the abilities of the professionals involved in care and treatment
Interpersonal factors	
10. Being heard	
10A. Distress acknowledgement	Having any distress or discomfort acknowledged by staff
10B. Emotional support	Receiving emotional support from staff when needed
10C. Patient knowledge	Patient’s knowledge of their body and condition taken seriously by staff
10D. Invited to be involved in decisions about care and treatment	Patient being invited to contribute their knowledge, needs, preferences and views to care and treatment decisions
10E. Carer's knowledge	Carer's knowledge and input being valued by staff
10F. Being listened to	Being listened to
10G. Having enough time	Having enough time to talk to staff

11. Being kept informed	
11A. Knowing what's going on	Knowing what is happening with treatment and care
11B. Knowing what to expect	Knowing what to expect with treatment and care
11C. Knowing reason	Knowing why things are being done
11D. Knowing how it went	Knowing how treatments or procedures have gone
11E. Knowing who staff are and why they're involved	Knowing the roles of staff and why they are involved in care
12. Staff-patient communication	
12A. Interpreter access	Being able to access an interpreter for conversations with staff (where needed)
12B. Information communicated was easy to understand	Being able to easily understand what staff say
12C. Making sure of understanding	Staff making sure that patient has understood important information
12D. Communicated respectfully	Staff talking to patient in a respectful way
12E. Clear written info	Receiving important information in written form
12F. Carer information	Carers receiving important information
12G. Information choice	Being able to choose how much information is received
13. Feeling known by staff	
13A. Knowing history	Staff finding out about important aspects of patient's past medical history before seeing them, whenever possible
13B. Knowing current condition	Staff finding out about patient's current condition before seeing them, whenever possible
13C. Knowing life circumstances	Staff knowing something about patient's life circumstances (e.g. home situation) before seeing them, whenever possible
14. Being treated as a human being	
14A. Fellow human being	Being treated as a fellow human being by staff

14B. Cultural sensitivity	Staff respecting cultural or religious needs
14C. Talking about without	Patient being involved in conversations about them which take place in their presence
14D. Sensitivity—dignity and respect	Staff being sensitive to your feelings
14E. Disability awareness	Staff being aware of the specific needs of people with disabilities
14F. Confidentiality	Staff maintaining patient confidentiality
15. Feeling cared about by staff	
15A. Staff availability	Feeling that staff are available if you need them
15B. Staff responsiveness	Feeling that staff will respond to any concerns or questions
15C. Left to cope alone	Not being left to manage alone when you need support or help
15D. Genuine caring, attempt to understand, empathy	Feeling that staff genuinely care about you
15E. Thoughtfulness and personal touch	Being treated in a kind and thoughtful way
15F. Staff positivity, reassurance	Staff having a positive and reassuring manner
System and administration factors	
16. Giving feedback	
16A. Feedback mechanism awareness	Being made aware of how to give feedback
16B. Welcoming feedback	Feeling that the health service or staff would welcome feedback
16C. Complaint assistance	Being assisted by the health service or staff to make a formal complaint
16D. Complaint responsiveness	Having a complaint taken seriously and followed up
16E. Receiving apology	Receiving an apology from the service if a mistake is made
16F. Learning organisation	Improvements to services being made as a result of feedback
16G. Patient advocate	Having access to a patient/peer advocate

17. Appointments and waiting lists	
17A. Unexpected delay	Appointments or admissions happening when expected
17B. Wait information	Being told how long a wait is likely to be
17C. Wait reason	Being told the reason for the length of a wait
17D. Wait acceptability	Waiting an acceptable amount of time for an appointment or treatment
17E. Appointment convenience	Appointments/admissions being arranged around patient’s needs and preferences
17F. Wait list management	Not being lost off the list
18. Health records and documents	
18A. Accurate records	Written records about patient’s health and treatment being accurate
18B. Complete records	Written records being complete
18C. Record availability	Records being available to all staff treating patient
18D. Electronic records	Written records about patient’s health and treatment being available electronically to authorised staff
18E. Documents comprehensible	Documents that patient is asked to read being easy to understand
18F. Form filling	Documents that patient is asked to fill in (e.g. forms) being easy to complete
19. Patient orientation of health organisation	
19A. Patients first	Feeling that the hospital or health service is set up to put the needs of patients first
19B. Preventive system	Feeling that the hospital or health service is set up to make sure health problems are prevented or addressed early
19C. PEx focus	Feeling that careful thought has been given to making patients' experiences as positive as possible.
19D. Supportive of carers and families	Feeling that the hospital or health service is set up to value and support carers and families
19E. Flexible system	Feeling that the hospital or health service is set up to be flexible around individual patients’ needs

20. Management of health services	
20A. Cost transparency	Patient being told what out of pocket costs they will have before treatment begins (if any)
20B. Overall organisation	Feeling that the health service is well organised overall
20C. Sufficient services	Sufficient services being available to meet patient needs
20D. Sufficient staff	Sufficient staff being available to meet patient needs
20E. Staff morale	Feeling that staff morale is high
20F. Staff training	Feeling that staff are well trained and supervised.

Notes

Australian Commission on Safety and Quality in Health Care (ACSQHC) 2017, *Australian Hospital Patient Experience Question Set: Summary of development and testing,* ACSQHC, Sydney, Appendix 1, pp. 12–16.

Appendix 11: Patient Experience Question Set

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

AUSTRALIAN HOSPITAL
PATIENT EXPERIENCE QUESTION SET

Australian Hospital Patient Experience Question Set

The Australian Hospital Patient Experience Question Set (AHPEQS) questions and response options are listed on pages 2 and 3 of this document, as endorsed by the Australian Health Ministers' Advisory Council in November 2017.

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In audio/spoken forms of AHPEQS

You must include words to the following effect in any audio recording or audio conversation:

> The following questions were developed with patients by the Australian Commission on Safety and Quality in Health Care, to assess the experiences of patients across Australia.

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AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

AUSTRALIAN HOSPITAL
PATIENT EXPERIENCE QUESTION SET

	Questions	Response options
1	My views and concerns were listened to	Always Mostly Sometimes Rarely Never Didn’t apply
2	My individual needs were met *[if answer always/mostly, skip to Q4]*	Always Mostly Sometimes Rarely Never
3	When a need could not be met, staff explained why	Always Mostly Sometimes Rarely Never
4	I felt cared for	Always Mostly Sometimes Rarely Never
5	I was involved as much as I wanted in making decisions about my treatment and care	Always Mostly Sometimes Rarely Never
6	I was kept informed as much as I wanted about my treatment and care	Always Mostly Sometimes Rarely Never
7	As far as I could tell, the staff involved in my care communicated with each other about my treatment	Always Mostly Sometimes Rarely Never Didn’t apply

	Questions	Response options
8	I received pain relief that met my needs	Always Mostly Sometimes Rarely Never Didn’t apply
9	When I was in the hospital, I felt confident in the safety of my treatment and care	Always Mostly Sometimes Rarely Never
10	I experienced unexpected harm or distress as a result of my treatment or care *[if answer is no, skip to Q12]*	Yes, physical harm Yes, emotional distress Yes, both No
11	My harm or distress was discussed with me by staff	Yes No Not sure Didn’t want to discuss it
12	Overall, the quality of the treatment and care I received was:	Very good Good Average Poor Very poor

Appendix 12: The Report Card

Table 4. The patient-participants’ Report Card

Factors	(n)	%	Factors	(n)	%	Total (n=18)
Interpersonal Interactions						
I am heard	1	6	I am NOT heard	17	94	18
I am cared about	2	11	I am NOT cared about	16	89	18
I am informed	8	44	I am NOT informed	10	56	18
I am known	2	11	I am NOT known	16	89	18
I am treated as a human being	3	17	I am NOT treated as a human being	15	83	18
I understand what professionals say	2	11	I do NOT understand what professionals say	16	89	18
Clinical Quality Interactions						
I can get the right care at the right time	3	17	I CANNOT get the right care at the right time	15	83	18
I experience high-quality and safe clinical care	4	22	I do NOT experience high-quality and safe clinical care	14	78	18
Care Delivery Interactions						
I have confidence in the professionals treating me	4	22	I do NOT have confidence in the professionals treating me	14	78	18
I am discharged at the right time with the right plan	9	50	I am NOT discharged at the right time with the right plan	9	50	18
My personal care needs are attended to	2	11	My personal care needs are NOT attended to	16	89	18
My care is tailored to my needs	4*	22	My care is NOT tailored to my needs	14	78	18
My hospital is clean and welcoming**	NA	NA	My hospital is NOT clean and welcoming	NA	NA	NA

Different parts of my care are coordinated	3	17	Different parts of my care are NOT coordinated	15	83	18
I am treated equally no matter who I am	4	22	I am NOT treated equally no matter who I am	14	78	18
Administrative Interactions						
My hospital puts the need of patients first	1	6	My hospital does NOT put the need of patients first	17	94	18
My hospital is well managed overall	1	6	My hospital is NOT well managed overall	17	94	18
My appointments and waits are well managed***	NA	NA	My appointments and waits are NOT well managed	NA	NA	NA
My feedback is welcomed and acted upon****	1	25	My feedback is NOT welcomed and acted upon	3	75	4
My health records are well managed	2	11	My health records are NOT well managed	16	89	18

Notes

* None of the participants (n=18) received consent forms in an accessible format.

** Factor not commented on.

*** Factor not commented on; however, participants frequently noted waiting.

**** Only four participants gave feedback.

Appendix 13: Explanation of the (un)lucky dip model

The ‘(un)lucky dip’ model seeks to map social disadvantages, information inadequacies, situational vulnerabilities and power relationships from the critical insights of participants with DBDSI. It links power disparities and ontological insecurity with poorer outcomes, which is the focus of **Chapter 12: Deaf, blind and mute**.

This model is constructed of text boxes (with labels and further information) and arrows. These are described visually, from the top of the page down, as follows:

1. Two boxes, labelled ‘hospital-institution’ and ‘professionals’ are at the top of page, connected by arrows back and forth.
2. These arrows join to flow down to the next level, a box labelled ‘power disparity’. This text box contains further information, which is the features of exclusion from decision-making, failure to communicate, failure to provide access to information, failure to provide accessible forms, flouting conventions and protections, reduced or denied access to aids and support network, non-provision of interpreters, failure to orient people with DBDSI to the environment, lack of participation and inclusion, failure to provide dignity, misattribution, lack of understanding, not reading the notes, not doing their job, negative touch, neglect, abuse, dehumanisation/ depersonalisation, lack of proficiency and unpredictable care.
3. The ‘power disparity’ box has an arrow flowing down to the next text box, labelled ‘ontological insecurity and not knowing what is going on’. This contains further information about this component, which is the features of risk, fear, uncertainty, distress, decreased agency, loss of dignity, exclusion, avoidance, delayed health-seeking, non-compliance, loss of agency and emotional labour.
4. The ‘power disparity’ box has two arrows flowing out either side of it. To the left side, an arrow flows to a box on the same level, labelled ‘personal factors’. This box contains further information, which is absent or incidental support, emotional labour, living in aged care, gender, interpreter issues and oralism/non-verbalism.
5. The second arrow from ‘ontological security and not knowing what is going on’ text box flows out of the bottom of the box. This flows down to a box labelled ‘poorer outcomes of health and wellbeing’. This box is at the bottom of the page and is the conclusion of the model.

Appendix 14: Explanation of the ‘they should look after us’ model

Using the participants’ wish lists and positive experiences, a model linking ontological security, knowing what is going on and power parity is presented—the ‘they should look after us’ model. This is an affirmative framing of the research, and includes societal, institutional and professional factors as well as elements pertaining to the individual.

This model is constructed of text boxes (with both labels and further information) and arrows. These are visually described, from the top of the page down, as follows:

- A box labelled ‘society’ is at the top of the page, with further text explaining this aspect: enforcing legal protections and conventions.
- Flowing down from this box are two more text boxes, one to the left and one to the right of the ‘society’ box. One is labelled ‘hospital-institution’ and the other is ‘professionals’. These two boxes are on the same level and are connected to the ‘society’ text box by arrows pointing back and forth, indicating that both hospital-institutions and professionals enforce the legal protections and conventions within society.
- The ‘hospital-institution’ and ‘professionals’ boxes are also connected to each other by arrows flowing back and forth—reiterating that society, hospital-institutions and professionals all enforce legal protections and conventions. This is where change must occur to see better hospital experiences for PWDBDSI which, in turn, will result in better health and wellbeing outcomes for them.
- From the centre of the ‘society’ text box, one arrow flows to a larger text box labelled ‘provision of care and communication’. This is the largest text box of the model and takes up the most space. It details what needs to be done in the provision of care and communication: cultural change; complying with conventions, and legal and policy frameworks; providing accessibility support; changing the environment; funding what is needed; listening to PWDBDSI; asking patients and reading the notes; providing communication support; providing orientation and mobility/environment information; updating and upskilling staff on DBDSI; non-discrimination; positive touch; being kind; introductions; and trustworthy care and staff.
- Flowing down from this box is an arrow to another box labelled ‘ontological security: “knowing what is going on”’. This box contains further information about what is needed to both provide and personally experience ontological security: a high sense of coherence, ability to query and complain, inclusion in care, shared decision-making, patient-centred care, dignity, informed consent, trust, and compliance.
- On the same level as ‘ontological security’ is another box labelled ‘personal factors’. From this box flows an arrow pointing back to the ‘ontological security’ box. This box notes aspects of care that remain with the individuals receiving care, namely: wristbands; emergency

contact information; support networks; and information about health, sight and communication.

- The direction of the arrow flowing from the ‘personal factors’ to the ‘ontological security’ box indicates that these personal factors fall within the concept of ontological security and ‘knowing what is going on’.
- An arrow flows down from ‘ontological security’ to the final text box labelled ‘better health and wellbeing outcomes’. This is the overall goal of the changes, which are both requested and required by the participants with DBDSI, and thus concludes the model.

Appendix 15: Using haptices in health care settings

Article written by Riitta Lahtinen (Ph.D), Russ Palmer (Music Therapist), and Sanna Tuomaala (Youth Instructor), *Deafblind International Review*, January, pp. 18–19.

Haptices are touch messages which are produced onto various parts of person's body which resemble wands or signs. Haptices have their own grammar, and they form their own linguistic system, the social-haptic language. Haptices are formed in different ways; some are a natural description of an activity, while others are based on writing, signing or visual symbols.

When signals are changed into haptices, their grammatical structures change. The skin, the sense of touch and the kinaesthetic sense[3] (or movement sense) form a distinct channel for receiving messages as compared to the eye or the ear. Haptices are comprised of haptemes (compare phonemes, and the grammar of signing). Haptemes are for example pressure, duration, direction and speed (Lahtinen 2008).

The social-haptic language is composed of haptemes. During social-haptic communication, two or more people produce/receive touch messages, whereas in haptic communication, information is received from a technical device by using touch (e.g. haptic feedback). The intentional development of haptices began in the 1990s. The first lecture on the topic was presented in 1993 at the 7th Usher Study Group[4] meeting in Potsdam, Germany (Lahtinen & Palmer 1993). Haptices can be grouped into several sub groups. One type are those used in a particular situation or by a specific group of professionals. This article illustrates haptices used in hospital by health care professionals. As developers of haptices Sann and Russ tell us of their own experiences.

Sanna Tuomaala reports about her experience with haptices in a recovery ward

I have Usher syndrome.[5] With the profession of this condition, my hearing and vision will both deteriorate. Presently, I use two cochlear implants (CI)[6] with which I can hear fairly well in quiet surroundings. My vision is very narrow, only about 10 degrees. I become deprived of sight temporarily due to bright lighting conditions. Mobility is unfamiliar places is difficult without a guide. I communicate in speech, sign language and also in tactile signing, if necessary. In addition to these, I use social-haptic communication.

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[3] See: medical-dictionary.thefreedictionary.com/kinaesthetic+sense

[4] Usher study group is now called the DbI Usher Network (http://usher.deafblindinternational.org).

[5] See: www.nidcd.nih.gov

[6] See: www.nidcd.nih.gov

The hospital is one place where haptics are useful. Imagine a patient, who hears and sees barely anything as a result of medication, a hearing and vision disability, or some other reason. In such a situation, touch is an excellent channel for receiving information; for example, what is happening in the room or what will be done next.

I participated (with others) in developing haptices and testing haptices in a hospital situation. The nurses informed me of the most important incidents and actions to be taken by using these touch messages onto different parts of my body. The following haptices were tested in authentic hospital setting when I had my first CI-surgery: *doctor*, *don't worry*, *vaccination*, *blood pressure*, *it will hurt now*, *the time* and *Is everything fine?* In that situation, the touch from another person gave also a sense of security an felt reassuring.

Russ Palmer reports about his experiences with haptices in several medical situations

I also have Usher syndrome. I use two cochlear implants, with which I get along in peaceful surroundings. I am also blind and when out of my home, I always need a guide. I communicate using speech, English finger spelling and social-haptic communication.

For me, social-haptic communication is a natural, linguistic means of communication.

I have been developing haptices, teaching their use and analysing their grammar (i.e. haptemes) since the beginning of the 1990s. I use haptices all the time in various kinds of situations both with family members as well as with interpreters and personal assistants. For me, social-haptic communication is a natural, linguistic means of communication.

When I face a new situation, for example my cataract surgery, I tried to consider in advance what is a safe way of getting situational information. I knew that during the cataract surgery I could not use my cochlear implants. In that situation I am deafblind. Riitta and I used haptices that we had agreed beforehand (see photos) which worked well.

I have used those haptices also in other hospital and health care situations. Recently, for example, haptices were very useful while in the hospital in Brazil (Palmer, 2015) where only Portuguese was spoken by the hospital personnel. It was quicker for the nurses to learn to use haptices than to learn to pronounce English words. Haptices can be used together with cochlear implants or without them.

Pictures of the most common hospital haptices are shown. Deafblind persons may use this list of haptices and take them along to in healthcare situations and introduce them to the healthcare personnel. Haptices are easy to learn because they are based on the activity and provide logical messages regarding the medical procedures to be done.

For further information about haptices, contact: riitta.lahtinen@icloud.com and www.russpalmer.com

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