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Cover Page Footnote

Dr Annmaree Watharow has been an Australian physician for 27 years.

***Out of Adversity Can Come Opportunity:
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Adversity

The un-creation of Annmaree Watharow had its embryogenesis at birth. I was born with a hearing loss, severe but manageable with increasingly efficient hearing aids (well the early ones were large metal boxes that made the world a tinny sounding place so manufactures could only improve on that). Like so many people with disabilities in the 1970-1980s I worked hard to pass as able-bodied and normal. But there comes a time, with worsening deficits and/or the acquisition of new ones, that normal is no longer possible nor safe. That is what happened in my last year of training to be a doctor — I began to go blind. At first it wasn't too bad but throughout the years as I practiced medicine difficulties grew, and when my hearing began to diminish as my sight shrivelled, I was unmade. My career despite all the adaptive changes I had made throughout the years, was over.

Opportunity

I am a physician with a recently past professional life. In my work I was shocked by what some of my patients told me about being deafblind or sensory impaired in hospital: “I felt like a caged bird, never knowing where I was or what was happening to me,” one man said. Another stated, “I felt invisible, all day I waited for someone to tell me something, anything about what was happening to me.” One woman didn't understand her post-operative discharge medicine instructions so she didn't take any medication and “put up with the pain instead.” Yet another went four days without any food or water – no one had shown him where it was. On the fourth day of his hospitalisation he was dehydrated and in acute kidney failure — an avoidable medical misadventure.

The way forward starts to crystallise — a PhD in hospital communication experiences of the deafblind and dual sensory impaired looks to be a tangible contribution I can make to changing the current landscape of laissez-faire attitudes towards care of and communication with these patients.

And then, and then, and then,

I, too, become a patient.

Despite having a rogue influenza infection and bilateral crappy lungs, I never felt inherently in any biological danger. The way I was treated (or not) by staff made me realise the hospital communication experience was worse than the illness. One doctor thought I had cognitive injury caused by hypoxia. He was asking questions without giving me time to put my hearing aids in. Another nurse refused to pin the buzzer to my sheets so I could find it — she cited occupational health and safety concerns. So, when it came to an acute crisis at three AM, I couldn't locate my oxygen nor my spacer and inhalers, nor the buzzer. I was fortunate in having roommates who awakened and buzzed their buzzers. Nurses rushed in, registrars were called and intensivists came. On going home eventually, the pharmacy gave me multiple drug dosage regimes and reducing schedules in teeny tiny print. At all times hospital staff were informed I had dual sensory impairments “profound hearing loss, and only one degree of vision”.

And yet, and yet and yet...

None of this information seems to have connected in a meaningful way to provide quality patient-centred care. I didn't feel safe. So recovered and resolute, and profoundly shamed by the ignorant conduct of my own profession, I begin my doctoral studies.

Observations

While telling stories is a fundamental human practice, the value of storytelling in healthcare has been unrecognised by mainstream medicine for a long time. Physician and academic Rita Charon describes narrative medicine as medicine practiced with narrative skills (2006). She details three key elements of the doctor /patient interview:

1. Attention (attentive listening to the story).
2. Representation (reflecting back what has been heard).
3. Affiliation (engaging to work together) (Charon, et al., 2017, 3).

But these elements presuppose a narrative space that is accessible to the co-creation of shared dialogue and story making by doctors and patients. Communication back and forth is mostly effortless and relatively time efficient for sighted-hearing persons unlike the effortful epic of accessing information for us — the sensory impaired. In the hospital these things have to come to pass for communication to occur: the physician has to recognise that there is a communication disability, then find out what communication method is best, and finally organise the practical necessities. For instance: booking interpreters, and the physical space to accommodate all interested parties — patient, carer, assistance animal, family, interpreter, health staff. Finally, hospital staff must find a mutually agreeable time for all to gather to listen, reflect and plan a treatment trajectory. A wearying and cumbersome process often neglected and thus opportunities to promote good care and outcomes are missed. For the deafblind, communication effort is an ever present, daily, unremitting, blanketing constant.

I am engaged in my doctoral project: a hurt-healer-consumer-researcher-hybrid, asking what is it like for deafblind and sensory impaired people in hospitals. I work from dual perspectives, that is, on both sides of the stethoscope as it were. When professional persona merges with the patient role, new knowledge and understandings are reached. This is one such moment.

It is time consuming to set up ethnographic interviews with deafblind participants and locations to everyone's satisfaction. But then, here we all are. I am struck by the balletic relay process in which I ask a question, the interpreter unpacks and touch signs to the interview participant, who puts her right hand on the right side of her face (I am thinking) and then she fingerspells and signs to the interpreter who tells my assistant and I what is being said and thought. Perhaps resembling modern dance, and its more fractured movements, more than ballet. My assistant tells me what is going on visually with hands, facial expressions, and aurally with vocalisations and silences. And there are pauses while the interpreter has a mandated break, while the participant ponders the questions, then signs a reply, while the interpreter grapples and grasps the reply. I follow up with another query and so it on goes, a balancé. There is much respectful, permission granted touching, bodies in proximity. We are

in a room of four people and a guide dog, for one conversation. A sighted hearing duo, would take less than half the time, involve fewer people and definitely require a smaller room.

Here, however, attentive listening and reflection, the telling and showing of stories, occupies a different space and an elongated temporality.

Evidently having sensory impairments changes the narrative space for health workers and patients alike. Patients in my study say they feel invisible and spend hours and days waiting in unfamiliar territory for unknown things to happen. They wait for someone to tell them in the way that works for them, what the day's events are. They worry in the silence. The communication failures are worse than the illnesses themselves, some of them say. Sometimes they go home not knowing what is wrong, or what the treatment plan is. Physicians can be frustrated by the communication difficulties, but often they are unaware of what the patient with sensory impairments actually needs to progress participation in their health care processes.

What are features of people with deafblindness or dual sensory impairments that make for complexity in the clinical narrative space?

Firstly, deafblindness can be defined as "...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." (World Federation of the Deafblind, n.d.) Sometimes the phrase dual sensory loss or impairment is used interchangeably with deafblindness. Often it is used to denote the elderly population with combined hearing and vision loss. With the population aging, the numbers of older people who will bring single and dual sensory impairments to the doctor-patient conversation will increase.

Heterogeneity is the key feature of people with sensory losses: there being myriad causes, presentations, communication methods and coping styles. Deafblindness in all its forms and expressions affects communication, access to information and mobility. Touch and smell become important conduits of information, and beyond these senses there are assistive devices including human support to maximise any residual hearing and vision. Rarely are deafblind people completely soundless and sightless, but residual hearing and vision are not enough to understand the world and its people clearly and safely.

Living with sensory impairments means living with fragmentary information; the deafblind patient may struggle to piece these information fragments together in the way intended by the physician. This confers risk in healthcare settings. Thirty units of insulin is very different from thirteen units, which is altogether different from three, but these amounts **can** sound similar to someone with hearing loss. People with dual sensory impairments and deafblindness may use one or more aids to communication. They may use speech, sign and tactile languages, and/or braille, for instance, and the above-mentioned assistive devices including hearing aids and cochlear implants and many, many more. There is no one-size fits all for the hearing and vision impaired and no common language. They may use orientation and mobility methods such a combination of guide dogs, white canes, digital guiding technology, personal assistants and sighted guides.

Some with deafblindness are members of an emerging culturally and linguistically diverse (CALD) group. These Deafblind people may use a capital D for Deafblind to denote their CALD status and identity. They use closeness and touch extensively in social contacts

and have their own social norms (Roy et al. 2018). They are a barely studied group poorly understood by health care systems and professionals. This confers complexity for encounters in the clinical narrative spaces.

Not only does the deafblind/dual sensory impaired patient potentially bring accessibility and socio-cultural issues to the clinical narrative space; they may bring an entourage. Those with severe sensory losses have increased dependence on others for information, accessibility and mobility. This means interpreters, family members, partners, carers, sighted guides, support workers, and service animals may also participate in the clinical conversation with doctor and patient. In addition, these many others occupy physical space too. The patient's bedside in shared wards is not the appropriate place for such a gathering of information gatherers and conduits. If there is much material to share, such as discharge arrangements and complex chronic disease management plans, a larger space must be found. Considerable time may be needed for the exchanges. It is not enough to abrogate this duty of care by conferring solely with sighted-hearing family members or support workers. Patients with sensory impairments have the right to participate and make choices in their health care conversations. They need to have their stories heard; they require support to do so.

As well as the narrative space occupied in a physical way by more people and assistance animals, time is also inhabited differently by the deafblind/dual sensory impaired. Time is both spent and lost in all aspects of daily life and those involving participation compound this loss. Multitasking is usually not possible for most. Tasks can be attempted individually, so using residual hearing to attend to medical information may preclude using residual vision to look at diagrams at the same time. More time needs to be taken to explain and understand items individually. There are no formal studies I am aware of that quantify this temporal loss, but Moller (2003) states loss of time has a negative impact on quality of life.

People with deafblindness and sensory impairments may spend considerable periods in the healthcare system. Having sensory impairments is associated with health threats such as: increased accidents, other impairments and psychological distress to name a few. This means in practice many phone calls, emails, online form completion, booking transport, interpreters, support workers or family members to assist. Time is spent waiting for each to reply, and to translate each communication into an accessible format. Moller also found that professionals report "they booked twice as much time for an appointment with a person with deafblindness than for other clients" (2003, 141).

One observation many of my participants are making is about the conversations they are not having. The deafblind are **not** complaining about problematic health care experiences though these are many. There is a silence in the narrative space around these negative events. If you need significant supports to have a dialogue with your doctor, then you also need support to be able to make complaints. One participant told me that he is so used to bad service and having a bad time it has become normal. The doctor patient dialogue is a space where the voices of the deafblind should be sought and heard.

All these understandings are important if physicians and health care professionals are to gain knowledge of the patient's reality and worldview so necessary for healing. But these understandings can't happen if we are failing to recognise their very presence. Most patients with sensory impairments are elderly, and many are invisible. Be this I mean they haven't

been diagnosed, they haven't been counted in data sets and they haven't been treated, remediated or supported. Some think not hearing and not seeing so well are normal aspects of ageing (Shakespeare, 2015; Sense UK, 2013). The risk of communication errors in hospital and health care settings is therefore higher. The narrative space is compromised.

If clinicians can nurture the narrative space with the deafblind, then there are opportunities to build knowledge of these understudied people. This in turn adds to the scant narrative resources for others with deafblindness and dual sensory impairments as well as increasing physician understanding(s). Stories are needed that say this is how I live, cope and these are the specific supports I need. Remember heterogeneity? Narratives are therefore needed of the many and varied.

This essay is about starting a conversation about the communication and other requirements of those with sensory impairments and the need for clinicians to acquire knowledge, skills and cultural sensitivity. One implication for clinical practice is just how do physicians get the requisite information on communication preferences? I suggest A.S.K.: Acquire Specific Knowledge. By this I mean ask the patient, ask the partner, ask the parent, ask the carer: what is the best way to communicate? Ask the patient again to make sure you have understood what is needed to make the narrative space work, to make the patient feel safe, respected and able to participate in their own health care.

People with sensory impairments occupy a different narrative space and clinicians must learn to question practices and assumptions in delivering diagnoses, results, plans and treatments. It is not just myself and my research participants who are speaking about negative communication encounters and problems in the narrative spaces. Poor communication and substandard care by clinicians of sensory disabled patients are found in the scant canon of illness and disability narratives and life writings. Some examples are: *Walk in My Shoes*, a collection of life experiences by people with Usher syndrome; *Take My Hand*, by Audrey Revell the mother of a young woman, Janis, with deafblindness; Scott Stoffel's *Deaf blind Reality*, a collection of lived experiences by deafblind people covering work, education and health care. The section on the latter is ominously titled 'Bad Medicine'; *Invisible*, a memoir of vision loss with deafness occurring later in life; and *Not Fade Away* by Rebecca Alexander, a young woman's life with Usher Syndrome detailing Alexander's diagnosis and consequent loss of hearing and sight.

The sensory impaired are vulnerable to increased suffering in their clinical encounters as they bring accessibility communication and mobility issues that complicate care and confound the narrative space.

As a physician confronted with the personal adversity of acquired deafblindness, who has embraced an unexpected opportunity to become a consumer-researcher, I am in a unique position to make these observations on the narrative space of the doctor-patient dialogue. Attentive listening, reflection and co-creating the treatment plans all requires additional effort, time and consideration if the doctor-patient narrative space is successfully traversed. Specifically, doctors need to identify sensory impairments, discover the communication method/s that work for each patient, and organise the communication support team. These will need an appropriate place for the conversation. More time is needed too for organising, communicating, engaging, reflection and planning. This time, so sorely needed, must be carved out of a health care system that predicates and values 'efficiency' and 'economy'. But

there is no other way to provide health care to the deafblind and dual sensory impaired that is socially just, individually specific and safe.

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