Navigating deafness and cochlear implants:
Parents' and young adults' experiences in an Australian setting

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Thesis submitted for the degree of Doctor of Philosophy in Anthropology and Development Studies, School of Social Sciences, and School of Psychology

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Table of Contents

List of publications in this thesis

Harris, C., Hemer, S. & Chur-Hansen, A. (2020) ‘Emotion as motivator: parents, professionals and diagnosing childhood deafness,’ *Medical Anthropology*, 40(3): 254-266, https://doi.org/10.1080/01459740.2020.1796659.

Harris, C., Hemer, S. & Chur-Hansen, A. (2020) ‘“It's an emotional rollercoaster” the spatial and temporal structuring of affect in diagnosing childhood hearing loss,’ *Emotion, Space and Society*, 37: 100729, https://doi.org/10.1016/j.emospa.2020.100729.

Harris, C., Hemer, S. & Chur-Hansen, A. (2021) ‘Informed choice and unbiased support: parents’ experiences of decision-making in childhood deafness,’ *Social Science and Medicine - Qualitative Research in Health*, 1: 100022, https://doi.org/10.1016/j.ssmqr.2021.100022.

Paper reviewed and resubmitted

Harris, C., Hemer, S. & Chur-Hansen, A. (2021) ‘Sensing technology: experiencing deafness and hearing through cochlear implants,’ *Body and Society* (publication pending).

Abstract

This thesis is focused on the ways that parents of deaf children and young adults with cochlear implants experience childhood deafness in an Australian setting. In the last three decades significant developments in deafness have resulted in greater access to earlier diagnosis and choices in rehabilitative interventions. These changes, brought about by universal newborn hearing screening and a capacity to identify deafness in the first few weeks of life, technological developments including the cochlear implant, and access to a range of education and language options, have been seen as advantageous by health and education professionals and by parents of deaf children. Furthermore, policies of informed choice and family centred practice have been developed as international benchmarks in service provision and to ameliorate the tensions and politics within the context of childhood deafness. Despite these changes, what is 'best' for a deaf child and their parents continues to be controversial and subject to debates that proliferate through the academy, public culture including social media, and in practices in deafness.

This ethnographic thesis unpacks childhood deafness to contribute insights and knowledge about everyday experiences of deafness from the perspective of both parents of deaf children, and young adults with cochlear implants. It explores parents' emotional reactions to childhood deafness and their interactions with health and education professionals, which were often contested and ambiguous. Additionally, I probe the experiences of young adults and the significance that technology had in their everyday lives to advance understandings about ways of being deaf and hearing through cochlear implants.

Drawing on sixteen months of ethnographic data collected in an Australian city from 2017 to 2018 I critically explore the complex and socially situated relationships and structures in a deaf health and education context. I focus on parents' encounters with clinical and education professionals as they experience a diagnostic referral process and undertake a 'follow the baby' approach to examine clinical and education encounters from first diagnosis through to a treatment seeking process. Drawing on phenomenology and an anthropology of the senses, emotions, and time and space, I show how parents' experiences of deafness are historically and socially situated, which contributes knowledge and understandings about how parents and young adults experience deafness.

I examine the role of emotion in clinical contexts including parents' emotional reactions to diagnosis, to medical uncertainty and to the ways parents make time sensitive decisions for their children. I argue that in the clinical context women's emotion is often characterised as problematic at the moment of diagnosis. Additionally, the experiences of young adults with cochlear implants are explored to understand the sensory significance of deafness and hearing through technology. The everyday experiences of young adults and parents are central to this thesis, which demonstrates the significance of technology, medicine, culture, and communication to diverse and creative experiences of deafness.

In exploring the everyday practices of families with deaf children I illustrate how deafness continues to be framed by a binary medical or cultural lens. While some scholars frame deafness as a medical experience that embraces a social imaginary of ‘normal’, this thesis presents a more nuanced view to demonstrate the ways that cultural and creative production of difference and multiplicity are generated through diverse deaf experiences.

Thesis Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

The author acknowledges that copyright of published works contained within the thesis resides with the copyright holder(s) of those works. I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Signed Date

___________________________________ 14/12/2021_________

Claire Elizabeth Harris

Presentations based on this thesis

C. Harris (Nov 2019) *"It's an emotional roller coaster"* Coping with uncertainty in the soundproof booth, for conference session 'Emotional Encounters: Affect and Health Care in the Pacific', organized by Professor Wardlow and Dr. Barbara Andersen. Canadian Anthropology Society and American Anthropological Association Conference, Changing Climates, November 20-24, 2019, Vancouver BC Canada.

Acknowledgements
I will be forever thankful to the many generous people who supported me on this journey especially the parents, carers, and young adults who invited me into their lives and agreed to be involved in this research. I am grateful for your patience in answering endless questions and your willingness to share your experiences and thoughts. I am also indebted to the medical and education professionals who provided me with access to their places of work and who also generously gave their time to respond to interviews and to many follow up conversations – thank you.

My deepest gratitude goes to my supervisors, Dr Susan Hemer and Professor Anna Chur-Hansen, who provided unwavering support and scholarship and generously and wisely guided and encouraged me through the long journey of a PhD – one that intersected with the unexpected and surprising complexities of life. Thank you for keeping me grounded with sage advice as I navigated the world of academia.

I am grateful to my fellow PhD candidates: we weathered the storm and social isolation of a pandemic and somehow came through – thank you for your friendship, humour, and rich conversation. The University of Adelaide Anthropology Department's weekly seminar program has also been a source of collegiality and a refreshing space to share and explore ideas.

I am thankful for the Australian Postgraduate Award scholarship I received to undertake this research, and for financial support from the University of Adelaide in the form of a Walter & Dorothy Duncan Trust grant for assistance with travel to

Canada to present at the 2019 Canadian Anthropology Society and American Anthropological Association Conference, which was held in Vancouver, Canada. It was an inspiration to attend and hear from leading anthropologists from around the world. I am also grateful to the 2016 Family Centred Early Intervention Conference for a parent grant, which assisted with attending the 2016 FCEI in Bad Ischl, Austria.

Finally, heartfelt appreciation to my extended and immediate family for holding the fort when I was absent from home and work, and especially to Angelica, Edwin and Roderick who managed to always ask, ‘how is it going?’ rather than ‘when will you finish?’

I dedicate this thesis to my grandmother Mollie Leitch and to my parents Gwendolyn Leitch Harris and Jeffrey Harris who have always provided love, and insight and fostered a lifelong creative engagement.

Table of Figures

Unless otherwise stated all photographs are by the author

Figure 1: A two-day old infant sleeping in a maternity hospital, undergoes universal newborn hearing screening.

Chapter 1: Introduction

> The art of care therefore is to act without seeking control.
>
> To persist while letting go.
>
> (Mol 2008: 32)

During the first weeks of fieldwork in an Australian capital city, a text message appeared one morning on my mobile phone. It was from Mary, a mother of two young children, who had just learnt that her daughter was deaf. We arranged to meet. She was a bright, engaging woman who talked openly about her hopes and expectations for her child's future. She said,

> I hope for her to be able to fit into her world as much as she possibly can and live as normal a life as possible, would be what we wish for her. So not to miss out on the opportunities that other children have and to be as happy and normal as possible a child, I think. Speech, that's huge I think, just for her to be able to communicate with us, her brother, make friends with people, learn in a way which other children normally learn I think is a hugely important thing for her. Like you say it can be a bit daunting having to make decisions for someone that's life impacting. They've said hearing aids for her should be fine, but you think… Clearly, she needs hearing aids and there's not really any other options apart from if her hearing was to deteriorate for whatever reason. Big decisions, aren't they?

Mary’s comment highlights the tensions and emotions she experienced in making ‘life impacting’ decisions and choices for her daughter. She expressed a desire for what she saw as central to communication - speech - and emphasised what she perceived to be a ‘normal’ life including fitting in at school, family life, connecting and making friends. Mary attributed these possibilities to choosing technology - the hearing aids and to oral language - her family’s method of communication. There was also an awareness of the potential of uncertainty and that her situation might change. Indeed, over time her child’s prognosis was experienced by Mary as increasingly complex and unclear. Clinicians worked to provide a diagnosis and to offer care and advice. Mary experienced a growing sense of confusion and uneasiness about her choices and options. How parents experience deafness including the emotions and tensions around diagnosis, medical uncertainty, and making decisions in a clinical and education context, are the subject of this thesis. I also examine the experiences of young adults with cochlear implants and thus explore intersections of the human with technology and the sensorium.

This ethnographic thesis contributes insights and knowledge about everyday experiences of deafness from the perspective of both parents of deaf children, and young adults with cochlear implants. It explores parents’ experiences and emotional reactions to childhood deafness and their interactions with health and education professionals, which were often contested and ambiguous. Additionally, I probe the experiences of young adults and the significance that technology had in their everyday lives to advance understandings about ways of being deaf and hearing through cochlear implants. While some scholars frame deafness as a medical experience that embraces a social imaginary of ‘normal’, I present a more nuanced view to demonstrate the ways that cultural and creative production of difference and multiplicity are generated through diverse deaf experiences.

I begin with an overview of childhood deafness and a brief description of the fieldwork setting. This is followed by a discussion of the history of deaf services and education and rehabilitation policies that operate within this context. The contribution to the field of study is presented before outlining, in broad terms, the conceptual or analytic lens that underpins this thesis. The last section of the introduction presents the thesis structure and concludes with comments about terminology.

Overview of childhood deafness

Permanent sensorineural hearing loss or deafness is one of the most significant medical issues affecting newborn infants (Parker & Bitner-Glindzics 2015). It is estimated that two to three infants in every thousand births will have a severe hearing loss (Johnston 2006; Mehl & Thomson 1999; Picard 2004; Yoshinaga-Itano et al. 1998). In addition, approximately three children per thousand become deaf due to environmental issues, medical or gestational complications. The World Health Organisation estimates that globally there are 34 million children with a disabling hearing loss, which when left unaddressed impacts a child’s communication and educational progress, their psycho-social development and future employment opportunities (WHO 2009). Genetic factors are attributed with causing almost sixty percent of cases of severe to profound congenital deafness (Dahl et al. 2013; Dillehay

2011; Parker & Bitner-Glindzics 2015). Over ninety percent of deaf children have hearing parents (Roberts et al. 2015). Deafness or hearing loss is classified in several ways according to type: sensorineural, conductive or through a combination of these; according to level or severity of loss from mild to profound; age of onset: pre or post lingual, and aetiology: genetic or environmental including syndromic or non-syndromic; and bilateral or unilateral: one or both ears (Busse et al. 2021; Porter et al. 2021). Hearing loss is measured in decibels, which record sound volume, and across hertz which test pitch or frequency as either mild (0-30db), moderate (30-50db) severe (50-75db) or profound deafness (80-110db) (Smith et al. 2005). A diagnostic hearing test produces an audiogram that plots hearing loss in decibels and hertz (Ross 2004). An audiogram is one part of a myriad of new information to be absorbed by parents. There is a large range of technological assistive listening devices, including hearing aids, cochlear implants and FM systems and the working, daily maintenance and troubleshooting of these must also be comprehended by parents.

The high incidence of hearing parents with deaf children is frequently drawn on to argue that parents enter a foreign territory where severe emotional responses to the diagnosis are common (Bosteels, Hove & Vandenbroeck 2012; Fjord 2001; Flaherty 2015; Gilliver, Ching & Sjahalam-King 2013). A sense of urgency to maximise infant development demands that parents make significant long-term decisions about medical interventions and rehabilitation. Choices about technology and communication options are made in the context of a complicated referral pathway that is shaped by discourses, practices, and the materiality of childhood deafness. Ideas about what is best for a deaf child and their family draw on tensions between what Mol calls a ‘logic of care’ and a ‘logic of choice’ (2008). These are explored further in this study in unpacking the ways that parents experience choices and childhood deafness in socially situated clinical encounters.

Significant developments in the past three decades in childhood deafness include: mainstreaming deaf children in local schools with their hearing peers, the early diagnosis of deafness through universal newborn hearing screening, and since the 1990s, the increasing accessibility and adoption by parents of cochlear implants for their children (Christiansen & Leigh 2010; Leigh et al. 2013). These developments have created major shifts in the ways that deafness is managed clinically and, in the ways that it is experienced by parents and children. The cochlear implant was first embraced by hearing parents of deaf children who began to have their children implanted in the early 1990s when it was passed by the Food and Drug Administration in the USA and by the Australian Medical Board in 1990 for use with children (Blume 2010; Clark 2003; Mauldin 2016). The device attracted significant controversy on ethical and medical grounds. Risk averse medical professionals doubted its efficacy and some people who were deaf rejected the cochlear implant. People who identify as an ethnic or cultural group because of their deafness, shared history, and shared membership of deaf social clubs, and who communicate with signed language, form what is termed Deaf Culture (Ladd 2003, 2007; Lane 1995; Padden & Humphries 2006). This group refused the cochlear implant as it implied their deafness, which they perceived to be their natural way of being, required medical correcting. Furthermore, the cochlear implant, with its possibilities of learning spoken language, was perceived as a threat to sign language and to the maintenance of Deaf Culture (Blume 2010;

Hyde, Punch & Komesaroff 2010). Moreover, Deaf Culture did not view deafness as a disability or as a factor that needed a medical solution.

Growing numbers of severe to profoundly deaf children in industrialised countries receive cochlear implants. Their parents frequently choose intervention services that offer speech only as opposed to bi-lingual or bi-cultural oral and sign language programs or those programs offering a 'total communication' approach.[1] Furthermore, cochlear implants are becoming increasingly available, although, unequally, in developing countries. While the early rejection of the cochlear implant by Deaf Culture retains currency into the present, there is acceptance of the implantable device by some adults and children from within the Deaf community (Paludneviciene & Leigh 2011). Johnston (2006) however, issued a warning that the cochlear implant might substantially contribute to Australian Sign Language becoming an endangered language and a challenge to Deaf Culture. Yet, the contrary may be occurring in Australia. The National Disability Insurance Scheme increased choice and funding for people with disabilities including people who are Deaf. Auslan interpreters are increasingly visible and in demand, which has contributed to the creation of more Auslan teaching courses. For the first time in 2021, the Australian Census included Auslan in the list of language options. Furthermore, scholars and deaf activists have campaigned for Deaf Culture representatives to be in leading roles in paediatric deaf services (Gale et al. 2019). International deaf conferences, including the biennial Family Centred Early Intervention Congress, are supporting these initiatives globally.

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[1] Total communication incorporates all communication strategies in a deaf child's development including sign language, gesture, lip reading, cued speech, finger spelling and spoken language.

Communication options for deaf children within early intervention and school settings are the subject of considerable research often focusing on the underachievement of deaf and hard of hearing children when compared with their hearing peers (Geers 2006, 2009; Marschark et al. 2011) The widespread adoption of cochlear implantation and oral only approaches by parents has been explored across a broad disciplinary scholarship (Hyde, Punch & komesaroff 2010; Friedner 2018, Mauldin 2016; Pfister 2019; Valente & Boldt 2015). Significant disputes about the efficacy of different methodologies or options are often presented as a binary either/or: oral or signed communication (Friedner 2018; Geers et al. 2017; Humphries et al. 2016). International deaf policy developments aim to ameliorate what is perceived as a focus on oral language through advocating for greater bilingual programs, increased recognition of sign language and the employment of adults who are Deaf or hard of hearing in childhood deaf services (Gale et al. 2019).

The ways that parents receive information about deafness in medical and early intervention settings are subject to examination and repeated discussion in literature (Young, Carr & Hunt 2006; Young et al. 2005). Concern that professionals provide information in ways that are impartial prevails (Kecman 2018; Young 2002b, 2010; Young et al. 2005). Cochlear implant practices including age of implantation continue to be controversial and challenged by parents. Age of infant implantation for children who receive a diagnosis of profoundly deaf in the first few weeks or months of life is generally between 9 and 12 months, although in parts of the industrialised world, including parts of Australia, infants are implanted under six months of age. Language and development outcomes of early implanted infants are the subject of significant health research (Ching et al. 2009, 2013; Dettman et al. 2007, 2021). How parents navigate and experience these multi layered, sometimes confusing, often contested ideas that operate within this space, and the ways they negotiate and advocate for their child, are the subject of this thesis. I seek to extend knowledge and understandings about how parents and young adults experience deafness.

Variable language and developmental outcomes for children with cochlear implants have drawn attention to the education options and choice for deaf children (Marshark et al. 2011; Garate 2011; Geers et al. 2017, 2006; Paludneviciene & Leigh 2011). Arguments about the development of deaf children’s language or communication are often subject to debate and draw on concepts about auditory and visual input in the development of language. The oral only approach, often called auditory-verbal or listening and spoken language therapy, argues that auditory neural pathways demand early reinforcing through exposure to audition only (Estabrooks, MacIver-Lux & Rhoades 2016; Flexer 2011). The infant is trained to listen, and visual input is discouraged. Alternatively, visual input through the development of signed language, is argued as beneficial to the child’s language development and a way of avoiding or mitigating infant linguistic neglect by preventing access to sign language from birth. Bilingualism, the simultaneous learning of sign and oral language, or signed language and written language, is promoted by those who argue that deaf children born to hearing parents are especially at risk of language deprivation. These discussions and debates are found in medical, deaf education and Deaf studies literature (Geers, 2006; Geers et al. 2009, 2017; Hyde, Punch & Komesaroff 2010; Knoors & Marsharck 2012).

The field site

In the fieldwork site everyday practices in paediatric deafness reflect international consensus statements about best practice, and World Health Organisation guidelines on paediatric ear health. Universal newborn hearing screening (UNHS) was established in 2004 and is carried out on 97% of infants born in this part of Australia. Before the implementation of newborn screening, children's hearing loss was often not diagnosed until a child was two or three years of age. Late diagnosis was attributed with causing long term, often irreversible delays in a child's language and other developmental milestones (Yoshinaga-Itano et al., 1998, 2017). Maternal guilt was ubiquitous as were stories about doctors not listening to parental concerns about a child's lack of speech or their unusual behaviour. The implementation of universal newborn hearing screening across industrialised western countries drew on the results of a ten-year research project held in Denver Colorado (Mehl & Thomson 1999). The window of developmental opportunity focused on ensuring that by the first six months of age a hearing screen, diagnostic test, fitting of hearing aids and family engagement with early intervention with teachers of the deaf had been undertaken.

Debates about interventions and options for deaf children are found in a broad literature as I have discussed above. They were regular topics of conversations within the field site amongst parents, and education and medical professionals. Clinical researchers and teachers of the deaf have illustrated how children who are deaf, unlike their hearing peers, do not develop language incidentally as they are not able to hear over distance or in background noise (Rhoades & Duncan 2010). They require explicit one-on-one teaching to develop listening skills, which endorse a focus on neuroplasticity and the notion of a ‘listening’ brain (Geers 2006; Mauldin 2016). The importance of early diagnosis and the stimulation or bedding down of auditory neural pathways was recognised. Discussions about neuroplasticity and potential language neglect caused by late diagnosis have been drawn on in debates about deaf children’s language acquisition. Those advocating for oral language argued that the child should only be exposed to listening and developing oral speech. Advocates for sign language pointed out that the visual areas of the brain supported the auditory pathways (Lyness et al. 2013; Nishumura et al. 1999; Ozyurek & Woll 2019).

In the fieldwork setting on average each year two to three babies per thousand live births are diagnosed with a significant hearing loss often within the first weeks of life. Each year, several other children are diagnosed deaf due to infection, illness, or ototoxic drugs, bringing the average number of children with a hearing loss up to three or four per thousand. Indigenous children have a significantly higher incidence of conductive hearing loss due to chronic otitis media or middle ear disease, which if left untreated can lead to irreversible deafness. Approximately 40% of children who are deaf have co-morbidities: syndromes or medical issues that complicate experiences (*Still waiting to be heard Report on the Inquiry into the Hearing Health and Wellbeing of Australia* 2017). Infants with a hearing loss enter a complex medical and rehabilitation referral network, and those who are diagnosed with a severe to profound hearing loss are referred to a state-run cochlear implant clinic. Parents engage with early intervention services that are staffed by teachers of the deaf, speech pathologists or listening and spoken language specialists who develop oral and/ or signed communication in children who are deaf. In the field site there were three main early intervention organisations: the government-run Hudson Centre, and two non-government organisations that are funded by philanthropic and government funding: The Children's Centre and Bright House[2].

The process of referring families into early intervention was framed as impartial and unbiased by medical professionals with no single service, communication, or teaching methodology, valued over another. However, for many years this process has been perceived as contentious, and shaped by gatekeepers, agendas, and opinion. Much of this gatekeeping centred on concepts of best practice, and what was 'best' for a deaf child and their family. Contested ideas about intervention included whether children should be taught to listen and speak only through audition, or taught sign language and speech, or a combination of lip reading, signed language, speech, and sign supported English. Gatekeeping and tensions within the field were also about responsibilities and capabilities for certain tests, assessments, provision of hearing aids, and about cochlear implant protocols such as age of implantation. These tensions reflect a history of debate about the response to deafness both locally and globally.

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[2] Please note, the names of all participants, and of the organisations that were involved in this research, have been given pseudonyms.

Scholars including Humphries and Humphries (2011); Ladd (2003) and Lane (1989, 2005) have documented a history of discrimination against people who were deaf and presented autobiographical accounts that highlight ideological and methodological battles fought over communication and education. Children were taught through tenuous methods that were experimental or had little proven efficacy including lip reading, cued speech, touch to feel the vibration of speech, blowing onto balloons to imitate certain hard to hear sounds such as ‘p’. At the same time sign language was discouraged.

History of deaf services and education policies in the State

Residential teaching institutions for the deaf were established in industrialised countries in the mid-19th century. The first moves towards educating the deaf in the Australian fieldwork site were by philanthropists and members of parliament after an 1872 bill was passed in the House of Assembly. In 1874 the State Institution for the Blind and Deaf and Dumb was established on 24 acres of land in a seaside suburb. Adults and children were initially educated together in this imposing, residential school, but children boarded and were looked after by a house mother. Children here, like in other parts of the industrialised world, were taught with a range of methods, as described above, including lip reading, sign language, and an oral approach. There was a process of experimenting and trialling different teaching and communication methods (Barkham 1974; Hutchins & Hutchins 1995). Many of these children, as with children today, came from hearing families, and many who are still alive have mixed or negative memories of their school experiences. The desire to normalise the deaf body through the acquisition of spoken language often caused tension. Technology was rudimentary with group hearing aids used in classrooms, and later individual, large body-worn devices that offered minimal access to sound. In 1949 the Institute for the Deaf and Dumb was renamed Hudson House, as terms like 'deaf and dumb' were phased out.

Figure 2: Side of the imposing Institute for the Blind and Deaf and Dumb: children with staff. (Photographer unknown, State Library of South Australia, B 3102).

Figure 3: The Deaf and Dumb Mission, this three-storey redbrick building was opened in the city in 1928 to support adults who were deaf.

In 1945, 70 years after the asylum had been established, a group of women founded The Children's Centre in reaction to the institutionalisation of children who were deaf. Most of these women had given birth during the 1940s rubella outbreaks, to 'rubella babies' whose hearing and vision was affected by maternal German measles acquired during pregnancy. The Children's Centre established itself first in a disused church hall before finding a more permanent site through the purchase of a domestic dwelling.

This architectural choice reflects the search for a space that was more 'home like' as an alternative to the practice of removing and institutionalising children and was the impetus to developing a program of 'oralism' where children were taught to speak (Hutchins & Hutchins 1995).

Figure 4: In 1946, mothers of deaf children established The Children's Centre in a suburban house as an alternative to institutionalised care. (Photographer J Hutchins, To Hear is to Speak, 1995).

International education policies and practices were sought by both The Children's Centre and Hudson House who either invited deaf educators to Australia or sent staff overseas to learn about new teaching methods. The Children's Centre was led by 'pioneering' women who were also mothers of deaf children and several of them trained to be teachers of the deaf. Their focus was on encouraging deaf children to wear hearing aids and to develop speech. In 1948 Helen Keller, American author, and campaigner for people with disabilities and herself deaf and blind, travelled to Australia and visited organisations to understand how deaf children were being taught; she advocated equity in government funding for schools for children who were deaf and greater cooperation between services for deaf and blind children (The Advertiser 1948). Hearing parents wanted their children to acquire spoken language, but the technology that might diagnose deafness or enable a person who was profoundly deaf to access sound and acquire speech, was limited. In the 1950s the state government Education Department reviewed deaf services and then established their own program. Sign language was taught intermittently by all but The Children's Centre and was not officially recognised as a legitimate language by the Australian Government until a 1987 white paper included it in the languages of Australia (Bianco 1987). Historically there was opposition between Hudson House and The Children's Centre's teaching methodologies, and competition and tension between the three early intervention organisations continues into the present day and was evident during fieldwork. The government run program exists into the present and in 2016 it began the roll out of a bicultural/bilingual early intervention, pre-school, and school service. Historically trial and error in teaching methodology was experienced by many children, as was explained to me during a commemorative event held for one deaf organisation, by a past student, who said 'we were made to sit on our hands' to prevent communication in sign language.

During the 1950s, 60s and 70s children were educated in separate schools for the deaf. Some schools maintained separate units for deaf or disabled children through a process of partial inclusion. Circumstances began to change with when disability discrimination acts were slowly legislated through Australian state parliaments in the late 1980s. In 1992 the Commonwealth Government of Australia passed into legislation the Disability Discrimination Act (AHRC 1992). Children with disabilities could no longer be discriminated against and schools could not deny their enrolment. Children were no longer restricted to ‘special’ education settings; all children, abled or differently abled, were entitled to enrol at their local school. These changes were welcome but families with deaf or disabled children continued to fight for equity and access within schools often needing to negotiate specific education and access plans for their children.

Terminology

The ways we think and talk about deafness and the ways people are represented is evident in the shifting terminology applied to the deaf body (Tremain 2005) and what is considered morally right or appropriate for that body (Berger 2010). Terminology about deafness and deaf people has changed over time as ideas and concepts about disability and deafness fluctuate (Padden & Humphries 2006; Senghan & Monaghan 2002). Terms and labels are contingent and socially situated. The language used to describe or categorise people who are deaf has included: deaf and dumb, hearing impaired, hard of hearing, Deaf, deaf, and hearing loss. Until recently, in Australia, ‘hearing impaired’ was generally applied to children and adults who had a hearing loss, but this went out of favour due to an association of ‘impaired’ with broken or damaged. The term ‘hearing loss’ is perceived by some people as problematic because it suggests hearing that is lost or absent, and so again implies a sense that needs fixing. The current preferred terminology is ‘Deaf or Hard of Hearing’ (D/HH) (Bauman & Murray 2012) with the capitalised ‘D’ in deaf referring to Deaf Culture; although in the fieldwork site both parents and professionals employed the term ‘hearing impaired’, hearing loss and small ‘d’ deaf. Parents often used the term ‘profoundly deaf’ when speaking about their child with a cochlear implant.

In this thesis I use the term, Deaf and hard of hearing (DHH), but this can be problematic through the association of ‘Deaf’ in uppercase with people who are signing deaf and the rejection by many parents of the term ‘hard of hearing’. Many research participants included in this study used the term ‘deaf’ when speaking about themselves or their children, although they were not sign language users nor did they associate with Deaf Culture. Some parents of children who are ‘profoundly’ deaf reject ‘hard of hearing’ because they say their child’s hearing does not exist; they are ‘deaf’. During fieldwork, different kinds of professionals made comments about deaf terminology and argued over what were the right terms to use. Specific terms were cited as ‘politically incorrect’ and others as ‘old fashioned’. When writing about people who are deaf and have cochlear implants, I use the term ‘deaf’, which mirrors the language used by research participants, and when writing about people who, through language and culture, identify as ‘Deaf’ then this term, or Deaf community or Deaf Culture is employed.

Contribution to the field

Anthropological focus on childhood deafness has been limited. Furthermore, the experiences of parents in deaf clinical and early intervention settings in an Australian context have had minimal anthropological attention. Anthropological studies of families with deaf children have often been based in cultures in the global south that have very different health care contexts to Australian settings. These studies are marked by a context with often unequal access to health care, hearing aids or cochlear implants and restricted education options. Moreover, there have been limited studies in anthropological literature on how parents experience the navigation of clinical assemblages of care in making choices about whether their children should get a cochlear implant or learn to speak or sign. This study contributes to scholarship through analysis of data collected from a broad and wide-ranging multi sited field. Experiences of young adults who are deaf and have cochlear implants have also been given inadequate consideration. This study explores the lived experience of a group of young adults with cochlear implants and provides insights into the culturally rich and embodied experiences of a life lived through technology as both a hearing and a deaf person. There has been considerable research in deaf education studies, medicine, and allied health on parents' reactions to their child's diagnosis of deafness, on rehabilitation processes, and in choices and decision making about biomedical interventions, technology, and communication options. Furthermore, deafness is highly politicized, and to paraphrase Foucault (1989) the (deaf) body is imprinted by history. This research furthers understandings of the experiences and significance of deafness for parents and young people and the professionals who work with them. With the increasing global proliferation of the cochlear implant, further research is important to understand the ways these experiences generate meaning and value across different contexts.

This thesis contributes to scholarship that explores deaf ontologies through the intersection and interaction of the senses, emotions, and space through a sensory and emotionally engaged ethnographic consideration of the social practices and experiences of families with deaf children, many of whom have cochlear implants, and young adults with cochlear implants. It contributes a deeper, nuanced insight into the significance and meanings embedded in deafness for families and for young adults with cochlear implants. It contributes understandings about the experiences of parents who embrace and value diverse notions of what it is to be deaf. It does this through untangling the connections and meanings embedded in deafness and articulated through sensory, spatial, and emotional experiences. The result is this thesis, which contributes to the literature about disability and deafness and offers an alternative to the binary cultural and medical models of deafness often found in literature about people who are deaf. It proposes recommendations for health and education services and responds to the call for more studies on people's experiences with cochlear implants (Friedner & Kusters 2020; Lloyd & Bonventre 2021; Mauldin 2016). It contributes to the small number of studies on deaf people's experiences of the cochlear implant to track a group of people who were amongst the first children in Australia to be implanted.

Experiences of deafness - a phenomenological lens

To analyse the experiences of parents and young adults this thesis draws on phenomenology to explore the connections between experience, the senses, emotions, and time, space, and place. Phenomenology's central focus is the workings of human consciousness including perception, experience, memory, and embodiment, or to put it another way, phenomenology is the 'scientific study of experience … an attempt to describe human consciousness in its lived immediacy' (Jackson 1996: 2).

While Husserl argued for an intentional consciousness which described the object of consciousness as being constituted through perception, memory, and signification, Merleau-Ponty extended this notion and emphasised perception as a bodily process. The body becomes the primary site through which our understanding and knowledge of the world is constituted, and processes of perception cannot be disentangled from the body; hence his ontology of the ‘flesh world’ (Merleau-Ponty 1962; Sallis 1981). The cartesian division of mind and body is refuted through the concept of a lived body that is in a continuous experiential state through the joining of consciousness with the physical or mechanical body. The notion of an experiential lived body is drawn on as a frame with which to explore everyday lived experiences or what Kleinman calls the ‘microcontexts of daily life’ (1995: 123). Emphasising lived experience through the domain of the everyday lifeworld focuses our attention on understanding the ways people experience and conceive of the world. Jackson’s radical empiricism offers a way to think about everyday lived experiences and the reciprocal relationship between how the self is both produced and experienced in relation to the ethnographic enterprise and in relation to the social practices, language, ideas, and objects with which they interact, which is important in considering deaf experiences.

Interlocutors’ experiences of deafness were complex, layered, and interwoven with themes that also centred on tensions, or what I call ‘the politics of deafness’. These concepts weave through this thesis. It became clear that any lens applied to this rich and multifaceted ethnography would also be multi layered and draw from a body of literature in addition to phenomenology. To untangle the politics and assumptions about deafness that are embedded in the field, I refer to the anthropology of medicine and disability including Foucault’s concepts of the body and governmentality (1978, 1989, 2001). Foucault’s theories about the body are a useful analytic as they conceptualize the ways that the body is measured, surveyed, disciplined, controlled, and normalised. This is described in more detail in Chapter Two in the discussion on key debates and models in deafness.

While my initial research interest centred on peoples’ experiences of deafness, and their navigation of structurally complex assemblages of care, during fieldwork the place and role of emotion became a central consideration. This led to reflecting on the ways that emotion was mediated and structured by time, space, and the senses, in specific clinical sites. In a similar way, while I intended to look at young adults’ experiences of deafness and cochlear implants through decisions made for them by their parents, I was drawn to their significant sensory and embodied explorations of living in and through technology and a window opened into a complex, non-binary experience of deafness and technology. In the next section I will look at the senses, emotions, and space and time as each of these offered a valuable lens with which to analyse interlocutors’ experiences and their narratives.

The senses

The anthropology of the senses ‘grows out of the interest in bodily modes of knowing’, (Howes 1991: 3), and in conceptual ideas about how we perceive the world (Merleau-Ponty 1961). This resonates with my examination of the complex and sometimes surprising, embodied experiences of deafness that offers a critical analysis and alternative to the mind body duality and the medical-cultural binary that is found in academic literature. While ‘one of deaf studies’ central projects has been to foreground visuality’ (Freidner & Kuster 2020: 39), this focus has ‘sidelined diverse deaf experiences such as those of deaf blind people including those involved in the protactile movement’ (39). This thesis takes as its departure that sight or hearing are privileged ways of knowing (2020), to explore a more complex and deeper significance of meaning through understanding the senses as interconnected and integrated in human perception. Our senses are intrinsically connected also with reciprocal neurological processes, and this is drawn on in analysing embodied experiences of deafness and cochlear implant technology. Sarah Pink (2010) points to neurology research, which has argued that conceptions of different sensing processes being attached to specific sense organs should be replaced by understandings of the senses as interconnected in human perception. ‘The five senses do not travel along separate channels but interact to a degree few scientists would have believed only a decade ago’ (Cytowic 2010: 46). This resonates with therapeutic practices witnessed during fieldwork where attention was paid to developing the (deaf) child’s sensory integration, seen to be interrupted by the absence of the sense of hearing, or by the presence of other sensory conditions, for example, autism.

Furthermore, while anthropology has been concerned with embodiment and the senses, and emotions, space, and place, Dundon and Hemer (2016) argue they are not often explored together. Considering how these elements are mutually constitutive is foundational to a consideration of lived experience in clinical and early intervention spaces that both evoke and constrain the senses and emotions: ‘space is composed through the senses and emotion’ (2016: 15).

This thesis works with the concept that the senses are socially constituted (Hochschild 1979, 2012; Howes 1991, 2003, 2006) and that the ethnographer should be alert to our own sensory experiences during fieldwork (Harris & Guillemin 2012; Rice 2013). Attention to the senses enables a reciprocal or dialectical relationship between observed and observer, and this is valuable in participatory fieldwork that is taken up with a sensory phenomenon of deafness and hearing. Furthermore, our perception of the world and the ways we find meaning in our experiences of that perception, is embodied and involves multiple senses integrating together. With the commonly understood senses of smell, touch, sight, hearing, and taste are other significations including the sense of balance: equilibrioception, the sense of direction: magnetoreception, and the sense of one's body in space: proprioception (Valente, Bahan & Bauman 2011). Interpretation of the senses change over time and are contingent on cultural interpretations; they entwine with emotions and with memory and perception.

Emotion

Anthropology affords valuable ways to think through emotion and the ways that emotion is conceptualised, experienced, and socially articulated (Beatty 2014; Dundon & Hemer 2016; Lutz & Abu-Lughod 1990; Lutz 1988, 2017; Wikan 1990). Anthropology's emotional turn in the 1990s led to a proliferation of works that questioned cultural assumptions about emotion and in particular westernised notions that perceived emotion as opposite to rational thought. Emotion and affect are socially produced, and Lutz states the concept of 'emotion has ideological functions, that is, it exists in a system of power relations and plays a role in maintaining it' (2002: 101).

Central to this thesis are the ways that emotion is understood within biomedical clinical encounters. Emotion, as an analytic and subject of research, provides a useful frame to refocus thinking about experiences in medical encounters. Reflecting on the ways that emotion is evoked and constrained through temporal and spatial considerations in the clinic threads through this thesis. An anthropology of the senses and emotion, broadly speaking a post structuralist phenomenology, combined with an analytic framework about time, space and emotion through the work of Dundon and Hemer (2016), Lutz (1998, 2002, 2017), Trigg (2016) and Tuan (1977) are drawn on throughout this thesis. A body of scholarly literature about the anthropology of emotions provides a lens to analyse the gendered construction of emotion particularly as applied to women with infants in clinical settings. Dundon and Hemer (2016) clearly articulate how emotion is both conjured and restrained in social settings and in a clinical context, parents' emotions including hope, anxiety, frustration, and worry are bound with a medical experience. Emotions emerge through a fluid and complex interrelation and experience of space, time, and place (Dundon & Hemer 2016; Hochschild 1979; Tuan 1977; Waltz 2016). In this thesis I demonstrate that while the cartesian dichotomy of mind and body structures emotion through several clear rubrics: affect and cognition, passion, and reason, feeling and thinking, and female as to male; in reality emotion works with logical thought and reasoning. Trigg (2016), and Tuan's (1977) notions about affect and space, and topophilia and topophobia are also significant in disentangling the intersection of emotion, time and space and the meaning generated in the clinical space.

Space and time

Socio spatial and temporal theories are valuable frameworks with which to probe and analyse parents' experiences and reactions to their child's diagnosis in a medical context. In the clinic, time and space inextricably link in specific ways to generate emotions and affect. Temporality, and the notion that timing is of significance clinically, developmentally, and cognitively, abound in this field. Parents' navigation of clinical and early intervention deaf spaces is examined. Taken for granted assumptions about everyday practices in deafness, including the ways that time and space shape experiences in deaf worlds, are untangled. Literature that analyses the dynamic and productive relationship between affect and spatial-temporal relations (Dundon & Hemer 2016; Hochschild 1979; Trigg 2016; Tuan 1977) underpin this thesis and illustrate how clinical spaces are both socially produced and productive of social relations. Socio-temporal connections and disconnections between the senses, emotions, place, and space are analysed to consider the ways these afford connections between people, and how they generate meaning in deaf experiences.

Thesis structure

This research is presented as a thesis by publication. Accordingly, the thesis opens with Chapter 1, an introduction that outlines the main argument and sets the scene and historical background. It also presents the thesis contribution and the theoretical framework and structure of the thesis. Chapter 2 provides a discussion of the key debates and models in deafness. I review key literature on deafness and discuss where this study is placed within that literature. This is followed, in Chapter 3, by a discussion of research methodology, positioning and reflexivity. The next section includes four articles (Chapters 4, 5, 6 and 7) that have been published or submitted for publication to peer reviewed, high ranked journals. The final chapter (8) presents a discussion of findings with concluding remarks and suggestions for further research.

Chapter Two situates the thesis conceptually and presents an overview of the key debates within deafness. Literature from social sciences including anthropology, disability, education and deaf studies, and health sciences, are drawn on to examine the social, cultural, and medical models of deafness. I show how understandings of these models shape experiences of deafness from reactions to diagnosis and ideas about communication and neural plasticity, to processes of decision making and embodiment through an intersection of technology and the senses. I consider literature in the anthropology of deafness with a focus on families with deaf children, seeking diagnosis and treatment plans and decision making and on deafness and cochlear implants.

Chapter Three outlines the methodological approach undertaken in this study, which included participant observation in a multi sited field. The study plan was to ‘follow the baby’ from diagnosis as the intention was to observe this world from the perspective of parents and families as they first engaged with deaf service providers and the people who work within these organisations. Due to delays and initial difficulties in meeting parents at or just after diagnosis, participant observation was undertaken in a variety of clinical and early intervention education sites. Participant observation occurred in blocks of time at different organisations and dispersed across time and place as I followed the complex navigations of families.

Chapter Four comprises an article titled *Emotion as Motivator: Parents, professionals and diagnosing childhood deafness* that was published in 'Medical Anthropology' in July 2020. The article examines emotion in health care encounters through parents' and professionals' reactions to the diagnosis of deafness in infants. It examines the ways that emotion is framed through a gendered cartesian lens which has significant implications in the diagnostic encounter. Recommendations are made for health professionals and for increased use of non-medical spaces in the management and treatment of childhood deafness.

Chapter Five is a published article titled *'It's an emotional rollercoaster' the spatial and temporal structuring of affect in diagnosing childhood hearing loss.* This article was published in August 2020 in 'Emotion Space and Society'. It considers uncertainty in the diagnostic context and addresses the tensions between diagnostic testing that does not provide a clear diagnosis as experienced by parents and professionals. Drawing on socio-spatial and temporal theories the clinical waiting room and soundproof booth of a paediatric hearing clinic are conceptualized as affective spacio-temporal places.

Chapter Six consists of an article titled *Informed choice and unbiased support: parents' experiences of decision-making in paediatric deafness* that was published in

December 2021 in ‘Social Science and Medicine Qualitative Research in Health’. This article examines parents’ navigation and decision making following a child’s diagnosis. It draws on Mol’s (2010) analysis of choice and care in medical settings and argues that the process of providing information and referral advice is socially situated. In this context, tensions between the rhetoric and everyday practices of informed choice and best practice effectively exacerbate anxieties for parents. It calls for greater transparency in information and service provision, and an acknowledgement from professionals that deafness is replete with contested ideas.

Chapter Seven comprises the fourth article, which was submitted in August 2020 to ‘Body and Society’. It is called *‘Sensing Technology: experiencing deafness and hearing through cochlear implants’*. The paper was revised following peer review by three readers and was resubmitted in December 2021. This article presents a nuanced view of the experience of having a cochlear implant through qualitative interviews and participant observation with young adult cochlear implant recipients and their parents. The paper posits that rather than being perceived as a means of ‘normalising’ deaf people by removing deafness, the device is a conduit to embodied, sensory experiences that embrace both deafness and hearing. This breaks with the binary medical or cultural model of deafness to offer a holistic and thoughtful insight into experiencing life through technology and celebrating opportunities for connection and entrancement with sound and with silence affording new understanding of deaf experiences.

Chapter Eight contains concluding remarks about parents' experiences of childhood deafness noting that these are often confounded by the complexities and politicised nature of the field. Recommendations are made about the ways that professionals working in the field communicate with parents specifically addressing language and terminology so that there is greater clarity and transparency. Suggestions are also made about clinical spaces and the provision of services in non-medical settings that are more familiar to parents. A greater focus on the role of parents in both medical and education services, including increased parent to parent supports are recommended. Many parents seek out families with children like their own. While certain groups within 'deaf worlds' have specific foci on the ways childhood deaf services are shaped these may be more self-serving than addressing the needs of parents with young children. Finally, there is a call for further co-designed research to be undertaken with young adults who have cochlear implants and families with deaf children.

Chapter 2: Key Debates and Models in Deafness

> At its most basic, the recognition of disability as a universal social fact helps us to understand the cultural specificities of personhood and to reconsider the unstable boundaries of the category of the human.
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> (Ginsburg and Rapp 2020: 4)

Introduction

In this chapter I draw on literature across the fields of social sciences, deaf studies, and health and education studies that has been produced about, or by, people who are deaf to analyse the key debates in deafness. It begins by introducing concepts of disability and the ways that deafness is framed in relation to these concepts. This is followed by a discussion of how deafness has been defined according to a medical, cultural, or social model demonstrating that this has often been an either-or lens of culture or medicine. Following this is an examination of how the scientific concept about the brain, neuroplasticity, has been drawn on in critical debates about deaf children and used, I argue, to further the medical and binary modelling of deafness. Concepts about the 'listening brain' and neuroplasticity, and the consequent emergence of discourses about timely interventions and diagnosis are examined to shed light on parents' experiences of childhood deafness and on young adults' everyday practices of living with a cochlear implant. The discussion turns next to the technological interventions that have been developed for deaf children including most notably the surgically embedded cochlear implant. Acknowledging that the cochlear implant was initially embraced by parents of deaf children, I consider clinical and anthropological literature about young adults and their everyday practices through this technology to critique dominant assumptions in deafness that constructs the cochlear implant as a normative exercise in erasing deafness. Finally, I examine the polarised communication and language debates in childhood deafness which encompass concepts about what is best for a deaf child including in early intervention and education practices. These concepts and debates have been shaped in recent decades by a growing deaf activism, an increased recognition of sign languages, and by ongoing biomedical developments including the cochlear implant.

While this thesis is framed by phenomenological analysis, it also draws on the scholarly work of Lock and Nguyen (2018), Foucault (1978, 1989, 2001) and Rose (2007) who offer ways to consider how biomedical technologies and 'their application brings about radical changes, not merely with respect to individual bodies but in society at large' (Lock & Ngyen 2010: 4). A body of literature from the anthropology of deafness is drawn on to think through the challenge deafness poses to disability and importantly as a way to unpack the ubiquitous and reductive medical-culture binary that is found in deafness. I probe how the deaf body is culturally or discursively structured and created in interaction, socially and with biomedical technologies of governance. Foucault's conception of power, as an element that is dispersed through social situations and networks as opposed to a force exerted by one individual over another, is a useful analytic in considering how deafness is constructed and experienced in clinical spaces. Power works through complex networks and prescriptive technologies of bodily governance (Foucault 1978: 141). The (deaf) body is imprinted by history and deaf experiences are shaped by shifting historical and socio-cultural contexts. Furthermore, drawing on Rose's analysis that biomedical technologies have histories and that their 'application changes what it is to be human' provides ways to consider how biopower works through bodies to offer ways of untangling the human, biological, natural, and cultural binaries (Lock & Nguyen 2018: 23; Rose 2007). Moreover, 'technologies should be understood as both produced through culture and as productive of culture' (2018: 23), which is particularly relevant in considering both everyday practices in deafness and the lived experiences of parents and young adults who are deaf.

Disability and deafness

Disability has historically been the province of medicine, but as an intrinsic feature of all human life produced through birth, and through processes of aging, disease, accident, war, and industrial pollutants, disability is worthy of greater scholarly focus (Ginsburg & Rapp 2020). Human difference is acknowledged to be relational, variable, and distinctly shaped by sociocultural contexts. This thesis is framed by a lens that acknowledges disability as a human variation of 'the normal condition of humanity' (Sutherland 1981: 18), with socially produced meanings that are subject to scholarly debate and discussion more broadly in society. Underpinning this is an understanding that, 'increasingly, researchers are focusing on social political and narrative strategies that address the experience of disability within the production, reproduction, and transformation of broader forms of social inequality' (Ginsburg & Rapp 2013: 53). Furthermore, Rapp and Ginsburg encourage academics, including anthropologists, to acknowledge 'public story telling' from families and individuals living with difference

(2001: 537). These narratives may be shared on social media platforms, in podcasts, documentaries and autobiographies or on talk shows, and they are,

> crucial to expanding what we call the social fund of knowledge about disability. In opening up the experiential epistemology of disability, as shaped by and shaping the intimate world of nonnormative family life, such forms of public culture widen the space of possibility in which relationships can be imagined and resources claimed. (Rapp and Ginsburg 2001: 537)

The scholarship developed by Ginsburg and Rapp is framed by their personal experiences as parents of children with disabilities. Their concept of a 'kinship imaginary' suggests that families, rather than narrating an experience of suffering, reframe their lives in all kinds of quotidian practices and experiences of family life around sharing food, schooling, employment, communication, and in parental transformations in taking on advocacy roles on behalf of their, and other people's, children. Seeking deeper understandings and acceptance of human variability offers ways to mitigate a persistent 'othering' of people with disability. It raises a challenge to the notion of 'normal' and to that of 'diversity', which is increasingly discussed in social science and disability scholarship and more broadly in society. The terms 'normal' and 'normality' entered the English language in the mid 19th century and Davis has noted that the construction of normality acted to create the 'problem' of disability (2016: 3).

The challenge of deafness to disability scholars has also been documented: many people in Deaf communities reject the notion that to be deaf is to be disabled. 'Not only are these debates, like many questions raised around disability categories, significant in and of themselves; they also are epistemologically challenging to anthropology's theoretical engagement with the question of culture' (Ginsburg & Rapp 2013: 60). In their seminal article, anthropologists Senghas and Monaghan (2002) identify and question the lens of deficiency that had routinely been applied to deaf people: 'deafness is not merely the lack of hearing' (2002: 69). Accordingly, they argued that deaf people have been treated as problematic by hearing people, and that until the 1980s, scholarly literature usually focused on deafness as pathology and sought cures or ways to mitigate the perceived handicap. In this way deafness was framed through a medical lens.

Medical, cultural, and social models of deafness

One prevailing way that deafness has been interpreted is through a medical lens that sees deafness as a human deficit requiring attention. The medical lens is routinely applied to newborn infants especially in the context of the global north, but for people with disabilities medical interventions are seen as a normalizing mechanism so that individuals with difference will be accepted into society. Foucault traces the emergence of clinical medicine through a focus on the human body as both the site of disease and the location for the articulation of social relationships and power (1989). He takes this further with his concept of biopolitics (1978, 1989) which refers to the ways that the state administers or controls both individuals and human populations. In the late 18th and 19th century deaf individuals were often incarcerated within lunatic and pauper asylums (Lock & Ngyuen 2018) until specific institutions for the deaf were established to educate and train, thus transforming the deaf into useful citizens (Berger 2010; Tremain 2005).

More recently deafness has been viewed as a problem to be ameliorated through medical technologies and rehabilitative interventions. There is a consensus among many social scientists and deaf studies scholars that viewing deafness through a frame of deficiency is in effect presenting a medical model of this sensory phenomenon (Bosteels, Van Hove & Vandenbroeck 2012; Friedner 2018; Fjord 2001; Huiracocha et al 2015; Ladd 2007; Mauldin 2016; Padden & Humphries 2006; Pfister & Vindrola-Padros 2018; Young 2018). Much current literature on deafness pays particular attention to medical and social models of disability, concepts that have historically dominated the scholarship. The medical perspective has given rise to binary and often polemical debates about deaf experiences. Mauldin, for example, states ‘tensions over whether deafness is a medical problem in the first place play out in parents’ lives’ (2016: 5). She suggests that parents of deaf children adopt a certain script of deafness and that the centrality of the brain in all interventions is the most ‘significant feature of the scripts regarding deafness that parents adopt’ (5) which map onto the gendered patterns of care with mothers carrying most of this burden of care.

The social model, found in disability studies, deaf studies, and social science literature, offers an alternative to the medicalisation of disability through highlighting the social and environmental barriers that shape or restrict individuals’ access. The social model focuses on the prejudice and stigma experienced by people, and the communication, physical or architectural barriers that impact people’s full participation in society (Ginsburg & Rapp 2020; Shakespeare 2006, 2013; Shakespeare and Watson 2001). As Shakespeare noted, the ‘social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits’ (2006: 199). In this model, impairment is conceptualised not as individually situated or private, but as structural and therefore public. Feminist scholars have challenged this dichotomy as it suggests that the impairment is irrelevant to an individual’s experience or everyday life (French 1993; Morris 1991). The social model, as defined by Shakespeare, is further complicated by attempts at improving impairments or to put it another way, ubiquitous medical experiences, which may frame the person with a disability within a medical category.

A third, cultural model, redefined the ways that deaf people were conceptualised through identifying a culturally, linguistically diverse community described through shared use of sign language and a mutual cultural history or ‘Deaf-World’ (Lane 1995: 179). This cultural-linguistic model, emerging through the 1970s and 80s disability and deaf rights activism, took inspiration from the civil rights movement (Blume 2010; Sacks 1989). Deaf Culture is valued as an alternative to the medical framing of deafness and to offer a counter discourse to that of medicalizations (1995). It is applied to a group of deaf people who carved out their own identity separate from ideas about disability including medical models of difference or deficit. Terminology, as I discussed in the Introduction, captures this identification through use of the capitalised ‘D’eaf, as in Deaf Culture, and other controversial terms, for example deafnicity (Richard 2010). Deaf Culture rejects the idea that deafness is disabling and instead views the absence of hearing through a cultural lens. This incorporates cultural or ethnic identity through language, history, and communal social, education and sporting networks including the Deaf Olympics. Deaf people are seen as having their own distinct social organisation and visual language as ‘the people of the eye’ (Lane et al. 2011). Deaf Culture increasingly demands this terminology be applied alongside the term disability indicating that they may share disability space but carve out a place of difference. Charitable funds and arts events for people with disability increasingly employ ‘Deaf and disabled’ in their nomenclature. Cultural identity is extended further through the concept of ‘deaf gain’: whereby deaf people have unique and significant contributions to cultural life (Bauman & Murray 2012; Ladd 2003; Edwards 2012). However, in considering Deaf Culture, Friedner & Kusters (2020) have questioned the idea of ‘deaf-same’ and cautioned against the concept that all deaf people share an innate similitude or a potential for equivalence. It is worth noting that the social model is drawn on by Deaf people in their on-going access battles to include captions in cinemas and sign language interpreters on television news services and other public events.[3]

Senghan and Monaghan state, ‘Perhaps it is unfortunate that these two contrasting models have been denoted as medical vs. cultural because clearly the medical model is one particular cultural model’ (2002: 77). I take this as a departure point in unravelling the medical-cultural binary, which at the very least is a reductive analytic. This binary is ubiquitous in scholarly literature. Moreover, social media platforms

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[3] The Australian Human Rights and Equal Opportunities Commission’s received a complaint under the 1992 Disability Discrimination Act which resulted in the 2001 Captioned Movies Enquiry: https://humanrights.gov.au/our-work/disability-rights/captioned-movies-inquiry-2001 (10/8/2020).

reveal ongoing vitriolic debates. A recent post on a deaf social media page asked, ‘what is the difference between Deaf and deaf?’ The first posted comment said, *‘Capital ‘D’ represents culture. Lower case ‘d’ represents a condition without culture’*. That there is a kind of deafness that has culture and another ‘without culture’ is a theme that dominates scholarship about deafness and limits enquiry about everyday experiences of deafness. In the same vein, divisions between concepts of artificial and natural, and narratives of deficit when discussing deaf experiences with cochlear implants are an ‘outdated mode of thinking’ (Lloyd & Bonventre 2020: 312). This persistent binary viewing of deafness, I argue, restricts understandings about other deaf experiences. Divisive disputes are encompassed in a broad literature, and in popular culture, about the ways children acquire communication and language, about culture and identity, and biomedical interventions including genetic screening and the cochlear implant.

Anthropological perspectives

Debates about deafness and the ways people are identified and classified continue to feature in studies from the multi-disciplinary fields of deaf and disability studies. People who are deaf have been categorised and valued differently by opposing models of deafness. Scholarship from anthropologists, while predominantly undertaken in the global south, offers more nuanced perspectives. These ethnographies often present a subtle analysis to reveal the ways that deaf communities generate value as ethnic minorities with their own sign language. For example, Friedner explores deaf people’s challenge to the notion of stigma through generating value by orienting themselves towards business development in urban

India (2013, 2015). Pfister's (2017) research in Mexico where many families live in poverty, showed that stigmatisation of deafness and sign language led to a lack of language socialisation for deaf children born to hearing parents. This was exacerbated by a focus on oralism in schools that further discouraged sign language. Access to technology was unequal including to hearing aids and to cochlear implants that were cost prohibitive for many families. Sign language access and teaching were posited as a method of enabling language socialisation in deaf children, but consideration of how this shapes family dynamics when parents are not versed in sign language is missing from the analysis. In a 2018 paper Pfister and Vindrola-Padros explored the ways that parents' identities shifted to incorporate the role of caregiver and seeker of treatment for their deaf children. In another Latin American ethnography, this time in Ecuador, Huiracocha et al., (2015) demonstrate that it is the experience of poverty rather than any specific aspect of deafness that shapes parents' experience of their child's diagnosis and access to supports. Unequal access to medicine, education and hearing technology are common experiences in these ethnographies and thus make them very different to studies undertaken in industrialised countries with access to health care, education, and language options.

Several other anthropological studies have focused on stigma, the marginalization of sign language communities and the tensions between deaf and hearing people (for example Friedner 2018; Kusters 2012, 2015; Pfister 2019). Nakamura (2006) has focused on the marginalisation and discrimination of deaf people in Japan who until the 1970s lacked citizenship, while Park et al (2015) call for an anthropology of 'not disability' arguing that d/Deaf creates a predicament and cognitive dissonance for perfectly able people who must engage with disability services. Patricia Laing (2006), anthropologist and hearing parent of a deaf child, looks to migration theory in an exploration of culture, language acquisition and socialisation. For Laing, hearing parents exist on the margins of Deaf culture, a 'dangerous' space and, for her, narrative and storytelling, are instrumental in enabling cultural migration to the Deaf world (Laing 2006: 98). A number of other parents, like Laing, have written about their experiences of raising a deaf child, including some anthropologists. Their accounts have focused on the difficulties of language acquisition within educational settings that emphasized 'oralism' while restricting children's access to sign (Spradley & Spradley 1985). While these studies demonstrate the ways that deafness is generative of social and cultural value, few studies examine the experiences of parents and young adults in industrialised countries where cochlear implants, and diverse language and education options are more readily available. An exception is Blume (2010), father of a deaf child, and a science and technology studies professor, who tracks the global and corporate development of the cochlear implant and responses to it across different sociocultural contexts. He teases out tensions and conflicts between different stakeholders including those from science, medicine, Deaf Culture, corporate medicine, and parents, and shows that while the biomedical device was largely rejected by members of Deaf Culture, it was taken up enthusiastically by parents of deaf children. This gave rise to significant arguments about the rights of children and debates about the medical and cultural views of deafness.

Neuroplasticity: the brain and deafness

Medical and scientific research in neuroplasticity has changed the way the brain and brain development are conceptualised. The brain, viewed as an organ with temporal plasticity, encompasses neural or auditory pathways that are laid down in the first months and years of life. Scientific ideas about the brain's neuroplasticity and decades long research in early diagnosis and language development in deaf children in Colorado, led to the view that diagnosing babies' hearing loss in the first weeks of life was an indicator of better outcomes for infants who were born deaf (Mehl & Thompson 1999). The first three years of a child's life were identified as a key age for spoken language acquisition and cognitive and psychosocial development. This resulted in a global push for the establishment of newborn hearing screening programs, which acknowledged that prior to the screening programs the general age of identifying hearing loss in children was between two and three years of age. The Colorado research demonstrated that the longer diagnosis was delayed, the greater the possibilities for long term issues in a child's development including likelihood of irreversible developmental issues in language, speech, and cognition. Furthermore, the process of acquiring spoken language was said to be an auditory activity; listening takes place within our brain and not with our ears (Flexer 2011; Kral & Lenarz 2015). Neuroplasticity and temporality are infused into Australian national newborn hearing screening guidelines that were developed by the Australasian Newborn Hearing Screening Committee.[4] The aim is to screen all newborns by the time they are four weeks old followed by diagnosis by three months of age and at the six months mark

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[4] https://www.newbornhearingscreening.com.au/

an infant should be engaged in early intervention programs and with services providing assistive hearing technology.

Concepts about neuroplasticity, temporality, and delay in language acquisition, either spoken or signed, are now harnessed by both sides of the debates about oral and signed language and communication. So called 'oralists' were first to harness scientific ideas about neuroplasticity and the listening brain in developing early intervention education programs for deaf infants and their families. Medical science sees neuroplasticity as a fundamental feature of the brain and argues that without early auditory stimulation the brain may atrophy or undergo pruning and refinement of cortical neural circuits (Cardon & Sharma 2013; Simon et al. 2020). The child born deaf, with no access to language or auditory stimulation is therefore at risk of cognitive delays and the development of 'pathology in the grey and white matter' which may affect cognitive development and behaviour (Simon et al. 2020: 2). Medical literature stresses that plasticity is a key component of the brain's formation and a child's development. Activating neural pathways in the first months and years of life is critical in the development of speech, language, and cognition. Clinical research with children with cochlear implants suggests that children who have early exposure to audition only, without access to sign language, have improved listening and spoken language outcomes (Geers, Mitchell & Warner-Czyz 2017). The notion that children might learn better without access to a signed language has created much controversy including within academic circles (Hall, Hall & Caselli 2019) and during fieldwork within deaf early intervention organisations. High profile organisations including LEAD-K (Language Equality and Acquisition for Deaf Kids) in

America advocate for legislative change so that all deaf and hard of hearing children will learn sign language. Sign language advocates argue that infants who are born deaf should learn sign language to prevent language delays while parents lobby for choice and earlier cochlear implantation to close the gap. Science is called upon by academics to argue that there is not a link between the use of sign language and poor oral language outcomes for deaf cochlear implanted children. Lyness et al. (2013) claim visual language, either speech reading or signed language, does not shape cross modal plasticity, rather, the reorganisation of the auditory cortex is viewed as an 'inevitable consequence of deafness' that will occur regardless of language choices (Lyness et al. 2013). Simon et al (2020) suggest that 'the learning of sign language could be used as a protective factor in the neurocognitive development of deaf children' (12). Although they caution that the effect of sign language on the neurodevelopment of deaf children warrants greater discussion and research (12).

Medical science also posits that the brain's neuroplasticity gives the brain the capacity to repair and develop new neural pathways (Doidge 2007). These concepts are explored in scholarly literature including by sociologist Mauldin (2016) who argues that neuroplasticity presents a double bind. Deaf children with cochlear implants may learn to speak, but she argues an enormous amount of work particularly on the part of the mothers, is required. One could argue of course that learning a new language, in this case a signed language such as Auslan, might also engender parental labour and pose challenges for parents unable to model an unfamiliar language for their developing child.

The brain's malleability and development are shaped by culture, and insights into neuroplasticity reveal this relationship between the brain and culture as intertwined and ongoing. Anthropologists Lende and Downey (2012) introduced the term neuroanthropology as an approach that would encompass or synthesise anthropology with neuroscience and psychology. They argue that ethnography offers key insights to science and health and a counter to biological reductionism: 'neuroanthropology does not limit itself to Western notions of mind, self or consciousness, which can dominate discussions in some academic settings' (Lende and Downey 2012: 42). That 'we can achieve significant advances in understanding how our humanity relies on the intricate interplay of brain and culture' (51) is valuable in considering entangled sensory or embodied experiences of people with cochlear implants who access sound through direct electrical stimulation of the brain and neural pathways.

The Cochlear Implant

The cochlear implant provoked a sharpening of the debates about deafness. The device has simultaneously been hailed as a miracle cure by health, medical and education studies and an instrument of 'ethnocide' or genocide from some deaf and disability studies (Kermit 2010; Ladd 2007; *Sound and Fury* 2000; Mauldin 2012, 2016; Valente 2011).[5] In the 1980s the device was rejected by doctors and surgeons who considered the risks outweighed possible benefits (Clarke 2003; Blume 2010). Many individuals from within Deaf culture also rejected the cochlear implant perceiving it to be another form of normative medicalisation. Scholars have noted that the rise in

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[5] See also: cochlear implant 'switch-on' youtube videos. These attract millions of viewers to the moment the device is activated thus performing a 'miracle' allowing hearing for the first time.

deaf activism, which brought with it the recognition of Deaf culture and sign languages as the official language of deaf people, coincided with the development of the cochlear implant. When it finally became good to be deaf (Sacks 1989; Blume 2010), the cochlear implant, an advanced biomedical implanted device that offered access to sound and possibilities for spoken language, was made available.

The implant is offered to parents of infants who are profoundly deaf and who do not hear above 80 or 90 decibels. Surgery is most often done by 9 or 12 months of age to maximise neuroplasticity and in line with paediatric cochlear implant protocols. Children are generally implanted in both ears. In the 21st century parents of unilaterally deaf infants are steadily being encouraged to consider the implant (Porter et al. 2021). The cochlear implant may have been framed in medical literature as a device that would eradicate deafness and make deaf people like hearing people, but the reality is more complex. Cochlear implants pick up sound through an externally worn microphone, which is processed and provided as electrical stimulation to the auditory nerve via the 22 electrodes that have been inserted into the snail shaped cochlear in the inner ear. The latest biomedical research is working towards the external parts of the device being included in the surgically implanted section so that the complete unit is situated internally within the head and ear with no visible register thus complicating the notion of deafness as the ‘invisible’ disability.[6]

Mauldin, whose research focuses on the cochlear implant, biomedicine, and the

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[6] In the field site parents and professionals spoke of the ways that deafness was misunderstood including the perception that it was as an ‘invisible’ disability.

construction of new social practices particularly for hearing women of deaf implanted children (2012; 2016), cautions against seeing the device as a miracle cure (2019). She argues that pediatric cochlear implantation has increased institutional cooperation between education and health state agencies, early intervention providers and cochlear implant companies that redefined parents' relationships to their child: 'implantation is an ongoing practice enculturating parents into a new community characterised by the adoption of long-term rehabilitative duties' (Mauldin 2012: 529). Using Rose's theory of ethnopolitics she states that the technology's success has increasingly been made the responsibility of women who are now charged with 'training their child's brain' (Mauldin 2016: 108). She tracks the ways that the cochlear implant has shifted the definition of deafness from a sensory to an auditory processing issue that locates the listening work within the brain. Consequently, she argues, the gendered responsibility for the efficacy of the cochlear implant falls to the mother. Social controls, adherence and compliance are factors in neuroplasticity's use for cultural ends or the development of new social practices (2016). Through a feminist analysis she focuses less on the controversy of the cochlear implant and more on the scientific claims about language development and neuroplasticity, which she argues have significantly altered women's roles as mothers and encouraged their compliance with medicine. This analysis presents women as lacking agency as they are 'socialised' into clinical practices, and I argue underplays women's perceptions or understandings of cochlear implants as culturally productive technologies.

Friedner and Kusters, in their 2020 article, review deafness in four sections that explore 'socialites and similitudes, mobilities spaces, networks, modalities and the sensorium and technologies and the future' (2020: 13). I draw here on their discussion of technology, which begins with a discussion of the ways that deaf people have historically engaged with technology and the role of interpreters in the lives of deaf people. While they acknowledge that interpreters are not explicitly a technology, they dedicate much of the section on technology to discussing an interpreter's role in mediating between deaf and hearing people (2020: 40). While there is a call for more research on deaf peoples' interactions with technology, they caution viewing the cochlear implant implant as a 'technology that seeks to remediate deafness itself' (40). They ask what is at stake for implanted people and their families and what kind of futures might be valuable for implanted children. They state that 'today's implanted babies and children, and their families, are pioneers on uncharted paths' (40). The implant has been in use for over forty years, but social science research with families with implanted children has been limited in its exploration. Their closing statement that 'concerns over deaf futures attend not only to hearing and listening status but also to communication and language paths, and even the right to exist' (p. 40) appears pessimistic.

The social experience of deaf people who have cochlear implants and use spoken language and experiences of their families is understudied in anthropology. Whilst some research has been carried out on the cochlear implant, congenitally deaf young adults who were amongst the first to receive the device, have had minimal consideration. A notable example is Laura Snell's (2015) discussion of identity, boundaries, and fluidity, which while relevant to this research has a focus on young people who were mostly late implanted. Other studies claim that the cochlear implant transforms the child into a fusion of artifact and human, in effect a cyborg (Valente 2011) although this notion is disputed by participants with cochlear implants who took part in this research. As Rose argues, 'the new molecular enhancement technologies do not attempt to hybridize the body with mechanical equipment but to transform it at the organic level, to reshape vitality from the inside: in the process the human becomes not less biological, but *all the more* biological' (Rose 2007: 20 emphasis in original). Lloyd and Bonventre (2020) analyse concepts of artificial and natural in their insightful discussion of the ways a cochlear implant and sensorium work together. By subverting the notion that the cochlear implant repairs sensory deficits through creating an 'artificial' hearing, they upend notions of natural and artificial to consider how the cochlear implant is culturally productive and shapes identity and embodiment. They contend, and I concur, 'that hearing through CIs must be understood as the production of a distinct sensory experience rather than as a reproduction of nature through artificial means' (2020: 312) and that this analytic focus might shift research towards narratives that are no longer framed by a lens of deficit.

Communication and education debates

Communication and education debates in deafness have been the focus of extensive scholarly work in health sciences, deaf studies and education including in audiology, otolaryngology, speech pathology, listening and spoken language therapy, sign languages and deaf education. There is a significant contested discourse around early intervention, education, and language options for deaf infants, which is found in deaf studies and deaf education literature and health sciences. These disputes are often polarising arguments about the medical cultural binary in deafness (Blume 2010; Pray and Jordan 2010; Power 2005; Valente 2011; Solomon 2010, 2014; Sacks 1989).

Key literature that is valuable in disentangling everyday practices in these medical and education deaf spaces include Foucault's post structuralist understanding of the human body, including how the body is surveyed, classified, disciplined, and normalised. He argues that the body is produced historically and that it cannot be separated from its political constitution (Foucault 1978, 1989). This is particularly relevant in considering the way that deafness is socially and historically located, and the decades-long debates about treatments and teaching methods for deaf children. For Foucault knowledge is socially situated: how it is collected, ordered, and interpreted changes over time and is intimately linked with power. The deaf body is objectified through the 19th century study of human speech and the rise of the speech pathologist and teacher of the deaf. Knowledge is produced and reproduced through language; it is given meaning through different practices. Governmentality, a useful concept in unpacking practices in deafness, is viewed as the assemblage of 'institutions, procedures, analyses, and reflections, the calculations and tactics that make possible the exercise of this power' (1989: 102).

The history and management over time of people with disabilities is drawn on in considering how deaf people have been framed. Prior to the 18th century people with difference were generally tolerated and lived within society. By the late-18th century an emerging medicalisation, at the individual and population level, saw an increasing control of the disabled, the poor, the mentally ill and the deaf. Individuals with disabilities were increasingly stigmatized and segregated into Institutions to control, contain and isolate (Berger 2010; Davis 2016; Foucault 1978, 1989, 2001, Lock & Nguyen 2018; Rose 2007; Tremain 2005).

Communication battles between advocates for sign language or oral language have been in part shaped by technology and also by Deaf and disability rights movements in the 1980s. Making children learn to speak, when they could not hear, and hearing aids or other technologies were not available, and preventing learning and communicating through sign language, caused innumerable psychosocial difficulties (Ladd 2003; Lane 1995, 2005). Historical debates about deafness shape the experiences also of a contemporary cohort of parents and children. Children of Deaf adults, (CODA's), siblings of deaf adults, health professionals, parents, educators, and philanthropists, all contribute to debates about deaf children's education and communication. Some argue for oral only early intervention programs for deaf children, while others believe a bilingual approach of sign language and written English, or sign and oral language is the best option. Discussions and debates about communication and language options for deaf people continue to be presented in the media, between hearing and deaf people and in academic circles. The complexities of language and communication choices are discussed in greater detail in the following thesis chapters Four, Five, Six and Seven.

Chapter 3: Negotiations and Navigations: Fieldwork, Positioning, and Reflexivity

> It is one thing to delineate cultural notions abstractly,
> quite another to make sense of the lived predicaments
> people face, of what is at stake for them in their daily lives.
> (Wikan 1990: 12)

The purpose of this thesis is to explore, document and analyse parents' everyday experiences of childhood deafness and the Australian organisations and policies that provide care to their children. In addition, the study focuses on experiences of young adults with cochlear implants. The intention is to demonstrate a nuanced significance of deafness to a cohort more often seen through a medical lens or a medical-cultural binary. I begin this chapter by introducing my connections with deafness, field work and the field site. Following is a discussion of ethical considerations and how these shaped the fieldwork process and access to the field. A description of research methodology and processes of data collection and analysis is presented, while the next section includes detail on the interlocutors who were involved in the research, comprising parents, young adults, and professionals. I conclude the chapter with a discussion of positioning and reflexivity within the study.

When your child is deaf

My curiosity and interest in deafness is in part personal as my second child was identified with bilateral sensorineural hearing loss when he was 19 months old in the late 1990s. His diagnosis preceded newborn hearing screening, not available in Australia at that time, and before a link between biomedical understandings of neural plasticity and linguistic and cognitive development in young children was commonly known or more commonly applied in general medical practices (JCIH 2007; Mehl and Thomson 1999; Yoshinaga-Itano et al. 1998). This was the start of a journey into largely unfamiliar terrain where making decisions, obtaining knowledge, and understanding what the diagnosis meant was challenging, although I had prior familial connections to deafness. My maternal grandmother, with whom I was close, was deaf, and I have other family in the United Kingdom who are deaf and communicate with either sign or oral language. None the less, the diagnosis was upsetting. Soon after, I was introduced to ConnectUP an organisation that was run by, and for parents of deaf children. A door opened to a significant number of families with children who were deaf. Many, but not all the children had cochlear implants. This informal network of parents was a source of advice especially in the early days of the cochlear implant. ConnectUP became a support system where friends were made, some for life, and information, knowledge, and experience were shared.

It is widely accepted that women as mothers often carry the heavier load of providing the care and supports to assist with language and communication development in their children who are deaf (McCann, Bull & Winzenberg 2012; Mauldin 2016). Our social practices as parents are changed through the diagnosis. We learn how to read an audiogram, partner in therapy, learn new languages, trouble shoot broken hearing aids and cochlear implants, and negotiate ideas about deafness and disability. The quotidian demands of managing technology, changing, or recharging batteries for hearing aids, cochlear implants and FM systems become as familiar as putting on the kettle. But technology constantly changes and upgrades, so it is a continuous learning process. Approximately forty percent of children who are deaf have syndromes or other disabilities and this complicates the experience for parents (McCracken & Turner 2012). Approximately ten of the ConnectUP women I knew returned to study and combined their lived experience with training to forge new career paths as audiologists, advocates, speech pathologists, teachers of the deaf, and auditory-verbal therapists. I am aware that some of these women retain an uneasy relationship with deafness, and with the politics within education and health services. They have some reservations about choices that were made for their children, which is not well explored in health or education literature.

Imagining the field: preconceptions

All my prior experience shaped my preconceived assumptions about the fieldwork I was to undertake. One of my assumptions when beginning this research project was that the early identification of childhood deafness, delivered through universal newborn hearing screening, would have changed the social experience for parents. I imagined that a new generation of parents would find the navigation of services and processes much easier. I made assumptions too around advances in biomedical and technology developments reshaping discourses, social practices, and parents' experiences of informed choice. I was motivated to understand the National Disability Insurance Scheme's[7] impact on informed choice and on the everyday practices of young deaf adults with cochlear implants. How was their deafness experienced, and how did they reflect on the decisions made for them by their parents?

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[7] National Disability Insurance Scheme (NDIS): a federally funded policy of insurance for people with disabilities. https://www.ndis.gov.au/

In the early planning stages of the research, while still negotiating access to the field, I held three individual meetings. I met a senior audiologist who worked for a government funded health agency, a public servant working in deaf education services, and a manager of a not-for-profit deaf children's early intervention service provider. Each person talked about parents coping with their child's diagnosis and dealing with 'people with agendas'. These early discussions pointed to possible themes in the data, and I anticipated that parents/carers would be central to my study. What emerged during fieldwork was that my interactions with health, education and disability professionals, and the conflicts and collaborations between organisations, featured considerably in the research. Organisations and services in deafness were networked into a complex referral process. This network shifted over time and was shaped by the emergence of the NDIS, producing new meanings and social practices.

Fieldwork

Fieldwork was carried out over sixteen months from October 2016 until February 2018, in a multi-sited field in an Australian city. During fieldwork I travelled over 3,500 kilometres across the broad metropolitan area, to the country, hills, and outer northern and southern suburbs meeting, participating, and observing families with children who were deaf as they navigated the diagnosis pathway. I was networked into a complicated pathway of hospitals, specialist medical clinics, ear nose and throat surgeries, audiology and cochlear implant clinics and rehabilitation and early intervention service providers. I was immersed in deafness both in the field and at home and reflecting on this positioning was essential throughout the ethnographic process. As mother of a cochlear implant child, with lived experience of the referral pathway, it was at times necessary to step back and consider how my positioning might shape the ethnographic experience. I kept a regular journal during fieldwork where notes, thoughts and reflections were written. This was supported by rigorous conversations with supervisors where assumptions were tested.

My intention was to create a documentary film as an ethnographic record. I have a background in the arts, and I have worked as a documentary researcher, archivist, and producer. The presentation of deafness in films, documentaries and the arts were a source of data collection for this project. I recorded several interviews and interactions in the field with a small digital video camera, but it became increasingly difficult to undertake participant observation and manage a camera and associated equipment. There is an acceptance of cameras in everyday social contexts and almost all of my research participants ticked ‘yes’ to video recording of interviews and participant observation, but I soon found that filming impeded my capacity to participate fully, and this was especially so in a site with curious small children. A camera operator might have helped but the process of observational documentary filming, which draws similarities to the ethnographic method of participant observation, would have involved a second person with me through the research; they would have become a ‘character’ in the film or research process and that added an ethical and logistical layer to the process. I decided to stop filming. This freed me up to participate more fully on the intimate and spontaneous moments of fieldwork.

My field location was multi sited and at home in an Australian city and included many organisations and services that supported children who were deaf and their families. The Family Health Network (FHN) incorporates the Neonatal Hearing Screening Program (NHS) and the Jefferson Hospital. My hospital access included a paediatric audiology department, a cochlear implant centre, an ear nose and throat, as well as genetic departments. I also had access to the Family Support Service, which provides a peripatetic role that is managed by the FHN and is another central support and information service for parents with deaf children. National Hearing, a federally funded hearing tester and supplier of free hearing aids and listening devices for children and young adults up to 26 years of age, was included in fieldwork. In addition to medical sites, over the sixteen months of fieldwork, participant observation was undertaken at three main early intervention services that support deaf children and their families. These are The Children's Service, The Hudson Centre, and Bright House. Service provision is centre based or carried out in a child's home or childcare centre, preschool or other setting, and participant observation was undertaken in these sites with the consent of research participants and staff from those organisations. To observe the everyday social practices of parents with a baby, in the first 12 months after diagnosis, I 'followed the baby' to appointments at the above-mentioned medical organisations that made up the Hearing Pathway, and to several other related health, disability or education organisations as emerged with specific families during the research period. In addition to following families, several periods of fieldwork were undertaken within several clinical and education organisations.

Ethics and the field

Receiving University of Adelaide ethics approval was relatively straightforward once it was clear that the research focus was parents and carers, and not children. The Family Health Network ethics took longer than the university process, largely because further clearance and support was required from individual hospital departments. After receiving both approvals from the Family Health Network and the university, I set off into the field. Then, early in fieldwork, while making a home visit to a woman with a recently diagnosed baby, I met a government teacher of the deaf who was supporting the family. Although I had received two ethics approvals the government education department required clearance from their research unit. This caused a delay in fieldwork but was eventually advantageous as it broadened the scope of the field site, providing access to staff and schools, and I was able to visit the education department's new bilingual programs.

Accessing parents: negotiations in the field

My original research aim was to follow the parents/carers to observe from their perspective, social practices and interactions with health and education professionals. The parents' interactions and navigations of the diagnosis pathway would be my conduit into the field. I soon discovered that meeting and engaging families with young children was not as easy as anticipated. My assumption was that parents would be keen to share their experiences and would respond to my ethically approved flyer that was on display in various centres. On reflection I underestimated how busy families were attending appointments and being on what one participant called 'the medical merry go round' (interviewee: Marcella). I also underestimated negotiations with deaf services, and the strength of their gate keeping, which caused delays in meeting parents but again provided early signals for key themes during fieldwork.

I gave the ethically approved recruitment flyer to as many organisations as would agree to distribute the notice. It was displayed at three early intervention centres, a large public hospital, and several audiology clinics. Recruiting parents began slowly. Access to early intervention sites was important as these were the spaces that families gathered in numbers. Gaining entrance would assist in gaining parents' consent, and yet this parental consent was a prerequisite to the researcher gaining entrance. This seemed like a Catch 22 situation and initially made meeting parents difficult. Early intervention services were careful about researchers or other interested parties having contact with families with babies or children who had just been diagnosed. Their preference was to email the information to families on their database. This had a small rate of return. It may have been reflective of the demands on families with young children. One organisation actively discouraged contact with families until after the family had been enrolled with the service for more than six months. The logic was that they needed time to settle in and that they were often emotionally raw. Another service said I was not able to visit their site with a participant on her first information gathering appointment as it was considered inappropriate. Yet another organisation agreed to participation but chose the families that I could meet. There was a general view from organisational staff and managers that families in the early stages of diagnosis were often emotionally vulnerable and coping with issues of grief and loss. I would also add that organisations appeared protective of their encounters with families at this stage. They were often sensitive to securing enrolments and to how initial information was delivered to parents.

Part of the diagnostic pathway is the provision of information for parents, from the family support coordinator, about early intervention services. This is to encourage parents' timely engagement with rehabilitative language and communication development for their child. This often takes place while the parent is still navigating a significant number of medical and audiology appointments following their child's diagnosis. Families receive a telephone call or a home visit from the support coordinator. I anticipated this home visit would have been an ideal way to encounter families. Reflecting on my insider experience as a mother of a child who is deaf, I believed I would sensitively handle participant observation in this setting and envisaged a valuable occasion to meet families. I soon learnt this was considered unsuitable as parents were 'suffering grief and loss' and still 'dealing with the shock' (Field notes: interview with Michelle, health worker). The notion of the devastated parent, particularly the mother, who needs care, was an early emergent theme in data, and the subject of Chapter 4. Furthermore, tensions between my dual insider/outsider role as a researcher and as a parent with lived experience developed. I questioned my assumptions about the ways that emotion was experienced in a clinical context by both women as mothers and by medical professionals. These early forays into the field site also drew attention to the role of gatekeepers.

Negotiating access to the field required time and patience. Furthermore, explaining the core research methodology of anthropology, participant observation, required multiple explanations to health and education professionals. Gaining access to early intervention organisations, as explained, was slow, consequently key health organisations were approached to allow participant observation and to increase prospects of encountering parents. Generally, once social science research methods were clarified, medical organisations were welcoming, and over several months two-week blocks of participant observation, with regular follow up visits, were undertaken at a major public hospital audiology department and cochlear implant clinic, at other hearing clinics and with an audiology clinic’s outreach rural service. I was given time to observe interaction between health workers and families at these sites and had open or negotiated access to accompany research participants to their appointments at other organisations. I was introduced to staff and parents/carers as a PhD researcher or university student and in the hospital clinics I was given a desk next to the soundproof booths, audiology offices and near the department administrator desk. This central location gave me a view into the day-to-day activities of the clinic. I sat next to the station for testing children’s middle ear health, and I was introduced to families at this point. Four thousand children came through this clinic each year, and while I saw a fraction of that number, I spent time with families experiencing a range of ear related issues including hearing tests, cochlear implant activations, ear health management, upgrades of cochlear implants including the latest technology in cochlear implants, the ‘kenso’.[8] I also observed the pre-cochlear implant surgery candidacy and assessment. While my role as a parent made me familiar with some of

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[8] A kenso is an externally worn device that connects to the internal implant by attaching magnetically on to the back of the head with no behind the ear fitting.

the activities, I am not an audiologist or health professional and some of these daily activities were very unfamiliar.

The range of services and complexities of individual cases made for a rich ethnographic experience. It gave me moments to reflect too on changes in the field since my son had been diagnosed. I met parents with children aged from only a few months old up to young adults. Parents spend a lot of time sitting in waiting rooms of public hospitals and this was a chance to connect and talk with parents. Building rapport was critical in early meetings with parents and these were intentionally kept conversational with an open enquiry about the children. This led women, and on some occasions fathers or other carers including grandparents or foster carers, to recount their child's diagnosis. At the hospital I met several parents who agreed to participate in the research and allowed me to follow their subsequent encounters with other service providers including the elusive early intervention organisations.

Having a deaf child is an embodied experience – parents literally go on a journey with their child that involves significant travel, often driving long distances to multiple appointments and spending long periods of time in waiting rooms. Once I had recruited parents as research participants, my fieldwork began to mirror this complex, embodied parent experience, and this provided insight into parents' everyday practices. Reflecting on my plan to follow parents and not base myself as a research student in a medical or educational setting was perhaps residual of my own experiences and may have been naïve research planning. My assumption was that these were challenging spaces and I wanted to be independent and see parents on their own terms. My non-health professional status gave me an outsider perspective during this fieldwork that enabled some distance to see the world from the view of the health professional. I began to see that they were often also caught in the same web of contested deaf discourses that parents' encounter. This navigation was a signposting of themes around tensions and controversies in deafness that developed during fieldwork and later through data analysis and caused me to reflect on my own experiences and the dual role of parent and researcher.

Figure 5: Visual Reinforcement Audiometry: an infant looks to the puppet when he hears a beep through his hearing aid.

Methods

Ethnographic methods including participant observation and qualitative semi-structured one on one interviews or guided conversations, with follow-up second or third interviews, were employed in this research. Semi structured interviews, working with a list of prescribed open-ended questions, were undertaken with the management and staff of organisations. Questions focused on discovering what service was provided to families, how families were referred into the service, what information they provided to families to assist with choices and decisions, and the impact the NDIS had on their organisation. They were asked also about the international call to action to have Deaf and hard of hearing adults and professionals working with families with deaf children from first diagnosis to provide information through the journey. I asked if this was working already at their organisation and how it might work for parents with infants who are deaf. I often went back with more questions and participated in conversations, talking in more depth about areas of interest or events that had emerged during fieldwork. The first interview with most parents took two hours and these were often personal narratives of their child's diagnosis and the parents' foray into the deaf world. We looked at family photographs together and these were often effective probes in extending conversations and memory (De Leon and Cohen 2005). I took handwritten notes during most interviews, and they were all, with consent, recorded on a smart phone for later transcribing. Some interviews were intimate or emotional conversations, and, in these moments, I focused on the person I was speaking with, and audio recorded the exchange, rather than note take. Subsequent interviews and participant observation took place with some parents and follow up or clarification questions were sent and answered via email. Text messaging was also a communication tool and some parents sent regular text updates on progress with photographs and notices of forthcoming appointments. All interviews were transcribed, and these were read and reread in a process of identifying patterns and connections in the data. Coding was done first in Excel spread sheets and then NVivo (NVivo version 10) was used to code and analyse transcribed interviews and other data.

While undertaking participant observation in the field, I made written notes and diagrams as often as was feasible. Eight A5 notebooks were filled with comprehensive observations that described the physical layout and design of a site, spatial considerations, notices, and posters that were pinned on walls and objects or equipment that was present. The date, time and duration were noted along with who was present and what occurred in any given encounter. I recorded what was said between people and made note of expressions of feelings and emotions. Comprehensively recording as much action and dialogue as possible including the mundane became a way to check positioning and tacit knowledge gained from years of experience of childhood deafness. I was aware of how this knowledge might shape the recording of these extensive field notes (Wolfinger 2002), which were logged into an excel spread sheet for referencing, coding, and analysis. Participant observation did not always allow for either audio recording or note taking and observations would be written up after the event. This was particularly so with therapy group programs where spontaneous engagement and play would occur with children and parents. In some instances, especially revelatory moments, I recorded direct to a smart phone after leaving an event. I made visual records through diagrams and took photographs and recorded video on a mobile phone. I also collected textual documentation from each organisation, as data for analysis.

Research participants and interlocutors

Families involved in the research were from a range of socioeconomic and cultural backgrounds including Anglo-Australian, Cambodia, India, Indonesia, Philippines, Singapore, UK, and USA. Interviews and guided conversations were undertaken with forty-two parents of which eight were men and thirty-four were women, two grandparents: male and female, eight young adults with an even ratio of male to female, and twenty-five workers of whom five were men and the remaining women. We met and conversed in places of work, cafes, and at participants' homes. Health and education workers were audiologists, ear nose and throat surgeons, general medical practitioners, paediatricians, ophthalmology, speech pathologists, teachers of the deaf, listening and spoken language specialists, counsellors, and occupational therapists. I accompanied fourteen women and six men and their children on regular visits to fifteen different medical and education sites.

In the field, observing at the neonatal hearing screening program, I met exhausted and joyful mothers in hospital, and watched their tiny babies, just a few days old, having hearing screens with a large retro telephone-like instrument placed over the ear and head. In city and country clinics I sat with mothers in small rooms, as they rocked babies to sleep, so that electrodes could be placed behind ears and on their heads, for diagnostic hearing testing. At hearing clinics, I watched babies complain loudly as their ears were filled with green gloop to make new moulds for hearing aids. In soundproof booths in a large hospital audiology department and at an early intervention site, I observed children's interactions with audiologists while their cochlear implants were MAPped or adjusted for sound. I observed nervous and expectant parents in dark, quiet, soundproof booths watching their baby as a cochlear implant was switched on for the first time. At several early intervention sites, I participated in months of small group therapy programs for babies and children and played in sand pits and learnt new songs. I sat on the sidelines in the warm chlorinated air of indoor swimming pools as babies had hydrotherapy. I visited participants' homes with teachers of the deaf, speech pathologists and listening and spoken language specialists, and watched as babies and children were encouraged to listen and/or sign and their parents guided to do the same. I observed families living in remote locations having weekly therapy via Skype and I went to noisy, jam-packed childcare centres and visited pre-schools and primary schools offering bi-lingual programs for students. I went to first birthday parties in parks and twenty first birthday celebrations in public hotels and met extended family members on holiday from neighbouring countries. In the process of deaf immersion, I attended deaf theatre, watched deaf films, and registered at an international conference in Austria, the 2016 'Family Centred Early Intervention Congress'. Hearing Loss was everywhere, and it was a mission to record the signage of deaf service providers. The language, words, messages, and the categories of deafness were under the research lens.

Figure 6: A cochlear implant clinic: an otolaryngologist sits with a patient and inspects a scan of his brain.

Participant observation and interviews were undertaken also with young adults with cochlear implants. We talked and walked together in parks and sat and listened to the sounds around us. I visited participants at their homes and met their parents. Interviews were done with them on their own, and in discussions with their parents. I observed and participated also at a regular social group attended by young adults including joining special events and a Christmas gathering. The health and education interventions that these young adults had experienced varied significantly. Participants talked about their speech processors, the externally worn part of the cochlear implant, and upgrades to technology. They spoke about the importance of their cochlear implants, but that they were 'still deaf'.

Reflexivity and positioning – the researcher and lived experience

My motivation for undertaking this project, as explained, stems from familial connections and largely through experiences of having a son who is profoundly deaf. I discussed the scope of the research with him, and he gave consent for me to write about my experiences as his parent. I had moved to Australia from the UK a year before my son was born and we received support from dedicated and skilled medical and education professionals. I learnt how to develop my son's speech and language, and this was a very different parenting role than with my first child. Lived experience and occupying an insider role as parent and researcher allows for knowledge or experience of the field. I was aware that while in the field my insider perspective was enduring, and autobiography was inherent to the research position not to 'chronicle personal history' (Davis 2011: 224), but that existing personal association or involvement in deafness was utilised to gain access to hard-to-reach interlocutors.

I was investigating a familiar environment and while tacit knowledge, gained through my experience as a parent, offered some advantages when reflecting on the process, it took some time to distance myself from the data and to understand my assumptions about the field. The role of 'mother of a child who is deaf' is most obvious to my research positioning, but my involvement is also through employment, in volunteering positions, on boards and committees. This positioning is what Ginsburg and Rapp call 'entangled ethnography' (2013: 187) as they explain:

> We add to the emerging vocabulary of engagement another term: “entangled ethnography”. In this language, we hope to capture the particularly complex and distinctive ways in which we are caught up as both researchers and parents. While we identify as kin responsible for the existential inclusion of our own and other children in a world that too frequently draws categorical boundaries that segregate those with disabilities, we ourselves are not (yet) disabled. We seek to express the vertiginous sense we had of being ethnographically entangled, simultaneously inside and outside the world we are studying through ties of kinship and caretaking (188).

It is widely acknowledged that deafness is a politicised field (Blume 2010; Mauldin 2016) and discourses embedded in deaf culture impact social practices and participants’ everyday experiences. This shapes my positioning, and an ongoing reflexivity played through the research process. Reflexivity has been a concern in anthropology since the disciplinary critiques of the 1980s (Marcus 2001; Van Ginkel 1994). A large and growing body of literature, including feminist literature, has focused on positioning, reflexivity, and auto ethnography in the social sciences (Bondi 2014; Carolan 2003; Oakley 2016; Shuttleworth 2012; Wilkinson and Kitzinger 2013). There were times during fieldwork when I would question my own early experiences, in an era before newborn hearing screening existed and on reflection, I recalled that advice from many well-meaning people was at times not helpful. During fieldwork, health and education professionals and parents’ interactions were a complex layering and tangling of deaf discourses. I would argue that in this field positioning was a factor for participants and researcher alike, and the ubiquitous idea of bias in deaf services was ever present and contributed to this sense of ‘entangled ethnography’ (Ginsburg and Rapp 2013b p. 188). Building rapport with participants enabled a collaborative reflexive research lens and positioning as researcher intersected with my role as parent: to paraphrase Charlotte Davis, the insider ethnographic researcher overlapped with the outsider researcher self (2011: 4).

Fieldwork ‘at home’ completed in the city in which I live, is complex, and positioning and familiarity can be a mixed blessing (Davies 2011). Cultural representations in deafness and social boundaries or groups of belonging can mark out difference. My son has bi-lateral cochlear implants and uses speech to communicate; he is ‘oral deaf’, and this is part of my positioning. Reflecting on this, I was at home in the field but there were times when I felt less conversant or comfortable in certain settings and this made research and positioning complex, but it also provided distance in a location that was sometimes too familiar. Aspects of the deaf world have changed considerably in the twenty years since my son was diagnosed and this gave space to experience the unfamiliar and sometime revelatory ethnographic experience. Universal newborn hearing screening, available since 2006, differentiates participants’ everyday experiences from my own, which are situated in a time when children were generally not diagnosed until they were two or three years of age (Roberts et al. 2015). This is a key differentiator of social practices. Despite my assumption that this biomedical development would have provided an ‘easier’ navigation of the diagnosis pathway, I discovered this was not always the case, which created some tension in the researcher role. Certain exchanges or events made me question the ethics of ethnographic research. As Shuttleworth states, … “the more roles and statuses ethnographers occupy in relation to their informants, the more likelihood that conflicts of interest, ethical dilemmas, and /or points of contention will occur" (2012: 46). I watched 'new' parents work their way through appointments and search for information to gain knowledge to make choices and decisions. There were times when I wanted to intervene with suggestions or advice though this may have been construed as influencing the field: ethically this was not my role, and so I did not.

While I was in the field, I kept a regular research journal where thoughts, ideas and reflections were recorded and explored. I questioned the part that experience played in my role as researcher and was aware while in the field that this role would sometimes collide with memory. This was a new role; I was more familiar with working in observational documentary filmmaking where intervening might sometimes be necessary to help move a story or narrative forward. As an ethnographic researcher it was not my place to shape or influence the field; my role was to observe and participate, and I understood that this was a restricted participation. This seemed paradoxical and I was aware of the potential blurring of boundaries and a duality in the role of researcher and participant (Taylor 2011; Wilkinson and Kitzinger 2013).

When interviewing and conversing with parents my positioning provided a commonality and connection through personal narratives but on reflection it also structured fieldwork in subtle ways. Positioning was navigated throughout the time I was in the field, and it was in part metered by what was revealed of my own positioning. I was identified by some participants through the choices I had made for my son and so became a ‘mother of a child with a cochlear implant’, which may have influenced some participants. Commonality allowed for deeper or more intimate conversations about social practices and generated shared meaning about parents’ experiences. This was often true with parents who were my contemporaries and had older children. Sharing understandings and emotions of parenting and deafness created a bond. Parents wanted to tell their stories and immersive ethnography enabled me to give their stories light (Scheper-Hughes 1993, 1995). This was similarly the case with a younger generation of parents, but I was aware that our experiences were marked differently by the passage of time. While some participants, aware of the politics within the field, censured themselves, generally interviews would begin with a list of questions and an organic, mutual conversational process would flow. There was a reciprocal nature to these interviews and building trust and engaging in empathetic conversing was critical to the research process: to cutting through the politics embedded in the field, and in the interviewer and interviewee relationship to collect ‘trustworthy’ data (Oakley 2016). This was particularly so with interlocutors who were parents, and it also applied to several health workers with whom, over several months, relationships of trust developed.

When I came out of the field and began the process of collating and coding data for analysis the challenges of being close, of being part of the field of study, continued. It took a significant amount of time to find space to stand back from the material to allow a clearer vision. A theme that emerged during this reflective process was the place of family or of the parent/carer in the deaf field. Parents of deaf children had been central in much of the fieldwork and while their experiences were shaped by a complex field, they were often active agents in shaping their and their children's, experiences of deafness.

In this chapter I have outlined the fieldwork site and described the challenges of undertaking research in a field where one feels both an insider and an outsider. I have provided a description of the research methodology and why these methods were adopted including the use of open-ended qualitative interviews to record intimate and in-depth narratives, participant observation field notes, and writing a regular diary as a space to reflect on fieldwork and positioning.

I have discussed reflexivity and my positioning as researcher to highlight the complexities and value of lived experience in ethnographic undertakings. I have shown the ways that the researcher's experience intersected with interlocutors during my fieldwork to consider the ethics and purposes of carrying out research. I have been reminded of why this research is important to me and I am encouraged by Nancy Scheper-Hughes, who wrote, 'I have had to pause and reconsider the traditional role of the anthropologist as neutral, dispassionate, cool and rational, objective observer of the human condition' (1995: 410). I am cognisant that when engaging in the ethnographic process, in undertaking fieldwork with interlocutors, a balance is navigated that considers positioning, ethics and the voices of the people with whom we work.

What follows from this Chapter are four manuscripts. They explore parents' and professionals' reactions to a diagnosis of infant deafness, uncertainty in diagnosis, parents’ decision-making practices in childhood deafness and young adults’ experiences of deafness and cochlear implants.

Chapter 4

Emotion as Motivator: Parents, professionals and diagnosing childhood deafness

Title of paper	Emotion as motivator: parents, professionals and diagnosing childhood deafness
Publication status	Published: Accepted for publication (as presented below) 12 June 2020.
Publication details	Harris, C. Hemer, S., Chur-Hansen, A. (2020). 'Emotion as motivator: parents, professionals and diagnosing childhood deafness,' *Medical Anthropology*, p. 1–13. https://doi.org/10.1080/01459740.2020.1796659

Principal Author

Name of Principal Author (Candidate)	Claire Harris
Contribution to the Paper	Developed rationale for the study, devised research questions and aims. Planned and carried out ethnographic fieldwork and data collection and performed data analysis. Drafted, wrote, and submitted the manuscript (acting as corresponding author). Revised and responded to reviewer comments.
Overall percentage (%)	80%
Certification:	This paper reports on original research I conducted during the

	period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	10/12/2021

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

Abstract

Diagnosing deafness is a culturally situated practice generating considerable research in health sciences but limited work in anthropology. Diagnosis fast-tracks parents into a medical and education pathway but can also create tension for parents and professionals. Drawing on ethnographic fieldwork, we argue that in this biomedical context, emotions are often understood by professionals as impairing for parents, and hence problematic for the treatment process. In contrast emotions are characterized by parents as motivational and tools for decision making on a pathway that is experienced as a source of stress.

Keywords

Australia; diagnosing childhood deafness; emotions; motivation; parent reactions

Introduction

During fieldwork in an Australian medical diagnostic referral service for childhood deafness, a reoccurring theme in parents' and professionals' conversations with each other and with the first author centered on women's emotional reactions to their child's diagnosis of deafness. Everyone agreed that the experience was emotional; women were shocked and overwhelmed by sadness. The process was often framed as devastating, although this emotion was understood differently by women and the professionals with whom they interacted. Tensions were tied to assumptions about emotion and to sociopolitical and structural components associated with deafness.

A body of literature on parental responses to their infants' diagnosis of deafness cites grief and feelings of loss, sadness, confusion, uncertainty, and shock as ubiquitous (Bosteels, Hove & Vandenbroeck 2012; Fjord 2001; Gilliver, Ching & Sjahalam-King 2013). Women's and men's emotional reactions are articulated by health professionals, educationalists, scholars, and parents through sociocultural and gendered emotional scripts (Lutz 1988; Milton & Svasek 2005; Scheper-Hughes 1993).

Deafness (and its diagnosis) exists in a field where tensions play out between competing agendas, ideologies, and discourses. A call for an international policy for parents to receive unbiased information from professionals about technology, surgery and communication choices including access to Deaf Culture has featured in the literature (Moeller et al. 2013). The identification of deafness is therefore not a process of providing a "neutral" fact to parents. It is a culturally situated practice of diagnosis and information provision about a condition that is typically constructed as a loss or a disability by professionals. Parents often react by being completely devastated as if “affect marks a body’s belonging to a world of encounters” (Gregg & Seigworth 2010: 2). Drawing on the analysis of participants’ experiences of the cultural practices of diagnosis in a biomedical context in an Australian setting, we question assumptions about the role and nature of emotion in medicine, and about the management of childhood deafness. An ethnographic approach of intensive participant observation is salient to understanding the meanings parents attribute to emotion in these health care encounters and specifically in the diagnostic process.

The diagnosis is associated with causing disruption to maternal bonding through the delivery of a problematic new label “deaf,” “hearing impaired” or “hard of hearing” (Kurtzer-White & Luterman 2003) and conflict in the expected narrative of family (Bosteels et al. 2012; Pfister 2019; Young 2018). Studies in countries with marked social and economic inequalities demonstrate the ways that the interconnected nature of poverty, limited social resources and unequal availability of health care impact on parental capacity to access and cope with a diagnosis “rather than anything innate in the impairment itself” (Huiracocha et al. 2015: 556). In countries like Australia, social and economic disparities also shape social practices in deafness. The historical and shifting valuing of one communication modality over another – spoken language over sign language – and debates about teaching methodologies remain contested (Duncan 2011; Friedner 2018; Mauldin 2016). These debates call into question what childhood deafness and disability mean to a cohort of parents who generally are hearing and may have little prior knowledge of deafness.

In this article, we draw on the concept of diagnosis as a culturally situated biomedical practice (Duchan & Kovarsky 2005; Jutel & Nettleton 2011; Latimer 2013b; Mechanic 1978) and on theories of emotion (Beatty 2014; Lutz & Abu-Lughod 1990; Lutz 1988, 2017; Wikan 1990) to analyze ethnographic data from parents about their responses to their infant's diagnosis of deafness. Our aim is to explore the meanings parents attribute to their emotions in this setting. We attend firstly to diagnosis as a cultural practice, then map out the diagnostic referral process within this setting. Western sociocultural views of emotion as a binary opposite to reason that inform the medical context are challenged. Anthropological accounts provide a framework for understanding human emotion that is more complex, nuanced and interwoven throughout sociocultural life (Beatty 2014; Lutz 2017, 1988; Milton & Svasek 2005). This lens is used to argue that for parents, particularly women, emotion is understood as an embodied and very real experience, central to agency and a powerful motivator for action. Parents' narratives and their interactions with health and education professionals are examined to illustrate how discourses in a medical diagnostic-rehabilitation setting reproduce cultural notions about parenthood, emotion, and childhood deafness (Beatty 2014; Lutz 1988; Scheper-Hughes 1993). Negotiations between parents and professionals are investigated to unpack ideas about the role of emotion, dominance, and power in a medical context (Foucault 1976; Lupton 1994; Mechanic 1988).

Methodology and Positioning

This article is based on ethnographic data collected during sixteen months of fieldwork in a multi-sited field in an Australian city. Participant observation and semi structured interviews with 68 participants, including parents of deaf children, and health and education professionals, were undertaken by the first author from October 2016 to February 2018.[9] The field included a government and three non-government early intervention services (EI), a large public hospital, ear nose and throat surgeries, and audiology and cochlear implant clinics. The research method was a “follow the baby” approach, and 14 women and six men and their children agreed to the researcher accompanying them on regular visits to eleven different medical and education sites over the fieldwork duration. Fieldwork traced parents’ experiences of moving between locations, driving long distances, and keeping up with multiple and often changing appointment schedules, with constant navigation of space, time, and place.

The first author is the mother of a young adult with bilateral cochlear implants and has other deaf family members who use a range of communication methods and technologies. Her connection to the field through experience with her child afforded levels of access to organizations and participants. She presented herself, usually early in interviews or fieldwork, as anthropological researcher and mother of a child who was deaf. While many but, not all, parents in this study had children with cochlear implants, those who did spoke of belonging to an unofficial “cochlear implant club,” a community of families with shared experiences and mutual supports. That the first author was also a “cochlear implant mother” afforded increased levels of commonality in some settings, and occasional tensions in others. A fieldwork diary

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[9] All participants and field sites have been given pseudonyms.

recorded the first author’s reactions to fieldwork, and these reflections were referred to when analyzing data. A reflexive lens, including analytic discussions with co-authors, provided insights into a rich ethnographic field.

Participants

Forty-one parents (31 women and 10 men aged from 28-62) participated in the research. Five families had more than one child who was deaf and six children had a medical diagnosis in addition to deafness. Families were Australian residents from an array of socioeconomic and cultural backgrounds comprising Anglo-Australian, Indo-Chinese, Philippines, Singapore, UK, Cambodia, and India. Twenty-seven health and education professionals included audiologists, a general medical practitioner, otolaryngologists, counsellors, and occupational therapists, teachers of the deaf, listening and spoken language specialists, speech pathologists and managers or directors of organizations.

Data collection and analysis

Data were collected using ethnographic qualitative methods, through semi-structured interviews or guided conversations (Csordas et al. 2010; Warin 2010). Participants were given pseudonyms. Parents, most often women, shared emotional stories of their child’s diagnosis and entry into the referral pathway. These narratives were detailed and clear, regardless of how long ago the event may have been. Staff of early intervention and medical organizations were interviewed to learn about services, referral processes, and information provision. Interviews and field notes with parents and professionals were logged and transcribed and coded for key themes using NVivo.

Diagnosis as Cultural Practice

At an early intervention service for families with deaf children the first author met Jean, a 43-year-old university educated mother of two. When asked how she felt about her son's diagnosis, Jean said,

> Yeah, I needed to meet it head on. And yeah, I was going to cry. My crying didn't mean I was less capable of managing the situation or understanding the information that was presented to me. It just meant that I was upset. That seemed like a pretty reasonable response. It was as though my emotionality was an indicator of another problem that they (the doctors) had to deal with. They had to deal with my grief. I found it very patronizing.

Jean's experience of her son's diagnosis of profound deafness encapsulates key themes about the interplay of emotion and reason, and knowledge and agency in a medical and diagnostic context that are explored in this article. Affect and the public and physical display of reactions are recognized as realities while at the same time Jean articulates her capacity to manage the situation. She challenges perceived paternalism from professionals and reveals tension between medicine's expert delivery of diagnosis, and her reactions.

Diagnosis employs scientific and medical and allied health professional knowledge and technology to classify and categorize conditions or symptoms on or within the body (Duchan & Kovarsky 2005; Kovarsky, Snelling & Myer 2005). In the biomedical context, diagnosis is understood to be carried out only by professionals who are qualified to administer chosen tests at certain times. The patient is subjected to the "medical gaze" (Foucault 1976; Tremain 2005), with information deemed non-medical filtered out. Medical professionals then provide patients with a classificatory label, which determines access to ongoing medical treatments and encounters. It has been stated that "correct and reliable diagnosis is the basis of the sound practice of scientific medicine" (Mechanic 1978: 96). Professionals hold medical authority and a sovereignty to diagnose; a power dynamic is assumed to operate between this "voice of medicine" and patients or parents (Lupton 1994; Mishler 1984). Furthermore, in encounters with patients, clinicians are positioned as objective, ideally empathetic yet also emotionally detached (Kovarsky, Snelling & Myer 2005). The outcome of the diagnostic process is not a neutral fact given to parents—rather, there can be concern from professionals to not cause alarm, resulting in a process of moderating and monitoring information delivery to parents (Jutel 2011).

In diagnosing deafness, the practice is grounded in processes carried out by audiologists, ear, nose and throat surgeons, and geneticists. The test produces an audiogram, or visual graph that maps and classifies the levels and range of hearing through analysis of a person's perception of sound at decibels and hertz. "Medical diagnoses are also contested, socially created, framed and/or enacted" (Jutel & Nettleton 2011: 793), and while they are contingent on an ability to discern and interpret a range of symptoms, they may be elusive. Determining hearing loss in infants is often challenging due to fluctuating or deteriorating losses that mask a clear diagnosis. In a protracted diagnosis, over several months of repeated tests, a level of doubt is produced, which creates tensions for parents who seek certainty.

Furthermore, 30-40% of deaf children have other medical diagnoses (McCracken & Turner 2012), which often complicate parents' emotional reactions. Parents of children who are diagnosed with additional health issues or syndromic deafness often experience more complex emotions and grief that may become protracted (Luterman 2004; Parrish 2010).

Deafness is firmly located within a biomedical context through the process of diagnosis. The medical script of deafness has had significant attention from scholars (Bosteels et al. 2012; Mauldin 2016; Power 2005). It is generally framed by the early identification through universal newborn hearing screening, and the biotechnological development of the cochlear implant, which was given US Food and Drug Administration approval for implantation in young children in 1990 (Blume 2010). Deafness has a longer association with biomedicine than this, however. The connection between congenital rubella and deafness was made in Australia in the 1940s, and a preventative vaccine was developed in 1969 (Hutchins & Hutchins 1995). The identification of a key cause of inherited non-syndromic deafness, Connexin 26, or "the deaf gene" as parents call it, was discovered in 1997. Half of all cases of permanent congenital childhood sensorineural deafness are hereditary. Genetic counselling is offered to parents, and this becomes part of their medical experience (Latimer 2013a, 2013b). These events and the diagnostic process have located deafness at least partially within the medical realm.

Diagnosing deafness is a trigger for medical and therapeutic referral. The provision of information about communication, therapy options and funding including, in the fieldwork site, the new Australian Federal Government fund for people with disabilities, the National Disability Insurance Scheme[10] (NDIS), are intertwined in the process. In the biomedical clinic where diagnosis occurs, emotion is positioned in opposition to the scientific logic that exemplifies this context (Duchan & Kovarsky 2005; Lutz 1988; Mechanic 1978). Despite this, it is also understood as a highly emotional situation, where professionals expect parents, often women, to react to their child's diagnosis with grief and related feelings (Bosteel et al. 2012; Mauldin 2016; Mehl & Thomson 1999). Literature from health and education, presents parents' reactions through a medical lens of deafness as tragedy. The notion of "tragedy" is communicated in the clinic during diagnosis and deafness is framed as an impairment (Gilliver et al. 2013; Kutzer-White & Luterman 2003; Pfister 2019; Young & Tattersall 2007). While emotion is understood to be inevitable in this context (Kovarsky, Snelling & Myer 2005; Lutz 1988; Mauldin 2016), it is also positioned as an impairment to rational decision making, as demonstrated through ethnography below.

Diagnosing Deafness in an Australian City: The Hearing Pathway

In the field site medical specialists developed what they referred to as the "Hearing Pathway," a system of protocols to manage the diagnosis and ensure medical and early intervention referral for childhood deafness. The children's audiology service, where fieldwork was undertaken, consists of three statewide government programs: a newborn hearing service, a service for 6-18-year-olds, and a cochlear implant

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[10] The NDIS is a federally funded insurance scheme that provides individualized supports for people with disabilities.

program. Since 2009 an Automated Auditory Brainstem Response (AABR) screen has been performed in hospitals on 97 percent of newborn babies. Infants who fail the screen twice and babies born with risk factors for deafness are sent for an Auditory Brainstem Response (ABR) test, a non-anesthetic procedure performed by an audiologist that tests the auditory nerve function.

In a busy clinic Hillary, a receptionist, and her partner Mark, a fire officer, both in their mid-thirties, arrived with their newborn baby for an ABR. The audiologists showed the parents, and first author, into a room that held desks, a computer screen, a large comfortable reclining chair, and a small sink. Lights were dimmed, voices whispered, and the baby was held in her mother's arms and rocked to sleep as distracting sound seeped in from the nearby reception area. The audiologist asked the parents if they had noticed their baby responding to sound. She spoke quietly, explained the procedure, and methodically and patiently tested each ear. Almost three hours later, with the test complete, she called in a second audiologist to check the results. They studied the computer screen, glanced at each other and then the first audiologist broke the news to the parents. "Your baby has a hearing loss." Hillary looked surprised. "What do you mean?" The audiologist showed them the audiogram, a series of crosses and dots on a graph, and explained the results. She reassured the parents that help was available. Hillary became very upset. "What do you mean, she's deaf? How will she hear my voice?" They were given a booklet called "My Baby Has a Hearing Loss - Information for Parents." It starts with "Dear Parents…it is normal to feel sadness and grief, guilt or anger about your child's hearing loss. These can be difficult feelings to deal with…Be assured these are all the natural reactions of a loving parent”. This book normalizes an emotional reaction from parents.

Some weeks later Mark said: “I had to stay strong. I was worried, but I didn’t want to let Hillary see that.” In data collected during fieldwork, fathers often used terms associated with strength and restraint including “holding it in” and “keeping themselves together.” This theme was echoed by other men who often said they found the tests and diagnosis stressful or distressing. They “held it together,” to quote Rick, for their partner’s sake. Rick recalled how he had been unable to attend his second child’s test because he was not sure he could control his emotions and did not want to risk a public display as if this might reveal weakness. In contrast, in the diagnostic setting, the mother was most often seen as impaired by her emotion. Reflecting on the diagnosis Hillary articulated her feelings: “I was devastated, and completely fell to pieces.” These terms were used by many women interviewed in this study and by many health professionals and service providers when talking about women during diagnosis. These comments reflect gendered responses of parents to the diagnosis, and was commonly reported by participants during fieldwork, as we discuss below.

Information and referral on the hearing pathway

Information for parents from professionals was framed as objective and impartial so that, according to best practice scripts, parents could make an informed choice. Within 48 hours of the diagnosis, Hillary and Mark were given health and education referrals and were strongly encouraged to make decisions about technological listening devices. To manage a battery of specialist medical appointments, they were referred to a “hearing impairment coordinator.” The coordinator acts as a bridge from the medical clinic to education service providers, specifically, four early intervention (EI) services that offer different intervention methodologies. The expectation is that parents will meet with Teachers of the Deaf, Auslan (Australian Sign Language) Teachers, Listening Spoken Language Specialists, or Speech Pathologists who tell them about their services and communication options for deaf children. Here, parents come across tensions in deafness with different services, which often promote one language option more strongly than another.

Despite an explicit framing of objective information, professionals advised families about communication or technology choices often in ways that revealed bias and the valuing of one methodology over another. At the audiology clinic, the first author met several women with young babies and small children. What emerged from talking with them was how each had a story that told of trouble navigating or accessing services. A key theme was that the experience was overwhelming. This was compounded by expectations from health workers that they engage in a rapid and significant process of decision making, soon after the diagnosis. June, a cattle farmer, explained she was “gutted” when her son was diagnosed with profound hearing loss just before Christmas. She spent that first weekend after the diagnosis “shut away at home.” The hearing impairment coordinator was on leave so the family were put in touch with a locally based government Teacher of the Deaf, who advised the family to relocate to the city, so they could enroll their child in an Auslan school. Life in rural and remote locations often complicated the availability of medical care, and travel over long distances was required to access services. This often took an emotional toll. June was devastated at the thought of leaving their home and by the lack of services. Eventually she discovered a supportive early intervention program that offered therapy options online, via Skype.

Parents retold stories about how service staff spoke in disparaging terms about other service providers, and professionals spoke to parents about their choices in ways that confused them and added stress. Parents spoke about negotiating medical protocols and funding agencies, which made them feel frustrated and angry. Contention within the field is tied to medical, social, and cultural models of deafness (Blume 2010; Friedner 2019; Matthijs et al. 2017) and to the bureaucratic organization of health care that compartmentalized specialist supports into complicated structures that fragment patient experiences (Latimer 2013b; Lupton 1994; Mauldin 2016; Mechanic 1978).

Professionals perceived that parents from low socio-economic backgrounds were least likely to return for diagnostic tests. Professionals recounted that parents with what they called “complex needs” often had less resilience and capacity to cope with the diagnosis or referral. Parents who coped well were talked about as being, to quote one health care professional, “very positive” and “quite cluey.” Concern was expressed for women who had not engaged in early intervention therapy because, one said, they “were still on the floor” and grief stricken. This may have been attributable to parental levels of resilience although one woman told the first author that encounters with services and confusion in the field kept her away.

Another young couple, from a low socioeconomic household, said that when their son was diagnosed with moderate hearing loss, they were scared he would be bullied were he to use hearing aids, so decided against them. The mother wanted him to learn to speak and visited early intervention centers: each one said their methodologies were more effective than the others but without clear explanation. She was told by one service that until her son was fitted with hearing aids "there was nothing we can do for you." Structural complexities and contradictory discourses intersected, and she chose to "do nothing" as she put it.

How parents received information at the diagnosis and in referral meetings is relevant as here the intersection of discourses and social practices of deafness begin, as Emma, a 55-year-old librarian and mother, explained,

> When a person enters a room as a parent, no matter how capable they are, how educated, how responsible their job, they are so frequently reduced by professionals, particularly when there is an imbalance with more professionals in the room, as too emotive, and incapable of processing the complex information that only the 'expert' professional can possibly understand.

There is a disjunction between how emotion and knowledge is understood in this setting and how parents are situated *vis*-à-*vis* a balance of power with professionals (Lupton 1994; Lutz 1988; Lutz & White 1986). The audiologist expert may be the purveyor of "bad news," a term used in the field by professionals and parents, which may signal to parents that the diagnosis of their child's deafness is a devastating event. While “knowledge is power” and in this diagnostic setting unbiased information is key, socially situated practices that underpin the diagnostic referral process effectively reproduce ideas about deafness, emotion, and parents’ reactions, which leads to the theme of the “devastated mother.”

The Devastated Mother

During fieldwork, the most commonly used word by professionals to describe the emotional state of parents and particularly mothers after the diagnosis was “devastated.” Women too employed this term when describing their reactions. Devastation causes “severe or overwhelming shock or grief;” the etymology of devastated is vastare: to lay waste, ruin or desolate from “vastus” meaning “empty” (Hoad 1996). Mary, an audiologist in a large clinic, spoke about parents’ reactions and said “babies are hard as parents don’t usually expect anything is wrong. First babies are the hardest.” While devastation is understood as inevitable, it is also construed by professionals as contributing to parents’ incapacity to digest information, as a health professional in a busy audiology service explained: “I think because most people go into that shock or are traumatized by what you’ve just said, then their ability to ask questions just shuts down.” The implicit and explicit assumption is that emotions caused women to experience some impairment in their ability to make choices and decisions.

The construction of the devastated mother and assumptions about affect and parents’ reactions to their children, were actively reinforced by professionals through discourse and interactions. A senior professional said in interview: “I think it starts from, you deliver a perfectly healthy, wonderful child and then you're told your child is not perfect. They're deaf. Which is devastating because they're (the baby and parent) not the same."

Alongside of evidence that professionals understood parents as highly emotional, there was evidence from parents that audiologists found the diagnostic process emotionally tough. Duibhne, mother of three-year-old Rachel, recounted, "the audiologist gave me the results and she started crying….and she sort of looked at me like, why aren't you crying?"

An audiologist spoke about the difficulty of telling a new mum that her baby was deaf: "The mum was on her own and she was a complete mess, just devastated. We had to stop halfway through the test while she got her husband to come. It was awful." The audiologist clearly found the process emotionally confronting, which was communicated to the mother. The mother was "devastated" during the diagnosis but when recalling her reaction, she said: "The audiologist seemed uncomfortable…like she was telling someone bad news. Anyway, with the third test I was completely devastated. We were devastated about the future, about Maisie's future. For the first two days I was inconsolable, and I just cried." The mother explained in subsequent interviews that initially she was devastated by the diagnosis, but receiving conflicting information from professionals, acting as gatekeepers, and the clinician's display of affect, was emotionally confusing.

There was ongoing debate from professionals about whether parents needed counselling and if the referral protocol was providing parents with this support. There was minimal involvement of trained counsellors at the point of diagnosis with only one early intervention program providing a dedicated family counsellor. Julia, an education professional, said: “One of the biggest things missing in all of this is counselling. There’s never any counselling for parents to work through their grief.” Despite the lack of counselling, women as mothers were often viewed by professionals as vulnerable and requiring sensitive support and a level of protection. This was evident in conversations and interactions the first author had with health and education professionals who kept researchers, media, and other interested parties away from parents for a predetermined period of time until they had, to quote one teacher, “found their feet.” This indicates a clear sense of care from professionals at what they understood to be a difficult time. Managers of early intervention services spoke about the roles parents might take within their organizations. One manager believed that parents were unsuitable for board membership because they were “too emotional,” and therefore unable to separate their child’s needs from an organization’s needs. The sociocultural construction of emotion and the notion of the “devastated mother” can be seen as a process of performativity. An active reinscribing, through the discourse of “devastation” as a gendered emotional experience, occurs during encounters between parents and professionals (Beatty 2014; Butler 1990; Salih 2002). In addition, “it is expected that women will be more emotionally responsive than men; consequently, society relegates more emotion work, including love work and grief work to them” (Scheper-Hughes 1992: 427). Parents, and in particular mothers, in their reactions to diagnosis, concur with the experience of devastation, yet resist the notion that this emotionality is negative or undermines their capacity. Rather, emotion is conceptualized as motivating. The positioning of parents, women especially, as devastated, or irrational due to their emotional responses, may implicitly justify a shift away from an idealized patient centered practice towards a paternalistic and dominant medical model of care.

Parents' responses to the diagnosis: emotion as motivator

Two months after Hillary and Mark's baby was diagnosed, the first author met Hillary at an early intervention center where a group of women were talking about their child's diagnosis. Hillary said, "It's true, I was devastated and sad, but then my response was to go deep and find out what it all meant and take some action, we read papers and studies, downloaded sign language apps, and on day three talked to all the intervention services." She pulled out her smart phone and showed the other women an image she had found on an online parent's group. The image featured a version of the classic feminist icon from World War II, a woman flexing her bicep, only this time a cochlear implant was tattooed on her arm and the slogan read, "cochlear implant mom: not for the weak." The women in the group responded with laughter and to Hillary's inference that she was indeed strong and not impaired by her experience.

Parents in this study, particularly women, all revealed the centrality of emotion in the diagnosis and in their decision making. Deeply felt emotions shaped their narratives and strongly held beliefs about cultural belonging, communication, and inclusivity for their children. Emotions were perceived as empowering. Women talked about "doing battle" with and navigating services and the NDIS, which, June said, "makes me so frustrated!" Ongoing struggles for funding for certain kinds of listening equipment, eligibility for cochlear implant surgery, or access to therapy were regular foci of conversations. Feelings of anger and exasperation, love and hope were transformative, and many women became advocates. The construction of the devastated mother as vulnerable or impaired, we argue, is therefore negated, and a more nuanced meaning—of feeling and thinking, of holding sadness while logically making decisions—came into play (Lutz 1988; Lutz & White 1986; Wikan 1990).

Emotions were multi-layered and contingent on diverse biographical, temporal, and sociocultural factors such as how, and what, information was delivered, whether this was a first baby, if there was already deafness in the family, the socioeconomic status and cultural background of the family, and if either parent had had previous contact with people who were deaf. While "the most pervasive cultural assumption about emotion is that it is antithetical to reason or rationality: that is sensible actions and ideas" (Lutz 1988: 59), our data support the notion that for parents, emotion is associated with a process of thinking, taking action, and logically assessing options. Mollie, a 39-year-old mother of three said: "There seems to be an assumption that if you have grief you can't…handle the information…and make sense of all information, sensible choices ... That's how I was being treated."

There was a reoccurring theme in fieldwork of emotion as irrational and chaotic. There is a disjuncture between the ways women were perceived in this setting. This is paradoxical. On the one hand most professionals understood that women will have a range of emotions and that they are the "experts" for their child, while at the same time women were viewed as being so vulnerable that managing information and decision making might be impaired. Gladys, a 40-year-old mother of three children, said: “We were grieving…. but I rationalized my grief quite quickly. What I didn’t like was the way everyone told me how to manage my child. There were too many people interfering in our lives and after two weeks I said [to myself] this is your new life, get on with it!” In this context “getting on with it” related to the myriad referrals and appointments with audiologists, ear, nose and throat surgeons, pediatricians, and teachers of the deaf.

Women often talked about “doing the best for my child” and “taking the bull by the horns,” an approach that was reiterated by Josie who was sad and worried her child would stand out yet, after a relatively short period of time, was moved to action,

> I was so emotional following the diagnosis. I was filled with sadness for Tilly and scared for her future. I was concerned about bullying at school and that she would be different due to having hearing aids. This lasted a couple of months then my attitude changed to a deep motivation to find out what I could do to ensure she would have the same life as any other child.

Some parents sought alternative non-medical approaches for their child’s deafness. During fieldwork the parents of three-month-old Aesha travelled home to Pakistan, as her mother explained, “to pray to our gods for a miracle. We want her to be cured.” Their Teacher of the Deaf explained: “They followed their faith. When the mum came back to Australia she was better, before she cried all the time and was devastated.” The mother said: “I will do the best for my baby, and you know what, if she’s not cured then maybe the miracle is that we live in Australia where we can get cochlear implants and she will hear me.” While she experienced sorrow at the diagnosis, her faith and western medicine, seemingly contradictory knowledge systems, were harnessed as motivating forces. On returning to Australia, she said to her therapist, “right, let’s get back to business,” which became the business of developing her daughter’s spoken Urdu and English.

After the diagnosis many parents spoke of going through mixed emotions and then rationalizing feelings. The days following a diagnosis were experienced as a period of intense, embodied emotions, grieving and tears. Initial grief was ameliorated for some parents by support from family, by finding trustworthy information and by a passage of time, which supported a process of reflection, contemplation and engaging with decision making. For others, emotional reactions encouraged religious pilgrimage or seeking alternative healing. Many women found solace in peer support either online or through small group programs where meeting other women and sharing experience was made possible. The search for knowledge and understanding began, for many mothers, through talking with other women, finding community with new families, meeting and developing trust with professionals, and searching the internet or accessing online chat groups. Justina, a hearing mother of a deaf child, was so motivated to find what she perceived as truthful or unbiased information that she enrolled in a university course to train as a Teacher of the Deaf. She explained why she chose to alter her career: “My goal was to get information and professionals don’t really tell you the facts, they always, they can’t help it, but they give you a version colored by their own experiences, or their own philosophies and I wanted accurate information… my goal really was to get the information that I needed to make decisions for my child."

A feeling of journeying into a new world was a common theme about understanding the situation or diagnosis. Diagnosis is often a transformative and powerful experience that shifts identities and gives rise to "biographical disruption" (Bury 1982), in this case shifting notions of parenthood and family narratives that "constitute a 'new kinship imaginary' with temporal and social implications" (Rapp & Ginsburg 2001: 383). The child who is different creates a relational social space that shifts family dynamics, sibling relationships and maternal labor expectations (Landsman 1998, 2001: 386-387; Pfister 2019). Valentina, a parent, said in an interview: "I was shocked at the diagnosis. I didn't know whether I should be disappointed, or I should cry or feel sad or what. We didn't think about speaking or signing. We were just totally like, 'well, what we are going to face from here?'" Valentina had multiple children who were deaf, but the diagnosis of a subsequent child was not easier. When her third child was diagnosed, she said: "I expected it, but I was still devastated. People say you know how to deal with it because you have other deaf children. Yes, you do but you've got to do all that work."

Professionals recognize that this onerous work is often maternal labor. But when pressed, Valentina said it wasn't the weekly sessions of early intervention, it was negotiating with professionals, and in particular the National Disability Insurance Scheme, which she found arduous and frustrating. Her "journey," a term she and other parents employed, referred to a navigation process, a battle with structural and discursive practices. This theme was repeated by other parents and calls into question policies in deafness and assumptions of professionals that all responses are necessarily about the child’s diagnosis. Feeling devastated may be for the self as well as for the child, and it may be situated in the interrelated systems within the field that the parent negotiates. An interplay exists between parents’ emotions and the organizational structures framing the diagnostic setting, and many parents said that navigating and negotiating highly bureaucratized protocols and policies within the pathway was distressing and at odds with their ideas about parenthood.

Emotion featured in parents’ stories and reflections on their experiences of the clinical process. Parents spoke of their fear for their child’s future and wanted “everything to be normal.” They spoke of gaining a sense of direction and feeling motivated when they found other families with young children and early intervention services that helped with understanding options and future opportunities for their children. Many parents said this provided a sense of community and strengthened their sense of belonging. As one mother reflected, “we decided very early on we needed to share our life experience with other families. And we learned a lot from other parents as well as being in that community.” This theme of community and commonality, of shared lived experiences as sources of emotional support and information, was central to many women’s experiences and was perceived by them as a valuable form of support.

Parents questioned what deafness meant and communication was seen as central to the transfer of cultural knowledge, and to their capacity to bond with and raise their child. Many parents viewed their child's capacity to communicate in the same way that they communicated, through spoken language, as key to who they were as a family and to their sense of cultural belonging. Sharing an oral culture was valued as a way of sharing stories, social practices, and culture. Five families spoke English as a second language and their children developed two spoken languages through combining service-based therapy sessions with language learning at home. One mother, whose deaf son was an adult, reflected that "I felt my right to do this was continually challenged, both subtly and at times, explicitly." In navigating the deaf field and searching for an intervention program that provided an auditory verbal approach, stakeholders who claimed to be impartial told her "that sign language was the natural language for deaf children." This mother felt conflicted but as she explained, "that's the politics of deafness."

Tiffany said she knew when her baby was first diagnosed that she needed a visual language and wanted her to learn Auslan. She also chose a cochlear implant for her daughter, and it took time to access an early intervention bilingual program. Education providers from different early intervention organizations held contrasting views about deaf children and their families. Some advocate for a listening and oral only approach, or a bilingual or bicultural approach of Auslan and spoken or written English, or a "holistic approach." Scientific discourses including evidenced based practices and the politics of neuroscience were employed to encourage engagement with early intervention and maternal compliance for "training their child's brain" (Mauldin 2016). Alternatively, access to signed language for all deaf children to prevent linguistic neglect (Friedner 2018) was posited. Medical and education views about communication and language may have worried Tiffany, but she was determined to find what was right for her child "in my mother's heart."

Conclusion

Through this ethnography, we challenge pervasive sociocultural assumptions about the role of emotion in health encounters. Tensions are revealed between how, in the diagnostic process of childhood deafness, emotion is understood by parents and professionals. The clinic is an affective space where emotion talk is negotiated and translated in encounters between participants (Latimer 2013b). Disentangling assumptions in this setting, our data indicate that concepts of emotion and medical diagnosis can be upended to shift normative ideas for more subtle understandings of the role of emotion in parents' experiences.

We have demonstrated that diagnosis of sensory loss in a child *is* often devastating for parents. Narratives, especially from women, indicate that this emotion is perceived simultaneously as affect and motivational force. Emotions including hope, love, fear, anger, and sorrow are central to parents' experiences of moving from devastated to motivated. Parents navigate and advocate and "take the bull by the horns," to quote Gladys again.

Reactions are shaped by multiple factors including sociocultural backgrounds and access to services. Emotion is at the core of this journey. Parents reflected on deeply sensed reactions about their children and were motivated by thoughts of love, hope and inclusion. Professionals spoke about parents who had "dropped off the radar" and did not return for referrals or further tests, suggesting that mitigating factors may complicate experience and level of engagement with the medical process.

Health and education professionals often perceive emotion as a problematic reaction by parents to, and affecting the efficacy of, diagnostic referral. The parents with whom we worked, however, present a more complex and nuanced state of being, where reactions are not separated from processes of reasoning and logical thought. Herein lies the dilemma. The diagnostic hearing pathway aims to be supportive, follow best practice policies, and offer inclusivity, but parents experienced it as confusing, disempowering, and paternalistic. Professionals also experience and display emotion that problematizes their role in the medical setting. Professionals are trained in their encounters with patients and parents to be dispassionate and objective. Parents' emotional reactions are not attributable by professionals solely to receiving "bad news" about a newborn infant.

Attending closely to parents' narratives through ethnographic methods, we demonstrate how reactions are inextricably connected to structural barriers that may create stress and feelings of frustration. These feelings often motivate women to seek alternative sources of knowledge and support and to become advocates for their children.

This study calls for a greater consideration of the way parents and in particular women are perceived in clinical encounters and referral processes associated with childhood deafness. Parents' deeply felt emotions after their infants' diagnosis were real, embodied experiences. Women spoke of withdrawing after the diagnosis and seeking solace through “being left alone,” seeking space and time for reflection. Many women sought the communality of other women and other families. The support gained from sharing lived experience, and an ongoing exchange of care, knowledge, and commonality, helped many women build resilience and make decisions about the next steps.

Social practices in medicine lead to broader questions about the role of emotion in other biomedical diagnostic contexts. Perceiving emotional reactions as an impediment to logical thinking may justify health professionals’ inherent control, which is problematic in a contested deaf setting. For parents, emotions are central to their experience of diagnosis of childhood deafness and fundamental to the meanings constituted in this context. Emotions are embodied, socially produced and for many parents in the medical encounter of childhood deafness, moments for reflection and motivation.

Figure 7: Soundproof booths in an audiology and cochlear implant clinic. Thick, heavy doors decorated with underwater imagery create a subterranean feeling.

Figure 8: A baby has a hearing assessment in the audiology booth. Two audiologists in separate booths work together, the mother holds the infant and dad, sitting in the corner, looks on.

Chapter 5

"It's an emotional rollercoaster" the spatial and temporal structuring of affect in diagnosing childhood hearing loss.

Title of paper	“It’s an emotional rollercoaster” the spatial and temporal structuring of affect in diagnosing childhood hearing loss.
Publication status	Published: Accepted for publication (as presented below) 17 August 2020.
Publication details	Harris, C. Hemer, S.R. and Chur-Hansen, A. 2020 “It's an emotional rollercoaster” the spatial and temporal structuring of affect in diagnosing childhood hearing loss. *Emotion, Space and Society*, *37*, p.100729.

Name of Principal Author (Candidate)	Claire Harris
Contribution to the Paper	Developed rationale for the study, devised research questions and aims. Planned and carried out ethnographic fieldwork and data collection and performed data analysis. Drafted, wrote, and submitted the manuscript (acting as corresponding author). Revised and responded to reviewer comments.
Overall percentage (%)	80%
Certification:	This paper reports on original research I conducted during

	the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	10/12/2021

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

v. the candidate's stated contribution to the publication is accurate (as detailed above);

vi. permission is granted for the candidate in include the publication in the thesis; and

vii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Abstract

Despite well-established screening for hearing problems, and objective, diagnostic techniques aimed at dispelling uncertainty, some parents spend months waiting for clear diagnosis of their child's hearing loss. In the clinical setting, providers use international best-practice policies in diagnosing and managing childhood deafness, yet limited attention is given to the role of emotion in this context. Drawing on socio-spatial and temporal theories we conceptualise the clinical waiting room and soundproof booth of a paediatric hearing clinic as affective spacio-temporal places that both constrain and evoke emotion. Tensions between parents and professionals grew, and emotion and affect were problematised in the clinical setting where temporal notions held significance. We consider contentious or difficult areas in the management of childhood deafness through a number of cases of parents experiencing uncertainty as they grapple with decisions for their children. Alternative spaces and experiences in non-medical settings that hold value for parents are discussed in considering new approaches to managing childhood deafness.

Keywords

soundproof booth; waiting rooms; temporality; deafness; uncertainty in diagnosis; emotions; parents

Introduction

During fieldwork in a busy waiting room of a paediatric hearing clinic, the first author sat with June[11], a forty-year-old mother. Her youngest daughter, aged two, had been diagnosed with a hearing loss and fitted with hearing aids. June had been taking her to weekly therapy, but progress had been slow. We were waiting for an appointment with an audiologist for an assessment of her hearing. June appeared distracted and was quiet. She turned to the first author and said she was feeling ‘pretty anxious’,

> I sit here and wait and wonder what they’ll tell me this time. Has it [hearing loss] got worse, are the hearing aids still working? Can she hear me? It makes me feel sick.

June’s embodied feelings of apprehension and anxiety, caused by medical uncertainty: ‘what will they tell me this time?’ and by long periods of time spent waiting in the waiting room, were repeated in conversations the first author had with other parents. Waiting and a lack of certainty affected parents emotionally in their capacity for making important decisions and how they thought about their child’s future. Medical professionals in the field acknowledged that diagnosis and management of what they called the ‘grey areas’ in childhood deafness, were very challenging. The process of diagnosing and managing hearing loss is uncertain in cases of so-called fluctuating, progressive or deteriorating hearing, or where an infant has co-morbidities that complicate or mask identification in these contentious ‘grey areas’. The temporal connections between emotions and place when diagnosis and

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[11] All names of people and sites are pseudonyms.

prognosis are not linear or certain and where lay and medical knowledge are contested, hold significant implications for parents.

We consider how emotions are constituted through temporal experiences of a clinical waiting room and an audiology soundproof booth. The connections and tensions between emotion, space and temporality are analysed to understand the meanings embedded in this encounter of knowing and not knowing (Street 2011, Tanner 2002). We argue that emotions, including anxiety, fear, and uncertainty, are evoked and managed in the socio-temporal experiences of the hearing clinic. Theories about emotion, time and socio-spatial concepts are drawn on to disentangle the complexities of these understudied clinical spaces and their occupants (Agnew 2005; Davidson, Bondi & Smith 2005; Strathmann & Hay 2009; Tanner 2002; Tuan 1997).

This article considers the everyday practices within a waiting room and soundproof booth of an Australian paediatric hearing clinic to illustrate how time, space and place evoke and shape emotional states, which have consequences for feelings of self-efficacy, and for engagement with treatment plans (Strathmann & Hay 2009, Triggs 2016). The waiting room and soundproof booth are analysed in the context of affective, temporal encounters, and practices within the audiology clinic are described to explore the intersections of time, space, and emotion as they shape experiences for parents. A case study is presented: two parents who experienced embodied anxiety and ambiguity over repeated tests to examine the ripple effect of not knowing. The paper concludes with a call for greater consideration of the temporal and spatial dimensions of clinical encounters and for further research into alternative non-medical spaces in the practice of supporting families with children who are deaf. We argue that greater currency should be afforded to alternative non-medical diagnostic spaces that were perceived by parents as familiar, comforting and highly valued. Alternative spaces give greater agency to parents and improve their sense of wellbeing.

Methods

This ethnography included fifteen months of fieldwork across eight diagnostic clinics and early intervention centres for deaf and hard of hearing children in an Australian city. Participant observation and interviews were carried out with 80 participants including 41 who were parents of deaf children, two grandparents, 27 medical and education personnel and ten young adults with cochlear implants. Interviews were primarily conducted away from the clinic in parents' homes. Interviews were transcribed, and field notes were written up from scratch notes. Data were entered into NVivo and analysed thematically. Ethics approvals provided the first author with permissions to spend extended periods of time in structured clinical settings including in three hospital departments, allied hearing clinics, and in non-medical and non-government sites. Approvals to accompany or shadow families and medical workers through clinical and education spaces were also afforded. She observed parents and clinicians, and followed families as they attended appointments with infants, young children, and teenagers. She is the parent of a child who is deaf, and she has other family members who are deaf or hard of hearing.

The Waiting Room and soundproof booth: an affective, temporal encounter

The audiology waiting room and soundproof booth are affective, temporal sites. They are places of waiting and encounters with health specialists, where hearing loss is diagnosed, informed choice is enacted, and cochlear implant eligibility is determined. Knowledge and emotions intersect in this space and are transacted and negotiated between parents and medical professionals. Parents’ emotions including hope, anxiety, frustration, and worry are bound with the clinical experience signifying an interrelation of space, time, and place where emotion is both evoked and constrained (Dundon & Hemer 2016; Hochschild 1979; Tuan 1977; Waltz 2016).

Moving in and through geographical environments, medical sites, homes, or workplaces, the embodied and situated nature of emotion, affect and memory connect to form webs of meanings (Davidson, Bondi & Smith 2005; Dundon & Hemer 2016; Tuan 1997). A body of literature recognises that many parents have strong emotions when their infant is diagnosed deaf (Bosteels et al. 2012; Friedner 2018, Mauldin 2016; Pfister 2017). The hearing clinic is made up of interrelating patients, parents, play therapists, siblings, doctors, nurses, and biomedical bureaucracies, and technologies, are relational and co-constitutive sites (Cresswell 2015; Tuan 1977; Wright et al. 2016). This is relevant in untangling the meanings in parents’ conversations about and experience of medical encounters where diagnostic uncertainty features and is accompanied by feelings of worry and apprehension.

Parents are intricately bound to the hospital and medical assemblages as they make repeated visits with their child. Tuan’s (1997) concept of topophilia, defined as an affective bond or emotional tie to a place, has relevance in considering the affective nature of the clinic. The perceived conception of space or physical location becomes social space or place through lived experience, and temporality connects to perceptions of place to add another layer to spatial knowledge (Tuan 1978). In the biomedical context an affective bond is often shaped by feelings of ambivalence and by the power differential that structures relationships between patients (parents) and medical specialists. We put our trust in doctors' expert knowledge, and place ourselves in their hands, but tensions emerge when clinical events, particularly around diagnosis and treatment strategies, do not go according to plan. Medicalisation can be both empowering but also requires a process of surrendering to the medical gaze and the processes and consequences that comes with the engagement (Foucault 1975; Mauldin 2016; Latimer 2007, 2013a). Hospitals evoke mixed feelings: hope, trepidation, anxiety, anticipation, worry, and expectation. Ongoing uncertainty and anxiety can be seen to fracture perception of place and 'presents itself as the unmasking of beliefs about how we think the world ought to be' (Triggs 2017, p.4). We demonstrate that for parents, repeated medical encounters and lack of diagnostic clarity produce anxiety. Perceptions of inhabiting a clinical space that is imbued with temporal dimensions create an embodied sense of trepidation. Anxiety is informed by, and informs, perceptions and experiences of the clinic (Triggs 2016, 2017). A symbiotic relationship iterates through multiple encounters.

The diagnostic management of paediatric deafness is firmly located in a medical setting where objective knowledge is taken for granted and with medical science is the basis of determining hearing loss (Duchan & Kovarsky 2005; Lupton 1994). A hearing test produces an audiogram of a patient's audible thresholds across frequencies of decibels and hertz. This diagnostic document enables action and treatment; a linear movement across time, while 'effective action depends upon a momentary and localised stabilization of knowledge' (Street 2011: 819). The referral pathway is embedded with temporal notions about effective interventions that maximise a child's development. Parents navigate through what is perceived as a complex diagnostic pathway to make choices that have temporal dimensions for their children about hearing aids, surgery, communication, and early intervention options.

Medical waiting rooms are recognised as spaces that create anxiety and stress for patients and their families. They are often crowded and noisy sites where patients sit and ponder whether the news about a medical condition will be good, bad, or unexpected (Waltz 2016; Tanner 2002). They are liminal places that draw people away from their everyday lives and transform identities through testing, labelling and treatment processes (Long, Hunter & van der Geest 2008). Designed as spaces of order, patients wait for their turn to be called. Waiting is structured by linear time and pre-scheduled appointments although clinical emergencies, longer than expected surgeries, and health funding all effect staffing, resources and waiting times (Long, Hunter & Van der Geest 2008; Lupton 1994; Mechanic 1978). Time 'drags' in the waiting room, it feels like time 'wasted', which reflects the commodified and perceived linear nature of time in Western culture (Munn 1992; Postill 2002; Waltz 2016). Delays and uncertainty cause emotional strain which must be managed (Strathmann & Hay 2009) and this sense of time lost; of missing the window of opportunity in an infant's development, is structured, and reinforced by the clinical experience.

In contrast to the waiting room, a hearing clinic's soundproof booth is designed, and purpose built to provide an environment that is insulated from external sound. It is here that parents take their infants for testing. The sense of quiet inside the booth is a sharp contrast to the pandemonium of the waiting room. Thick walls, acoustic panelling, and sound reducing windows provide a space that is absent of audible sound. Heavy, vacuum sealed doors create a border between the outside world and the focused intensity of the booth; a place for determining hearing acuity. Audible range at levels of pitch and decibel, assessments of aided and unaided speech perception and the activation of cochlear implants, are carried out in the silence of the booth. Two-way windows between booths enable audiologists to work together, and each space contains desks with chairs and shelves of children's toys. Lights are generally low; the space is quiet and offers an oasis from the commotion of the clinic.

Everyday practices in an Australian paediatric hearing clinic

The audiology and ear nose and throat clinic located within a large public hospital, is an affective space where ideas about healthy, 'normal' babies interconnect with medical interventions and diagnosis. Hospitals are recognised and experienced as sites of emotional resonance, they are places of birth and death, and locations for illness and healing. They provide diagnosis, prognosis, and the management of disease; they offer patients answers, hope and comfort. In treating childhood deafness, audiologists, ear nose and throat (ENT) surgeons, paediatricians and geneticists assist parents with determining a child's diagnosis, which can be complex. Emotional reactions in the clinic include fear, worry, shock, guilt and sadness (Mauldin 2016; Pfister 2017; Young 2010) and these are mediated by 'feeling rules' or social norms, which shape appropriate feelings in a given social context or encounter; emotions are mediated and induced or constrained through experience and perception of social settings (Hochschild 1979, 2012; Lutz & White 1986; Strathmann & Hay 2009). Parents react to the news about their child in different ways: a diagnosis of deafness or 'disability' may be welcome, or it may challenge, and be transformative as parents adjust to raising a child who is marked 'different'. The waiting room may cause stress for parents when a child's difference is visible and on display: 'the medical waiting room represents a rare space of public display for the otherwise private fact of illness or imminent death' (Tanner 2002: 115).

The impact of anxiety and ambiguity when a diagnosis remains elusive, is complex emotionally and shapes interactions in the clinic. The lack of clarity is likened to being on an 'emotional rollercoaster', to quote Mary, a mother of two children, with marked, and emotional highs and lows. This emotional rollercoaster reveals a set of tensions between medical and lay experience that is underpinned by empirical and embodied or objective and subjective knowledge. Diagnostic uncertainty creates temporal pressure as attempts are made to explain or control the seemingly inexplicable or intangible. This was apparent in observing parents whose children were undergoing Visual Reinforcement Audiometry (VRA). The test provides an indication of how responsive a child is to sound. An auditory stimulus is presented to the child who typically sits on a parent’s lap or in an infant highchair. A loudspeaker is positioned at 45 or 90 degrees from the child and the auditory stimulus will cause the child to turn to the sound. Reinforcement is followed with an animated toy next to the speaker. Ideally this test provides clear indications of a child’s capacity to hear. Yet medicine does not always provide definitive answers and when it is tied through a referral process, with rehabilitative early intervention and hopes for a child’s future, the narrative becomes complicated. These themes were generated in data analysis and are explored in the discussion below.

In interviews and through long term participant observation it became evident that the clinical setting often created anxiety and worry for parents. Emotional tone was shaped by fears about infant communication and development, and by unexpected labels, but more so by being in an ongoing or liminal state of not knowing. The diagnosis was a time of embodied emotional response that envisaged or enabled a moving forward, an acceptance and engagement with referrals. Parents’ temporal concerns were linked with the future: a child’s progress, decisions about school and post school options, and possibilities for kinship, friendships, and social belonging (Rapp & Ginsburg 2011).

Waiting and the waiting room were often the subject of conversation amongst the parents who participated in this research. Early in fieldwork, the first author waited one morning with families for the clinic to open. Children aged from birth to 18 years with a suspected hearing loss, speech and language disorder, developmental delay or disability, attended the clinic. The ENT surgical department, aligned with audiology, provided services for patients with disorders of the ears, nose and throat and performed paediatric surgery including grommets, bone anchored hearing aids and cochlear implantation. The waiting room had rows of back-to-back seating arranged in close proximity for about 60 people. A children's play area occupied one corner of the space. An 'L' shaped reception desk divided the waiting area from a row of consulting rooms that framed the back wall of the space. ENT surgeons appeared intermittently from these rooms as they called patients in for appointments. To the right, behind the reception desk and past the ENT consulting rooms, was a door to the audiology clinic, which occupied its own space. Here, audiology offices and consulting rooms, and four soundproof booths, operated in a space unseen from the main waiting area that afforded a sense of seclusion and quiet.

The hearing clinic saw public and private patients as it was a key site for hearing assessments and for the state's cochlear implant program. Mothers, looking tired and strained, held babies while toddlers slept in prams. Teenagers were glued to their smart mobile phones. Energetic children ran between rows of seats and in and out of the play area. By 9am parents had already formed a long queue from the reception desk through the waiting room. "Welcome to the zoo", said one of the doctors. Pinned to the notice board near the desk was a hospital poster of a smiling child kissing a smiling woman. It said: 'Eight Ways to be Person and Family Centred' and top of the list was 'Respect for Consumers' and 'Emotional Support'. Later a dad with an eight-year-old boy called to a passing nurse, "I've been waiting for hours and would like to get home before midnight and home is a 6-hour drive". "I'll see what I can do", she said.

Notions of temporality play out in the clinic where anxiety about time is constant (Munn 1992). The waiting room tests the patience of the most tenacious parents, while the soundproof booth creates more intimate and temporal concerns about the child. Parents speak about a fear that their child may miss a critical growth period while professionals convey a sense of urgency that the diagnosis and referrals should be made as early as possible so that parents can begin a long process of aiding their child's communication development (Mauldin 2016). Temporality and emotion feature in parents' talk in the waiting room. The experience is described as frustrating: as one young mother said, "It is so disrespectful, like our time is not at all important. It drives me mad". They also become resigned to this as the reality of the medical experience. Perhaps it is no accident that the word 'patient' is both a noun and an adjective - to receive medical treatment we must accept delays. Delays are embedded here, as the three arms of the clinic - audiology, ENT and cochlear implant, are drawn on to respond to individual and unexpected needs of children and parents on any given day. The space of outpatients' waiting was not only about time passing but was weighted with emotion and worry about what might or might not happen in the future.

Engagement in relationships within the clinic, an affective space that is repeatedly visited as children are taken to multiple appointments, and environmental specifics of the site, are generative of emotions. A mother of four children told the first author that she felt she had become time poor as so much of her energy and time was spent attending appointments and waiting. Structural complexities or barriers in seeking medical or rehabilitative care was the main issue rather than any perceived maternal labour involved in parenting a child with a disability (Green 2007). ‘A waiting room, by definition, functions as a place we pass through on the way to somewhere else, a temporary stop rather than a destination. By and large, time spent in a waiting room represents time wasted; the shorter the wait, the more successful our stay’ (Tanner 2002 p. 116). Yet it was clear for parents in this study that the temporal and socio-spatial dynamics of the waiting room significantly shaped their experiences of the medical encounter.

Tuan’s (1997) concept of crowdedness assists in explicating the spaces of the clinic. The waiting room evokes strong feelings in many parents. They would comment that the space was ‘crowded’, ‘noisy’ and ‘busy’. The feeling of being in a physically crowded and chaotic space that was an intense (noisy) auditory environment increased parents’ levels of stress and discomfort and channelled feelings about the diagnosis and the child. The concept of crowdedness in this clinical setting signifies the opposite of spaciousness to conjure feelings of restraint. If spaciousness can be envisaged as providing a sense of freedom, then crowdedness becomes the opposite as ‘space that seems to close in on him’ (Tuan 1997: 52) or to put it another way, ‘the world feels spacious and friendly when it accommodates our desires and cramped when it frustrates them’ (1997: 65). In the waiting room emotions including fear, anger, frustration, and sadness, were constrained, or managed in line with cultural rules about appropriate emotional display (Hochschild 1979, 2012). People kept within themselves. There was very little interaction or conversation between people sitting in close proximity.

Many parents find the experience of hospitals and diagnosis emotionally unsettling (Lupton 2000; Strathmann & Hay 2009). In conversations and interviews with the first author, parents revealed that feelings of anxiety often started from before they entered the building as if anxiety acted to disrupt a sense of place (Triggs 2016). Parking, and waiting were significant factors in parents' hospital experiences, and the subject of passionate discussions. The car park and off-street car parking were often full, which caused frustration for parents with small children and multiple appointments. Off street parking did not meet the long clinic wait times and inspectors were ready with expensive fines. Parents often needed to leave the waiting room to move their car, which risked missing their appointment. Parents cited this as a cause of stress that combined with the anxiety of waiting and the sense of time lost.

Jill, a farmer and mother of three children said,

> I just get stressed out by the waiting and by the waiting room. It's terrible, it's dirty and crowded. I thought I could work out the system, so I booked an appointment six months in advance for 1.30, which is when the clinic starts. I thought this would do it. And then I got a letter, two weeks before the appointment, saying it had been moved to 2 PM.' She sighs. 'So, I have to wait for six people before me. I still have to wait two hours. I hadn't worked out system at all!

Trying to play the system by booking the first appointment when the clinic opened could not guarantee avoiding delays. This clinical space of on-going appointments evoked emotions in Jill, months in advance of the scheduled meeting and managing these feelings contributed to the creation of this emotional tone (Hochschild 2012). Jill was exasperated by juggling small children with minimal control over appointments and time lost waiting and parking.

While medical appointments were often slow and frustrating, the element of uncertainty in the audiology clinic was linked with the capacity to communicate with an infant, which held deep significance for parents. Communication was perceived as a vital connector between parents and infants and uncertainty was inextricably linked to stress and anxiety. As one mother Laura, explained, ‘I feel really sad and I worry that I won’t be able to communicate with my child, how will I teach her anything?’ The waiting room and soundproof booth, when connected with diagnostic doubt, provoked emotional strain that was tied to communication and responsibilities of child rearing. It was clear that ‘spatial and temporal dimensions cannot be disentangled, and the two comingle in various ways’ (Munn 1992 p. 97) and that waiting in medical spaces exacerbated feelings of uncertainty and anxiety (Sweeny & Cavanaugh 2012).

Several families with infants were undergoing repeated diagnostic testing due to complex health issues and indeterminate or fluctuating hearing losses. Mild hearing losses were an area of uncertainty because it was not clear whether the child should be fitted with hearing aids. Professionals worried that once these children were at childcare or pre-school, they would struggle to hear in background noise. Parents experienced uncertainty, being in a state of limbo, waiting and not knowing, which increased levels of anxiety and embodied feelings of worry or stress. Grace, a mother of two children, who is discussed in more detail below, told the first author that the lack of diagnosis was ‘causing sleepless nights’.

Audiologists test infant hearing with Visual Reinforcement Audiometry (VRA), or the puppet test as parents called it. It is considered the best testing method aside from a procedure performed on a child under anaesthetic, which doctors told the first author they liked to avoid as much as possible with infants. The method is regularly employed with infants when they are considered developmentally likely to respond, which is generally older than six to eight months of age. During fieldwork the first author observed this process many times: one audiologist sat in a booth with the infant and parent and acted as a distracter to keep the infant on task. The second audiologist was in the adjoining booth and operated the audiometer, which plays sounds and records the baby’s auditory responses. A window between the booths enabled the second audiologist to see the child’s reactions. The audiologists were connected across space, so they could speak with each other and discuss individual assessments in real time. Sounds were played into the air and the child was ‘trained’ to respond to the noises with the reward of a moving puppet or toy, which was controlled by the audiologist in the second booth. While this test was conducted in a space that was purpose built for the process and that entailed highly trained specialists, parents often questioned its efficacy. They were especially dubious when the results were not clear, which raises questions about medical dominance and perceived objective and subjective knowledge, and highlights tensions between parents and health professionals (Foucault 1978; Lupton 2010).

Grappling with uncertainty: Vincent and Grace

Vincent and Grace, two parents who participated in this research, grappled with an uncertain diagnosis and multiple visits to the soundproof booth. The first author met them when their son William was eight weeks old and followed the family for over 15 months. At six weeks of age William had been fitted with hearing aids for a mild to moderate hearing loss. Initially the parents said they adjusted quickly to the diagnosis and to weekly therapy sessions with Teachers of the Deaf to develop their child's speech and Australian Sign Language skills. Progress in speech had been slow and audiologists began to undertake VRA with William from when he was about six months old. Results had been unclear. One test noted a moderate hearing loss, some months later a severe loss was recorded and then tests produced a diagnosis of profound hearing loss. There was discussion about progressive or deteriorating hearing loss and middle ear fluid as possible causes of the test results. Surgery was advised for grommets – the insertion of a small tube through the ear drum to clear fluid – and the parents engaged in a round of multiple appointments. The parents were emotionally exhausted by their highly regulated visits to the clinic.

When the third VRA test revealed profound deafness, Grace said 'I'm really upset and annoyed. We are increasingly cynical of the VRA behavioural testing'. Their distrust of what they saw as a subjective, and therefore a potentially inaccurate test led to a growing lack of confidence in the medical profession. She said,

> There are so many ifs, we don’t know the cause, what happens if more of those cochlear hairs are breaking, what if it’s just fluid causing the issue? We’re not emotionally ready to deal with grommets. The whole thing is a mess, a trial-and-error approach. Most days… I just want to cancel everything and be left alone.

A lack of diagnostic clarity altered parents’ confidence. Not understanding or knowing what or if their child could hear had a ripple effect on other family members and made the process of deciding on hearing aids, cochlear implants and other interventions challenging. During fieldwork, it became apparent that uncertainty in diagnosis and slow development of language caused parents to question the therapy and communication interventions they had chosen for their child, which added to their feelings of anxiety and of time pressure.

Grace and Vincent decided to seek an alternative to the VRA process. They had read an article called ‘Wired for Sound’ in a national newspaper about research trials for a diagnostic assessment tool for hearing. They had become desperate for answers and decided on an interstate trip to a medical research centre where a clinical brain imaging tool was being developed that would provide a new objective hearing test. Scientific knowledge frames the brain as holding answers to so many mysteries of human life. This especially appealed to Vincent, and he and Grace saw this objective testing as superior to the 40-year-old ‘gold standard’ VRA method. The researchers explained that they were at an investigation stage and did not guarantee definitive answers. At the interstate clinic, William was fitted with a skull cap with several electrodes and wires that connected to a computer. A scanning process used functional near-infra-red spectroscopy, a light-based technology to measure oxygenated blood, correlating with brain regions that become active when certain sounds were heard.

Grace explained,

> It is a huge confidence building exercise for us, seeing results that are black and white. We are bowled over by the researchers' passion, these guys LOVE what they do, and they are so compassionate.

The parents were drawn into the potential for new scientific knowledge and became entangled in a clinical 'space of motility' (Latimer 2013b: 181). As they became engaged in the epistemological practices of the clinic, they were moved in certain ways in the spaces or discourses of the medical encounter. The research centre, in the same complex as other ground-breaking biotechnological developments, was held in a space of futuristic science. The sense of new frontier and hopeful possibility, combined with people the parents perceived to be passionate and compassionate clinicians, moved them to feel inspired and empowered, and they began to imagine future possibilities in diagnosis and medical interventions.

The first author met the parents the day after their return from interstate, at the hospital where William was having another assessment. Grace had decided to 'sit out' as she explained, she felt anxious about the outcome and believed her husband could better manage the appointment, so she would 'walk around the hospital' as if moving to alleviate spatial and temporal tension. A senior audiologist went over William's results, which had been received from a separate government hearing clinic. The audiologist said to Vincent, ‘so this last hearing test is very concerning’. The results showed the mild loss had become a profound hearing loss, and the hearing aids’ benefit was in doubt. ‘Do you understand what grommets are about?’ the audiologist asked Vincent, who replied, ‘yes, we prefer to avoid this, we have a bad experience in our family with sedation’. The audiologist reassured him and then said, ‘what we need to think about is how his hearing loss is impacting his speech and language development’. The men sat looking at each other across the table. Vincent said,

> I think it’s all subjectivity. What is he actually hearing, what is his actual range? It would be beneficial to have a different method of identifying that.

The audiologist replied,

> Well behaviour tests are all subjective. The Automated Brainstem Response test he had at birth will certainly give an accurate category of hearing loss but there’s always variability. Objective tests can be done but none of them are fool proof, they can all underestimate or overestimate the actual result. That’s why we lean more on the behaviour test. As long as the child is behaving reliably those results are actually more accurate than the objective tests.

Vincent said,

> Yeah, I heard the history of it, it’s been used for 30, 40 years in identifying the levels but the subjectivity thing, to confirm that he acknowledges the stimuli he has to turn to a puppet.

The father raised his eyebrows, and the tension in the room increased. The audiologist said,

> Well, we can try a different test if he [the baby] is not ready developmentally to respond to the VRA.

Vincent agreed to try this different test. He carried his son into the soundproof booth. The first author observed and listened through a window in the adjoining booth. Contrasting with the experience of the waiting room, the soundproof booth with its thick, porthole submarine door was silent and devoid of external noise. The lights were low, the work was focused and intimate, and time was indeed of the essence. Here, professionals often tell parents that closing the gap between diagnosis and the onset of therapeutic intervention is important to children's communication and language development. While engaging with early intervention services and decisions about technology are choices parents make, the emphasis on timely decisions and closing the gap between diagnosis, referral and therapy is articulated by professionals.

Vincent held William on his knee. The audiologist stood behind Vincent not visible to William and picked up a rubber squeaky bird and made a loud noise next to the baby's ear. There was no reaction. Next, he banged a drum. He worked his way through a range of other objects that created sound at different decibels and pitch. He stopped the test, put the toys back on the shelf and faced Vincent, and said,

> I can't see any responses, which makes me worry that he is not in fact picking up sound at any useful level to develop speech and language. We need to rule out middle ear fluid and talk to the ENT surgeon about how you would like to

> manage that. If you do decide to have grommets, then I suggest we do an objective test as part of that procedure under the same general anaesthetic and see if his hearing has come down.

Vincent listened and then quietly said, ‘so how would you reason, in the house setting, when I call his name, he turns. How would you explain that?’ The audiologist asked the father if he was sure it was an auditory response and not a visual response. The father assured him it was auditory because his son was sitting facing away. The audiologist said, ‘Ok, I know this is not at home now but let’s do that here, we’ll get him to face forward, you call his name and let’s see what he does’.

Still in the booth, Vincent held his son on his knee facing forward. Vincent quietly called his name ‘William… William…’ Then he increased the volume…’William… WILLIAM…WILLIAM’. Then he tried a shortened version of his name ‘Will…Will’. He stopped. ‘I can’t see any change or acknowledgment,’ declared the audiologist. Vincent looked beaten. He was sure his child could hear him. He went out to the waiting room to find Grace and said, ‘they say he can’t hear’. Emotion played across Grace’s face as she reached for her son. The sense of hope experienced in the futurist interstate research clinic was suddenly extinguished.

Vincent was taken to the ENT surgeon, who read William’s file and in a matter-of-fact manner said,

> Ok, the reason you’ve been funnelled into my super busy clinic is because William’s hearing has deteriorated and for that reason we’re looking more

> closely at the hearing and whether we need to look at cochlear implants. The next step is to fairly urgently get those grommets in.'

Vincent explained that he had concerns about the anaesthetic and so began a push and pull between the father and the surgeon as each one made their position clear. The atmosphere in the room was tense as the doctor and father expressed their thoughts and opinions. The father asked about alternative procedures and resisted the urgency for grommets. He was not keen on surgery but, as he stated, they didn't know what William could hear or what the issue was so why should he consider surgery for grommets. With uncertainty in diagnosis why should he make these decisions? The sense of urgency combined with anxiety about encountering a sense of lost time had a deep effect on the parents.

Some months later, Grace explained that it *was* a fear of surgery, but it was also not understanding what audiologists meant when they talked about a 'progressive hearing loss'. She said,

> Progressive had a positive spin rather than what it actually was - a hearing loss getting worse. I thought it meant getting worse over years like an old person, 'progressing', not over weeks or months. That was really upsetting.

A lack of clarity about terminology, in this case a temporal concept: 'progressive', increased parents' unease. 'Progressive' may be meant, clinically, as picking up speed or moving faster in time, but for some parents' it was associated with hearing loss progressing over many years and was associated with a time at the end of life.

Disparities in understandings about specific language, including between lay and medical terminology, acted to structure affect. Being in a state of not knowing or unknowing was perceived as disempowering and attributed to ongoing emotional distress. Grace said, ‘I didn’t sleep well and felt like vomiting with anxiety’. The ‘diagnostic moment’, (Jutel 2014: 185) when a clear definition is communicated, was not to be, and apprehension or nervousness, sensed through the body, would reappear on entering the space of the clinic (Triggs 2017). ‘Diagnosis might be devastating or a relief, but the ‘moment’ is ‘epiphanic’, with its powerful potential to change life and trigger new narratives’ (Jutel 2014: 185) and conversely a deferral in diagnosis is associated with embodied feelings of distress.

Everyday practices within the hearing clinic demonstrate the ways that perceptions of subjective and objective knowledge shape encounters between parents and medical specialists, and act to foster feelings of ambivalence and uncertainty. Parents believed their child was responding to sounds at home despite what professionals said. This sense of disruption was exacerbated by understandings of biotechnology and differing conceptions of high-tech versus low-tech diagnostic tools. Anxiety and doubt that are produced in the clinic, can fracture a sense of linear time that diagnoses and tracks a child through a series of normative developmental milestones.

Alternative Affective Spaces

Parents talked about alternative spaces for deaf children that were perceived as non-medical. These places evoked different emotions and meanings for parents, which calls for a consideration of how services for families are located and framed. Liz and

Steve, parents of a 4-year-old daughter who was deaf, chose a service that had ‘everything under one roof’. Liz said,

> We chose the Children’s Centre because the services are all here. We could get a speech path and audiologist and a counsellor if we wanted one. And then there’s the parent groups. So, it’s easy and I can connect with other parents and get tips and information from other parents.

Steve explained further,

> What it comes down to is you feel comfortable, you feel welcome and like you’ve always been part of the place. It feels like home. It’s not so much a safe feeling but a familiar feeling. It’s that gut feeling. This place feels good.

The place he and Liz were referring to was an old house, which evoked feelings of familiarity and home and was very different to a hospital, clinic, or institution. While ‘home’ is not always a rosy evocation (Creswell 2015) and some parents did not want to be connected with other families, these alternative spaces held value because of seemingly simple factors: access to a communal kitchen and family area, available parking, a central location, and minimal waiting times for appointments made parents feel relaxed, calm and not stressed. Parents spoke of the presence of other parents with similar lived experience and said this helped them feel like they were part of a community, which induced a sense of belonging and reassurance. This experience was clearly different from the hearing clinic waiting room, which did not actively support or encourage connections between parents.

Conclusion

This study highlights the spatial and temporal qualities of sites that shape the embodied experience of medical encounters for parents of children with hearing difficulties. The waiting room and soundproof booth are distinct spaces that evoke and contain emotions and require parents to work to manage emotions. We suggest that there is a need to think more deeply about the temporal and spatial qualities of such sites to reconsider their role in medical encounters. The significance of clinical spaces, factors of temporality and emotion shift as parents interact with clinicians. Findings of this study indicate a need for greater clarity in communication and explanation of medical terminology and processes. In the process of becoming informed about their child, parents move between and within medical practices and discourses about deafness and ability and disability (Latimer 2007, 2013b). This remains problematic if there is a lack of clarity in medical terminology or commonly used clinical language. Medical terms, even with links to the vernacular, may be understood differently by parents than what is intended clinically. Parents may not feel empowered to seek clarity around terminology, as one mother said, ‘when you don’t know what you don’t know, what do you ask?’.

Embodied emotion, temporality and a sense of place are constituted in the clinic and embedded with significance. The assumption that the biotechnical world of medicine, in this case audiology, has the technologies to definitively diagnose, is not always the case, as demonstrated in our data. Uncertainty generates anxiety, and this has significant consequences for parents. This finding recommends additional trained support and counselling to manage uncertainty through better testing methods, clearer explanations, and closer contacts and communication with early intervention services. This may alleviate parents doubts and temporal concerns about the future.

The notion of ‘family’ or ‘patient centred’ practice, operating within the hospital setting, needs reconsideration. Clinical structures around appointments and waiting could be better managed. Consulting with families on ways to tailor family centred practice, and ways to create affective clinical spaces, may act to alleviate stress. The clinical and referral pathway, including the transfer into early intervention services, is the element that most parents find distressing, not the diagnosis itself and this is an important finding for clinicians and educators.

Our findings also point to the importance of looking at new ways of offering services and the possibilities of non-clinical spaces for diagnosing and managing hearing loss. This includes making hospital more family friendly or allowing more diagnosis and management in non-clinical settings. The hospital waiting room is often experienced as problematic and generative of uncomfortable feelings. Noise, crowdedness, and tension from other people, who are also waiting, are embodied experiences that fold into feelings of anticipation and worry about a child.

Waiting in hospital waiting rooms is intensely felt as a passive, disempowering activity. It is an endeavour that has both temporal and spatial aspects. Waltz (2016) argues that waiting is a gendered activity with more women waiting with children or waiting with family members seeking medical attention. Waiting is a process of endurance where emotion work is performed, and this can be acute, as we have shown, when a diagnosis is not forthcoming, and feelings of anxiety, frustration and uncertainty are evoked and managed. Time is ‘lost’ in a waiting room, as the patient is beholden to medical economies and structural dynamics of clinical practices. Shifting or playing a hospital’s scheduled system rarely alleviates waiting. This is not to say that doctors do not make themselves available for emergencies or demanding cases; time constraints and pressures, often due to staff shortages because of funding, are experienced by both patients and doctors in clinical practice (Sterponi et al. 2019; Strathmann & Hay 2009).

Waiting to gain a diagnosis is acutely felt and the shifting between knowing and not knowing, in this clinical space of motility, leads to feelings of ambiguity, vulnerability, and anxiety. A complex entanglement of temporality, emotional labour and scientific knowledge affect parents’ experiences of childhood deafness. Tensions between embodied and empirical knowledge were revealed in encounters with clinicians. Temporality and a focus on ‘capturing’ time or on maximising stages in human development is part of the discourse in this setting. Grace and Vincent did not know what or who to believe. As their anxiety grew so too did the urge to challenge medical authority. In their need for certainty their responses demonstrated how they rejected some medical opinion and sought solace in both more familiar beliefs and in new or novel medical research.

Unclear diagnosis caused feelings of insecurity, confusion and ‘heart ache’ or sadness, and this emotional labour was carried and managed by parents in their interactions with professionals. Emotions evoked in these clinical spaces shaped relationships between health professionals and parents. This, in turn affected parents' decisions: making the process more difficult and highlighting parents' doubts about their choices and their child's futures. Alternative, non-medical spaces like The Children's Centre that prioritised and supported social relations between parents, and provided a sense of 'home', induced feelings of comfort and familiarity for parents. This was a sense of home where boundaries with medicine and therapeutic interventions seemingly blur; human in scale, the space is an evocation of nurture and shelter where time pauses (Bachelard 1964; Tuan 1997). Alternative non-medical settings were perceived as sites where it was possible to manage feelings of distress and anxiety, to find support and solace, which calls into question medical dominance of childhood deafness when alternative spaces to the clinic evoke more positive experiences for parents.

Chapter 6

Informed choice and unbiased support: Parents' experiences of decision-making in pediatric deafness

Title of paper	Informed choice and unbiased support: parents' experiences of decision-making in childhood deafness.
Publication status	Published: Accepted for publication (as presented below) 16 November 2021
Publication details	Harris, C. Hemer, S., Chur-Hansen, A., (2021) Informed choice and unbiased support: parents' experiences of decision-making in childhood deafness. *Social Science and Medicine-Qualitative Research in Health*

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Contribution to the Paper	Developed rationale for the study, devised research questions and aims. Planned and carried out ethnographic fieldwork and data collection and performed data analysis. Drafted, wrote, and submitted the manuscript (acting as corresponding author). Revised and responded to reviewer comments.
Overall percentage (%)	80%
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not

	subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	10/12/2021

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

Abstract

A body of research highlights parents' decision-making and the contested nature of deafness as an issue in clinical practices. Drawing on sixteen months of ethnographic fieldwork from 2017 to 2018 in an Australian city a 'follow the baby' approach was undertaken in a multi-sited setting. Forty-one parents and twenty-seven health and education professionals were interviewed. Informed choice, framed in this context as 'unbiased', aims to empower parents to make choices about technologies, communication options and early intervention. While many parents said they knew what they wanted for their child they also reported that making decisions was complex, uncertain, and confusing. Conflicting ideas about what was 'best' for a deaf child, clinicians' power, and other stakeholders' vested interests, shaped parents' experiences of making decisions. This article captures the complexities and ambiguities of parents' decision-making and illustrates the ways that informed choice worked to sometimes confuse and perplex parents, which may be counterproductive to good care practices. We probe whether complexities and structural barriers in childhood deafness might complicate parents' experiences and their satisfaction with services. Greater transparency in paediatric deafness and increased collaboration and understanding between parents and clinicians is recommended as a support to parents' decision making.

Keywords

Parents' decisions, childhood deafness, informed choice, best practice, early intervention, medical anthropology.

Introduction

A diagnosis of infant deafness is often portrayed as a traumatic experience for parents of whom over 90% are themselves hearing (Blume 2010; Mauldin 2016). Adjusting to this news also requires parents' engagement in a lengthy and complex process of critical decision making for their child. Decisions are seen as time pressured with long term significance (Harris et al. 2020; Moeller et al. 2013). The ways that parents envisage their child's future happiness are often entwined with their own deep-seated emotions and sense of self-efficacy. To assist parents, a clinical practice of informed support is embedded into a paediatric referral pathway. Informed support aims to guide and empower parents to choose options for their children and in this context is closely tied to a notion of "unbiased support" (JCIH 2007: 6).

Recognising that deafness has been subject to debate and controversy, the importance of supporting parents to make decisions for their child was highlighted in the international Joint Committee on Infant Hearing (JCIH) Consensus Statements, "families should be made aware of all communication options and available hearing technologies presented in an unbiased manner. Informed family choice and desired outcome guide the decision-making process" (2007: 2). While informed choice is guided by these consensus statements (JCIH 2000, 2007, 2013), a significant body of research continues to highlight parents' decision-making and the contested nature of deafness as an issue in clinical practices.

For many parents the process is perplexing and stressful, and support is not experienced as "unbiased", with different stakeholders positioning with their different, sometimes clashing, agendas (Bruin & Nevoy 2014; Crowe et al. 2014; Freidner 2018; Pfister 2019; Porter et al. 2018). This article examines Australian parents' experiences of informed choice to illustrate that while it was aimed at helping parents navigate the referral pathway it often worked in ways that were counterproductive to practices of good care.

The complexities of decisions about medical and rehabilitation interventions in childhood deafness vary significantly with individual children, but may include choices about genetic testing, hearing aids, cochlear implant surgery (Hyde et al. 2010; Okubo et al. 2008) and perhaps most divisive of all, communication options (Bruin & Nevoy, 2014; Crowe et al. 2014; Flaherty 2015; Friedner 2018; Porter et al. 2018). The latter is often presented to parents as a binary speech or sign language decision (Flaherty 2015; Friedner 2018; Hardonk 2013; Mauldin 2016, 2019; Okubo et al. 2008; Young et al. 2013).

Communication choices and surgery for cochlear implants take on considerable significance for parents. These frequently relate to the family's own communication method and to their future imaginaries about their child's socio-economic inclusion and psycho-social wellbeing. Parents are not faced with evaluating options at only one time. Rather, decisions are made and remade in what is often a long and unpredictable journey that is entwined with normative concepts about deafness and disability. Choices are made in connection to a child's progress, and to transitional periods, including moving between stages in life (Flaherty 2015) and to the ways that family life is structured over the long term by living with a child with difference (Rapp & Ginsburg 2011).

Deafness is highly politicised by long held arguments including, but not limited to, the pros and cons of oral versus sign language, ethical considerations about infant linguistic neglect, deaf identity, children's rights, and cochlear implant surgery. These form a core discourse in literature (Young et al. 2006, 2013). An over-determined binary within clinical and education settings is demonstrated through ubiquitous debates about communication options. These proliferate through parents' everyday experiences of childhood deafness and can make decisions and choices difficult (Bruin & Nevoy 2014; Humphries et al. 2016; Hyde et al. 2010; Kecman 2018; Young 2006, 2013). This stark binary is problematic in academic literature including in the field of deaf studies. The polarisation of deafness into a hearing and a deaf world has been recognised by scholars including by Friedner who argues that this, "dichotomy between worlds, typically discussed in terms of a 'deaf world' and 'hearing world' binary, is overdetermined in the discipline of deaf studies" (2018: 360).

Complicating informed choice and tinkering with care

Departing from literature in health sciences we draw on Mol's (2008) concept of the logic of care to examine the ways that situations of choice are understood and practiced in the context of paediatric deafness. The logic of care articulates ways of organising and understanding everyday practices, and interactions between, bodies, people, knowledge, and technologies. Mol (2008) demonstrates how the logic of choice is often inconsistent with this logic of care, despite the former being a central principle of the latter in health care practices in most industrialised countries. Mol argues that good care happens in clinical practice collectively as shared labour between a range of human and nonhuman actors. Care moves between clinicians, machines, drugs, technologies, and patients (Mol 2008: 32) and thus involves 'tinkering' between multiple elements (Mol et al. 2010: 14).

Interlocutors in this research demonstrate how their experiences of care were shaped by stakeholders' different relationships to the concept of informed choice and by different views about what was best for a deaf child. As Mol states, it "follows from this unpredictability that care is not a well delineated product but an open-ended process" (2008 p. 22). The logic of choice would suggest that parents, as 'customers', have options and a freedom and right to choose between different options, but in childhood deafness this is complicated because choices are often limited, presented as either-or options or overlaid with differing values. Furthermore, recognising the unpredictability of deafness especially where the diagnosis is complicated by syndromes or other illnesses, parents' choices, and the on-going nature of the decision-making, take on greater significance. The choice may at first appear to be an either-or choice about communication, but as we illustrate, parents' decision-making processes shift, and their journeys are marked by ambiguity and by an often-shifting concept of 'normal'.

By analysing the intersection of informed choice and parents' experiences of decision-making in clinical encounters this research contributes to a body of anthropological scholarship about deafness. While health sciences, disability, deaf and education studies have paid attention to the ways that parents receive information and make choices for their children (Duncan 2009; Humphries et al. 2016; Hyde et al. 2010; Kecman 2018; Young 2006, 2013), there has been limited focus in anthropology. Furthermore, the anthropology of deafness has often focused on experiences in the developing world (Friedner 2014, 2018; Huiracocha et al. 2015; Huiracocha-Tutiven et al. 2017; Kusters 2012, 2015). Hence this research adds to a body of anthropology scholarship (Blume 2010; Bosteels 2012; Huiracocha et al. 2015; Mauldin 2016, 2019; Park et al. 2015; Pfister 2015, 2019) about parents' experiences of childhood deafness and the ways they navigate an overly politicised context to make decisions and choices for their children.

The article begins with an overview of the literature on disability and informed choice in clinical settings, which is followed by a summary of methods. It then turns to the ethnographic data to firstly show how parents received information about deafness in an Australian context. We demonstrate the ways that informed choice shapes parents' experiences in sometimes unforeseen ways. We argue that the practice is often ambiguous and not always experienced by parents as helpful, which may be counter-productive to good care. This is followed by an examination of parents' lived experiences of decision making about clinical, early intervention and communication options to illustrate the ways that they are interwoven into ideas about family centred practice and what is best for a deaf child. We complicate the notion of informed choice across clinical and early intervention sites within the referral pathway. We probe whether structural barriers might confound parents' experiences. Finally, the discussion centres on the ways that clinicians' experiences of informed choice reproduced tensions in the field. Concluding remarks highlight the ways informed choice and family centred practice constitute experiences of clinical care in childhood deafness in an Australian setting. We make suggestions for further research and for greater transparency in nature and delivery of information and referrals for parents.

Literature on disability and informed choice in childhood deafness and the clinic

The process of making decisions in health care contexts is socially situated and often “enacted in relationships, in reaching out, opening to and joining with others” (Zivkovic 2019: 2). Informed choice is viewed as a fundamental principle of health care policy in Australia; it is “an ethical principle that guides ‘patient centred’ care” (Yuill et al. 2020: 2) wherein professionals act in respectful ways to provide comprehensive, impartial information that supports parents to understand the benefits and risks of various options, and to assist in a process of shared decision making (Coulter and Collins 2011). These principles are valued by professionals, and underpin referral policies in childhood deafness, but their significance is tested in this context that is simultaneously embedded with multiple opposing views and opinions about deafness. The illusion of the informed, value-free choice is complicated by the fact that medical and health professional culture more broadly, is one of the ‘expert’ (Nettleton 2013). Health professionals are socialised into this culture and exert influence or authority through the process (Collyer et al. 2017; Heritage 2006; Lock & Nguyen 2018; Lupton 2000; Nettleton 2013; Spinnewijn et al. 2020) whilst patients or parents acquiesce, resist, and exercise their own agency within clinical processes (Foucault 1989: 96).

A body of literature acknowledges the difficulties parents face as they consider benefits and risks of surgeries, biotechnologies, and rehabilitative interventions for their children (Flaherty 2015; Kecman 2018; Nickbakht et al. 2020). Ethical and moral issues abound in cases where parents act as surrogates in making decisions about life impacting and physically reshaping surgeries for infants not yet able to decide for themselves (Miller 2006; Parens 2006). Medical interventions might be resisted by parents for religious reasons, or they might be adopted in a normative effort to make a child more likely to fit into society (Parens 2006).

As a human variation of ‘the normal condition of humanity’ (Sutherland 1981: 18), disability is frequently framed by a medical lens that views it as a deficit requiring repair or by a social lens that locates the problem not in the body, but in the social barriers that prevent full participation in society (Shakespeare 2006, 2013; Shakespeare and Watson 2001). Deafness has been interpreted in both of these ways, but also through a third cultural model, which developed through the 1970s and 80s, disability and deaf rights activism (Blume 2010; Sacks 1989) and rejects the notion of deafness as disability. Instead, deafness is perceived as a cultural or ethnic category with its own signed language and shared social networks. This cultural-linguistic model applies to deaf people who communicate with sign language and identify as belonging to ‘Deaf Culture’. Recent shifts, and increased commonality across deaf and disability communities, including in the academy (Robinson and Henner 2018), suggests relationships between deaf and disability communities might be described as undergoing change; of being in a fluid state.

In most industrialised countries deafness in infants and children is highly medicalised. Parents' choices and decisions are often deeply shaped by the notion of the 'perfect' healthy or 'normal' baby (Landsman 2008). Parents are quickly caught up in the ways that disability in newborn infants undergoes rapid processes of medicalisation. The ways that disability shapes family practices are clearly described in the work of Rapp and Ginsburg (2011, 2013), anthropologists and parents of children with disabilities.

In childhood deafness informed choice draws parents into a contested world (Friedner 2018; Mauldin 2016; Young et al. 2013). As an ideal, informed choice is compromised in practice by information that is absent, or lacking in clarity, or that is delivered by professionals in ways that are not impartial (Kecman 2018; Moeller et al. 2013; Porter et al. 2018; Young et al. 2006, 2013). Parents are encouraged to become advocates for their child and stakeholder relationships often indicate parents' levels of self-confidence and satisfaction with services (Leiter and Krauss 2004: 135). A vast number of clinical and education professionals act as gatekeepers, which generate agency and power within the field. This is not to imply that parents are passive or partially empowered as they "surrender to medicalisation" (Mauldin 2016: 4) but asks how they might navigate uncertainty and "situations of choice" (Mol 2008: 8) when making decisions. Furthermore, the concept of health literacy (Brabers et al. 2017) is important. Not all parents understand, or accept, biomedical explanations of health and illness, including treatment options or definitions of what is able bodied and what is not. Moreover, not all parents choose taking responsibility for deciding - preferring collaboration with, or guidance from, health care professionals (Lupton 2000; Mol 2008; Nettleton 2013; Thomas et al. 2021; Young et al. 2006).

Moral concepts about what was advantageous for deaf children, including how they should be taught to communicate, have endured since the early 19th century when education institutions were established for the deaf (Tremain 2005). Information bias about communication modality that give greater focus and value to either speech or sign language, feature in debates that continue to proliferate along with ideas about best practice in deaf education (Geers et al. 2017; Knoors & Marschark 2012). Literature in anthropology and deafness has contributed to studies of parents, including their consideration of the risks and benefits of cochlear implants (Okubo et al. 2008), their pilgrimage to find alternatives including sign language to biomedical options for their children (Pfister 2019) and their experiences of oral and sign language early intervention in Southern India (Friedner 2018). Attending to parents' narratives about their navigation of networks and structures in childhood deafness reveal the contested and emergent qualities of culture, and these are productive in thinking about situated knowledge and power in clinical settings (Foucault 1978, 1989; Lupton 2000).

Method - fieldwork in an Australian context

This article is based on ethically approved, multi-sited ethnographic fieldwork undertaken between 2016 and 2018 in an Australian city as previously reported (Harris et al. 2020, 2021). Fifteen months of participant observation was carried out by the first author in clinical sites including four audiology clinics, two cochlear implant centres and three early intervention services for families with deaf children. In Australia, children who are deaf are provided for by Medicare, the public health system, which is available to Australian citizens, permanent residents, and some migrants and refugees (Krassnitzer and Willis 2016). Audiological assessments, hearing aids, batteries, and other listening devices are freely accessible to deaf people up to 26 years of age. In the field site Medicare funds approximately twenty cochlear implant operations each year. Parents, who have private health cover, pay for their children's cochlear implant surgery through their insurance. Early intervention programs, funded by government, charitable donations, and the National Disability Insurance Scheme, range from independent speech pathologists to specialist services from teachers of the deaf and listening and spoken language professionals.

Recruitment, data collection and analysis

To examine parents' experiences of making decisions the first author undertook qualitative interviews and a 'follow-the-baby' approach to accompany twenty-one parents/carers to their clinical appointments. Invitations to participate in the research were displayed in field sites and emailed to parents. Qualitative semi-structured, in-depth interviews and guided conversations (Csordas et al. 2010) were undertaken with sixty-eight research participants. Thirty-one parents (nine men, twenty-two women) had young children. The remaining ten parents had children who were older than eighteen years and therefore shared retrospective narratives. Parents/carers came from diverse socio-economic backgrounds and several families were from South Asian countries. Twenty-seven professionals also participated in this research.

Interviews with interlocutors took between two and three hours and occurred in parents' homes, places of work or in parks, cafes, and libraries. Parents were asked to describe their experiences of receiving information, of navigating the referral pathway and of making decisions for their children. Conversations were guided by parents' focus on their encounters with early intervention services and how these shaped their decisions. Listening to parents' narratives, to the ways that their stories were constructed and enacted in different settings (Mattingly & Garro 2000; Poltorak et al. 2005) enables researchers to "explore cultural life as an unfolding personal and social drama" (2000: 17) and to attend to the complex interactions and engagements between different "agents who occupy different social positions, with differential access to power, and different points of view" (17). Attending to these encounters was a key focus of participant observation.

Interviews were recorded on a digital audio recorder and transcribed verbatim by the first author. Transcripts were read and manually sorted before being imported into NVivo for a process of line-by-line coding. From this initial coding, ideas and key concepts emerged, which were thematically analysed. Eight books of detailed handwritten field notes provided comprehensive contextual information and understandings about childhood deafness and everyday care practices of a paediatric deaf referral pathway. Field notes were logged into an Excel document and sorted and coded for key themes. Adopting elements of a grounded theory approach themes generated from analysis of field notes were cross referenced with interview data and relationships between emergent themes were examined and refined (Charmaz 2006). The lead author is the mother of a child who is deaf and has cochlear implants and she has other family members who are also deaf. All research participants and field sites have been given pseudonyms.

Informed choice in deafness

In the field site, a medium sized Australian city, an audiologist was the first source of information for parents whose child had been diagnosed with a hearing loss. Parents were given a booklet to take home that explained paediatric deafness, how to read an audiogram, the referral pathway, and forthcoming clinical appointments. The booklet explained that there was a small window of time when early intervention could make the most significant difference to a baby in the long term - so it was important to act. Acquiring information, understanding choices, and making decisions was framed as a significant and temporal experience for parents. Parents were referred to several medical specialists who also provided advice and referrals including ear nose and throat (ENT) surgeons, audiologists, geneticists, paediatricians and hearing aid and cochlear implant clinics.

Parents were referred to a hearing coordinator, which was a key moment in the referral pathway whereby parents would receive what was framed as impartial information to assist their transition from medical appointments and begin early intervention in a timely fashion. The coordinator talked about three distinct early intervention services: Hudson House offered communication and sensory services, The Children’s Centre was an oral only approach through Listening and Spoken Language specialists (LSL) and Greenacres was a bilingual bicultural program teaching Australian Sign Language (Auslan) and sign supported English. The process was aimed at empowering and guiding parents so that they would quickly engage with early intervention programs, but over half of all parents interviewed said the experience of receiving information and visiting early intervention organisations had been confusing and that the information they received was not impartial. They said they felt that their confidence in understanding the significance of their choices and in some cases making decisions, was tested.

Sara, for example, had a six-week-old baby who had been born deaf, which had been a shock, but she said her strongest concern was focused on how she would communicate with a baby who couldn’t hear. This initial worry shifted when she picked up her daughter’s first pair of hearing aids and understood from the audiologist that her baby would be able to access speech sounds and therefore, probably, be able to learn to speak. She had been advised to engage with early intervention and choose a program that fitted her family and was ‘best’ for her child. Sara wasn’t too sure she understood the implications of what was best for her family or her child. She thought she knew what she wanted, until she started visiting early intervention services. As she explained, “I found people with their own agendas. They all said they did best practice, but they all offered very different programs. I didn’t know what to think”. This experience was reported by other parents.

A theme of what was best for a deaf child, overlapped with parents saying they knew what they wanted for their child, but that making choices was uncertain and overly complicated. This sense of complication was intertwined with the politicized nature of deafness and concepts about disability. Isobel, 29-year-old mother of two whose youngest child had profound unilateral hearing loss, explained,

> When I first went to see the ENT at the Jefferson hospital, they said ‘there’s no point in getting a hearing aid because it wouldn’t really work’. They also said, ‘if you have to pick a disability for a child - hearing loss is not a huge disadvantage’.

This was at odds with her experience of living with a husband who also had profound unilateral deafness. Parents were often critical of early intervention services, which they felt were biased towards the communication modality they offered and were looking to "capture" parents into the trajectory they recommended because the alternative was often a trajectory that did not include them. This took on added significance as the services’ financial survival was dependent on enrolling children.

A second common narrative thread in this ethnographic study was that parents were perplexed or confused by their interactions with professionals and ideas about family centred programs. Informed choice was linked to family centred early intervention programs (Flaherty 2015; Kecman 2018; Moeller et al. 2013). Family centred practices in this context were perceived by professionals as the family and child being at the centre of all decisions about treatment plans and interventions. Professionals did not always agree on what this might look like, and parents did not always experience being at ‘the centre’ of care practices. Some organisations drew boundaries between parents and professionals in their services while other services were more open to parent involvement. Parents valued services that created space for increasing their input in how care was delivered to families more broadly, and this included parents on program committees and in parent-peer supports wherein parents with recently diagnosed babies could meet and speak with other parents. Parents offered each other emotional and moral support and advice and ways to lobby for better or different services. As one mother of an 18-year-old son, said,

> You have a sense of empathy because it's a lived experience. It's easy for you to then say to another parent, 'You know what, if you make this decision and you make the decision as best you can now, it's not set in concrete. If it doesn’t work, let's look at it again and let's re-evaluate it. Whereas whilst the intent's probably there, I'm not sure a service provider's going to tell you that, because they don’t want you to go to another service provider. I'm not sure they'll necessarily tell you, you can't but I'm not sure they would openly address the fact that if you get it wrong and it doesn’t map to what you need it's not a big… Well, it's a big deal but it's not a deal breaker. You just re-evaluate and reassess and make another choice in the journey.

Parents shared their insights and lived experiences with each other, which developed from peer-to-peer support programs and parents’ attendance at group programs that were offered by early intervention organisations. Parents often helped other parents understand the complex networks in their encounters with professionals on the referral pathway.

Parents’ knowledge of deafness

An explicit assumption from professionals in this research, that is also found in the literature, was that most parents had no previous experience of hearing loss (Bruin and Nevoy 2014; Gale et al. 2019; Hyde et al. 2010). This was seen as especially pertinent to the 90 plus per cent of hearing parents of deaf children. The first author was often told by clinical and early intervention professionals that the deaf baby was probably “the first deaf person the parent had met”. Positioning parents as lacking in knowledge, in this case about childhood deafness or parenting, can be seen as producing “culturally imagined types” (Holland & Leander 2004: 30).

Furthermore, parents were viewed as lacking access to a form of cultural or social capital that was embodied in the culture of the Deaf world or through the concept of Deaf-gain (Murray et al. 2010). This narrative sees deaf experiences and parents through a binary medical versus cultural model that problematizes their role as parents and calls forth questions about knowledge, power, and agency. The paradox of this is that parents are also expected to make decisions that fit with their family and for which they will be held responsible by their child, health and education professionals, other family members, and the wider community.

Data, from immersive, long term, ethnographic fieldwork undertaken for this study, demonstrate that parents were often more knowing, and their experiences were more nuanced than is often presented in literature. Parents spoke about relatives, including other children, who had hearing issues, aged parents who were deaf, memories of going to school with deaf children, and films and television programs with deaf actors and storylines. They also spoke about the increasing visibility of sign language and captions at cultural events, in cinemas and on television. These connections and interactions provided experiences of deafness; thus, few parents could be assumed to be ‘unknowing’.

Parents “knew what we wanted”

All forty-one parents involved in this study said that soon after diagnosis they knew they wanted their infant to learn to speak. This was expressed by all parents including two who were also deaf. When speaking about their child parents used terms like: “fitting in”, “having the same opportunities as other kids” or “going to the same school as her brother” in interviews with the first author and in their encounters with clinicians. Five parents chose early intervention that included Australian Sign Language (Auslan) and they learnt the language alongside their children. Two hearing parents felt that their deaf child provided an opportunity for themselves to embrace a new Deaf culture, and this became an immersive process of learning Auslan and about the history and culture of the Deaf community. Several parents from South Asian countries were teaching their children two spoken languages: English, and what they called their mother tongue.

In gathering information, ten parents in this study sought what they viewed as independent information before making decisions. They accessed deaf websites including those that were run by parents; they talked to family members and people they felt they could trust. Parents read articles and books on deafness, which were often provided by their child’s therapist. One mother started an online parent forum, and it was through international connections that parents discovered that children in other parts of the world were routinely implanted under one year of age and given bilateral and unilateral implants. Parents began lobbying for changes to local medical practices. Another mother enrolled in a university deaf education course so that she could learn for herself and circumnavigate what she saw as professionals with agendas, ‘my goal really was to get the information that I needed to make decisions for my child’. One father and another mother also combined their lived experience with tertiary education and training to forge new careers in deaf education.

Tony, father of Maisie, a 4-year-old daughter who was born at 33 weeks and later diagnosed profoundly deaf and who received cochlear implants at nine months of age, said he and his partner had “read up”,

> Our way of gauging the best support for Maisie was evidence led and our strong drive and wish for her to be able to talk and hear - with these two coming together there was so much evidence available of the benefits of learning to listen and talk.

His partner, Tess, went on to explain that they were ‘big researchers, we read papers and studies and we felt comfortable quickly that her life would be normal’.

Martin, who had three children including a six-year-old son who was deaf, also undertook his own research on communication modes and then chose, with his partner, a service that they believed would offer evidence-based programs. He said,

> We were introduced to all the services that were available at the time, and that included The Children's Centre, and I think at the time we largely made the decision to go with them because we pretty heavily wanted Billie to speak. So, the methodology around that influenced our decision.

Martin's decision was based in part on how he felt about the therapists he met at the service. He explained, 'they had a lot of qualifications and seemed to know what they were doing and could explain it to us'. He was impressed by their training, knowledge, and capacity to explain how their therapy worked and that he and his partner could be involved in the process at home and in weekly sessions at the Centre.

Mark, a refugee who had arrived in Australia ten years earlier, had a daughter born in Australia with moderate hearing loss. He said the most important consideration in making decisions for his child was,

> Basically, we just want her to be able to talk. And with this hearing aid it does make her speech clearer and she's able to understand us. We just really not thinking to go into sign. Yes, we can speak together.

Mark said he and his partner, also a refugee, were determined that their daughter would have access to what he called a ‘normal education’ at their local school. Originating from a country where people with disabilities were poorly serviced, their choices were shaped by improved possibilities in their adopted country and as he explained, expectations for her prospects of education and employment. Early intervention choices were contingent on the location and length of commutes and the stressors this created on daily life. The availability of home visiting programs from early intervention services were a deciding factor for other women many of whom were new to Australia and did not drive, while other parents sought services that were near to a hospital or medical site where they attended multiple and ongoing clinical appointments.

Receiving contradictory information from service providers and trying to comprehend a contested notion of ‘best’, entangled parents in a web of complications. This would indicate a problem with the way informed choice was practised in this setting with information being partial or biased. A couple from a rural area, Marion, and Steve, were told they should relocate to the city so that their child could go to an Auslan school despite their explicit request for an alternative approach. Another mother, Mary, whose child had cochlear implants, recalled the diagnosis and being given a ‘your choices’ folder and basically told to choose between two communication modalities: sign or oral. She said, “I knew I might have learnt to sign but the rest of the family? It wasn’t going to happen”. Mary wanted a school that would focus on speech but felt the school had their own agenda, which did not suit what she felt was right for her son or her family. Mary made decisions that embraced an interplay of emotional and practical choices about her future expectations for her son and what fitted with her family. Looking back, she questioned whether her decisions or preferences were right and whether she had been respected by professionals. In these situations of informed choice stakeholders' strongly held views often complicated parents' experiences of childhood deafness.

Complex and confusing: was there a right or wrong choice?

Jeanette, a lively woman who worked at a local high school, spoke about what she called her "deaf journey" and the confusing procedure of meeting with professionals and making decisions for her child. She said that after her child's diagnosis of profound deafness she returned to the audiologist to collect their first pair of hearing aids,

> I said to the audiologist 'we'll be fine with technology behind the ears, we'll be ok.' I really think we would have been ok but what I didn't get was what it was going to be like dealing with all these people we had to see, who all had different agendas – it was a nightmare!

Asking her what she meant by a nightmare, Jeanette explained that it was partly about trying to make decisions while dealing with strong emotions but that meeting with professionals and service providers to find out about options for her child had just confused her. She visited early intervention sites, but the process did not help her make decisions. Jeanette was perplexed by three different programs all saying they provided best practice. She questioned what this meant and how it related to what she wanted, which as she explained to the first author, was connected to her future imaginings about her child finding their place in the world. She began to wonder if there could there be a right or wrong choice. Should her focus be on teaching her child to listen and speak only, or would sign language help? Should it be a mixture of ‘baby sign’ or key word sign or sign supported English? Trying to choose, she said, produced feelings of doubt that would seem to operate in ways that were counterproductive to notions of good care.

Parents often wanted to know if the choices they had made were going to work, or if the decisions made by doctors or audiologists, were the right ones. There was much talk in the field about children’s progress. Isobel, who ran a dairy farm with her husband, had four children and three, born profoundly deaf, had received cochlear implants. She, said, “I'm so driven about outcomes, and I so want to know, 'will this work?' If we go through all this, will this work? And of course, no-one can ever give you an answer to that”. Parents were concerned about whether the choices they had made would match with their hopes and desires for their child and often this caused mixed feelings of anxiety, confusion, and uncertainty.

Parents’ decisions and choices were shaped by other family members’ opinions about what was best for a deaf child, and this created tensions within families. For example, Tiffany, a hearing mother of three children, one of whom was deaf, explicitly chose a bilingual approach for her daughter. At the diagnosis, she explained that the audiologist,

> …told me she was deaf, with the audiogram, so she said she would begin to hear down here, the sound of a jet engine, and I knew I just needed to sign with her.

Tiffany went to the city's bilingual-bicultural preschool and met with adults who communicated with Auslan and identified as belonging to Deaf Culture. She chose speech and sign language for her child, which she then also learnt over several years at a local college. She explained the most "heartbreaking" decision for her was cochlear implant surgery.

> My husband said, ok you can give that a go (sign language) as long as we have her cochlear implanted as well. That is what broke my heart the most. Having her cochlear implanted because it risked my baby's life.

Her choice of sign language and the adoption of a bilingual approach, came at some cost, as she explained her mother did not agree with her choice and said to her,

> "You're making her disabled by signing to her". That was really difficult to deal with. I cried a lot and I immersed myself within the Deaf Community.

Another father admitted to being resistant to the idea of his child having a cochlea implant because he felt the visibility of the device would draw overt attention to his son. This would indicate that decision making within families could be complex for parents whose immediate and extended family members held different or normative opinions about notions of disability and deaf children. Tiffany's extended family perceived sign language as potentially identifying her daughter as "abnormal" or disabled. Parents' discussions recalled how these initial perceptions also changed over time as familiarity and knowledge about deafness was gained through experience and quotidian family life.

Tensions between different early intervention services shaped the way some parents experienced evaluating programs. Isobel, quoted above, explained that,

> The process was quite difficult. And each [early intervention] provider was conflicting; they all spoke badly about the other providers and offered completely different services. I had to take some extra time to really consider everything I was doing and deciding on from providers, types of hearing aids, cochlear implants, etcetera but to be honest the process was extremely stressful.

June, a mother of a four-year-old daughter, said,

> After my child was diagnosed…we were given all this information about places that would provide services for our daughter. For the life of me I couldn't make up my mind. I said to one organisation. 'I just want my child to learn to speak, where do I go for that?' I couldn't get a definitive answer, it was like no one was really helping and I started to wonder what was wrong with what we wanted.'

Care practices were compromised by these tensions and some parents resisted engaging with early intervention. Encountering inconsistent, opposing, or ambiguous information not only shaped parents' decisions and their feelings of self-efficacy, but also predicted their levels of satisfaction with the services.

Early intervention organisations said they employed a best practice model, and that unbiased information was essential to help parents make informed choices. The subject was discussed and scrutinized in the field. Eileen, a woman in her late fifties who was an early intervention worker in the field and also a parent of a deaf child, spoke passionately about the subject of informed choice,

> Unbiased doesn't exist unless you're not emotionally involved and in deafness all people develop a position, anyone who they've met and who influences them, it's just unavoidable. There is no such thing as unbiased support.

While unbiased information was an ideal that was advocated and promoted by clinicians, it became apparent that in this setting it was often complicated, and not what always what parents experienced as discussed above in sections 5.2, 5.3 and 5.4. As Eileen explains, in deafness 'all people develop a position' through their emotional engagement, lived experience and the influences of other people. During fieldwork there were times when opinion, lived experience, stakeholders' positioning, and ideal types of professional information delivery, were at odds. This created tension and shaped parents', and health and educational professionals', interactions, and everyday experiences in the field.

The concept of bias shaped everyday practices within the site. Despite time sensitivities in diagnosis and engagement with treatment plans, a hearing assessment centre would not alleviate waiting lists by providing parents with names of other services because, as the manager said, "we might be seen as being biased". The embedded perception of bias became more apparent when she explained,

> We have some concerns about The Children's Centre doing hearing assessments from an ethical point of view as well. If you're going to diagnose a baby and that baby does have a hearing loss, does that family then feel obliged to choose them as its early intervention provider? We don't think it's appropriate that an early intervention site is doing the diagnostic assessment.

The assumption was that parents would feel compelled to register with the service that had provided the diagnosis and therefore become tied or drawn into a choice in communication method. A health provider said, 'information should remain unbiased' and went on to explain the referral process wherein parents were given their options,

> That role is meant to provide families with their early intervention provider options. So, they should be giving the same information to all parents. The difficulty, I suppose is if they have a child with some very significant syndrome where developmentally they're never going to acquire speech regardless of the hearing.

Health care professionals' knowledge and understandings of disability or expectations about a child's future may be vastly different to the parents. Normative ideas and different kinds of knowledge about child development and about people with disabilities were experienced in different ways by parents and professionals as was evident in the field.

The notion of what was best for a deaf child and ways of providing parents with informed choice produced an undercurrent of competition and tension between interrelated assemblages of care that was experienced by health care professionals and parents. Tension between families and professionals in the context of deafness is well recognised (Bosteels et al. 2012; Friedner 2018; Young et al. 2013) but this study found tension between services was also prevalent. These tensions shaped parents' experiences of decision making within clinical and early intervention settings.

Conclusion

We have considered how parents' experienced decision-making for their children in a context where information was positioned as unbiased, and services were presented as family centred, best practice and evidence based. We show how informed choice, claiming to be unbiased, in effect, often lacked neutrality, and for parents making choices and decisions was rarely straightforward. Furthermore, good care was often confused by informed choice, which is paradoxical and may work in ways that undermine care practices in childhood deafness. Parents' decisions were multifaceted and embraced a range of influences, from 'gut feelings' to practicalities about location of services, to deeply felt ideas about communication modality. Parents' choices and options were not static and included alternatives in early intervention providers, decisions about medical interventions, whether to have genetic testing and what kinds of technology supports might suit their child. Furthermore, parents lobbied for options and challenged medical eligibility criteria, for example, with cochlear implants.

Drawing on Mol, we have shown how unpredictability and uncertainty in diagnosis and prognosis in childhood deafness suggest that ‘the art of care therefore is to act without seeking to control’ (2008: 32). Good care involves a process of give and take between clinician and parent and child, of sensitively ‘reading’ and responding to the broader concerns through taking time and a holistic view of the interaction between care, choice, and individuals’ complex lives.

Parents invested in technologies and interventions from multiple professionals hoping that their children would become independent adults and as such normative values shaped decision-making. But this was not the only factor influencing decisions. The importance of communicating with the whole family, where some family members were unable or unwilling to learn sign language, was a consideration. In this way, most parents chose an oral language approach and hearing aids or cochlear implants. Some parents combined this with sign language. We caution against framing parents’ choices as being shaped predominantly by binary concepts of normality versus abnormality or sign language versus spoken language. The journeys of many parents were often complex experiences and subtle understandings of disability became embedded and valued in everyday lives where differences were often not seen as deficits (Henner and Robinson 2021: 20).

This article demonstrates that informed choice remains a contested process despite policy reviews to improve supports for families with children who are deaf (JCIH 2013). Furthermore, there would appear to be a misalignment between the ways that clinicians and therapists think about providing information and how families experience receiving the information. Discourses about family centred practice and what is best for deaf children filter through professional networks, social media parent support sites and the referral pathway. Unpacking meanings embedded in these concepts establishes that choice and decision making are shifting processes often contingent on certainty of diagnosis, on interactions within a deaf field, and on ideas about parenthood, communication, deafness, and inclusivity.

This ethnographic study reflects the complexity and ambiguity of decision making for parents in a field where information claiming to be impartial, is in practice, often biased. Our data illustrate a dislocation between practices of 'informed choice' and more specifically the notion of unbiased support and debunk claims of neutrality. The concept of choice in healthcare is 'socially produced and structured' (Collyer et al. 2017: 685) and attending to complex interrelationships within a referral setting is productive in untangling how this concept is constituted and experienced. The notion of what is 'best' for a deaf child remains contested and parents will continue to experience childhood deafness and the referral pathway as overly complicated and confusing while professionals and stakeholders hold onto embedded, and often outdated binary views and agendas.

We suggest that acknowledging the contested nature of deafness and the positioning of certain stakeholders might add clarity to care practices and to parents' experiences of decision making. We endorse cooperation and transparency between different agencies working in the field and call for lucidity in professionals' early discussions with parents including an acknowledgment of the political nature of the field. Attending to parents' views, to the complexity and ambiguity of their experiences, and providing opportunities for incorporating these into program development in children's services, is recommended. Helping families with tools to interrogate what it means for something to be "best" for a particular family is also complex and ambiguous but a worthy notion that deserves further research.

Figure 9: A young man has his cochlear implant Mapped, or programmed, to adjust the threshold levels.

Figure 10: A mother's collection of her three children's cochlear implant devices laid out for nightly recharging.

Chapter 7

Sensing Technology: experiencing deafness and hearing through cochlear implants

Title of paper	Sensing Technology: experiencing deafness and hearing through cochlear implants
Publication status	Submitted to Body and Society 20 August 2020. Paper revised and resubmitted 10 December 2021
Publication details	Pending

Name of Principal Author (Candidate)	Claire Harris
Contribution to the Paper	Developed rationale for the study, devised research questions and aims. Planned and carried out ethnographic fieldwork and data collection and performed data analysis. Drafted, wrote, and submitted the manuscript (acting as corresponding author). Revised and responded to reviewer comments.
Overall percentage (%)	80%
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature		Date	10/12/2021

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

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Overall percentage (%)	10%		
Signature		Date	8/12/2021

Abstract

This article ethnographically considers the experiences of Australian young people who are deaf and who hear and listen through cochlear implants to explore the intersection between the sensory body and technology. The article draws on phenomenology and theories of the senses to examine how experiences of deafness are productive in analysing articulations of sensory embodiment and the meanings embedded in a body that is valued as both deaf and hearing. Leaving aside binary conceptions of deaf versus hearing, and understandings of the cochlear implant as a remedy for sensory deficits, we instead make a case for nuanced understandings of the device and embodied experiences through technology. This analysis identifies how a cochlear implanted body navigates connections to the sensory world and to others in turning on and off engagement. We contend that the device has an intrinsic value for recipients through enabling their access to hearing while not removing their experiences of deafness.

Introduction

Melanie was eighteen years old and had received a cochlear implant when she was an infant. She sat in a park with the first author and talked about her everyday experiences of living with a cochlear implant and what it was like to be deaf yet also to hear through a surgically implanted biotechnological device. She said,

> I normally keep my implants off at night when I'm going to sleep; it's peaceful and quiet and I don't have to hear any noise. Sometimes I keep them on to feel secure and it's nice to hear things while I'm going to sleep, my breathing or music. In the morning when I'm awake, I always put them on to hear the house. Once I can hear the world it's like my radar –are people talking, moving around, making tea? The house is awake.

Melanie was attuned and perceptive to the sounds of her body and her house as she moved through her daily ritual of waking and sleeping and connecting and disconnecting; her cochlear implant enabled a sensory perception and navigation of the world as both deaf and hearing. Melanie's cochlear implant is 'her radar' that discerns external activity beyond her bedroom: 'the house is awake'.

In this article we examine the intersection of the senses and technology to probe what counts as a lived body (Blackman 2008, 2010). Drawing on phenomenology and theories of the senses our analysis considers the way an implanted body perceives and navigates the world through a capacity for connection; to turn on and turn off sensory perception and engagement. We consider how intentionality shapes encounters with social and sensorial realities through time and space both within and without the home. Intentionally moving away from a more-than-human or cyborg lens (Chorost 2005; Haraway 1991; Mills 2012; Valente, 2011) we explore articulations and enactments of bodily and sensory experience through cochlear implanted bodies that are in flux and open to processes and relational connections between the body, the senses, technologies, and artefacts. We illustrate how these assemblages are perceived through bodies that are both deaf and hearing, which challenge binary and bounded categories in deafness and unsettles a deaf-hearing dichotomy. Rather than seeing the implant as a means to eradicate deafness, this article illustrates the way every day practices are transformed by cochlear implants to allow for a deep embracing of sensory experiences.

In considering deaf people with cochlear implants, our study supports a call for 'researchers to gather their stories' (Friedner and Kusters 2020; Mauldin 2016: 171; Snell 2015). We examine the significance of the implant in analysing narratives of young adults and consider the notion that 'the body is not an object to be studied in relation to culture but is to be considered as the subject of culture' (Csordas 1990: 5). Lived experience through bodily or sensory engagement reveals the 'perceived world' (Merleau-Ponty 1962: 6) and our senses provide a way to make sense of this world (Le Breton 2017: 1). We perceive through an intentional consciousness and embodied perception, or to put it another way, 'a body which embraces and constitutes the world' (10). We consider how daily life is experienced by a body that perceives and senses through implanted technology.

Sound and hearing are socially constructed (Howes 1991, 2003, 2006) and we contend that deaf people with cochlear implants understand the world both through being deaf and also through hearing. Furthermore, the device has an intrinsic value through enabling hearing while not removing deafness. Deafness is not eliminated, but rather emerges in different forms as part of human diversity. We show how deaf peoples' lived experience and embodied sensorial engagement with the world is agential, complex, and relational.

Scholarly research about the ways the senses are experienced through technology is considered before background on deafness and the cochlear implant, and a description of the research methods. Turning to the everyday sensorial practices of young people, empirical data are discussed in three sections: embracing and valuing technology and deafness, navigating connection & disconnection through switching on and off sensory engagement and finally, how the cochlear implant might allow or provoke agency and choice. In these discussions we draw on ethnographic data from young adults and from parents of children with cochlear implants.

Sensing through technology

Phenomenological understandings of human consciousness, including that perception is a bodily experience and that subjectivity is a 'bodily being in the world' (Jackson 1996: 32), frame the body as the fundamental site through which our understanding and knowledge of the world is constituted. Perception cannot be separated from the body; hence the ontology of the 'flesh world' (Merleau-Ponty 1962). This concept of a lived body in a continuous experiential state through the joining of consciousness with the physical or mechanical body refutes a Cartesian division of mind and body. Furthermore, the body is affective and affected by technology, the senses, time and space and other people: it is relational (Blackman 2008: 55).

In analysing experiences of bodily modes of knowing through cochlear implants we capture the 'back and forth between sensing and sense-making… between sensation and signification, feeling and meaning' (Le Breton 2017: ix). We explore the ways that the sensorium is experienced through an implanted body to understand the significances of this sensory perception in the navigation of sound and the social world. Dundon and Hemer argue, 'the senses not only provide people with a means to experience the world, but also link people to place, most notably through the emotions' (2016: 10). Through everyday practices of people who have only known an implanted body, the nexus between sound and silence, space and emotion are productive in considering intersections of deafness and technology.

Technology mediates sensory interactions in and through the world and structures the ways that we relate and communicate with each other (Howes 2006; Le Breton 2017). Anthropological theories of the senses are founded on a fundamental premise that sensory perception is socially situated; sensory experiences and significations are as much cultural as they are a physical bodily phenomenon (Classen 1997; Howes 1991: 167). Hence the relationship between sensing, sense making, place and time is socio-culturally shaped. Research with people with cochlear implants illustrates the significance of lived experience of the sensorium (Ingold 2000, 2011). Being deaf *and* hearing tested constrained categories of deaf, hearing, disabled and normal to offer a ‘new kinship imaginary’ (Ginsburg and Rapp 2013a: 57; Rapp and Ginsburg 2011). Sensory perception is both a physical act and vested with cultural meaning and ways to ‘transmit cultural values’ (Classen 1997 p. 401). Likewise, as Blackman expresses in relation to the permutations of bodily integrity, bodies are ‘extended and multiplied through their structural coupling with technologies, environments and human and non-human others’ (2010: 1).

Literature on the human technology interface includes the use of digital health technologies in examining sensory ways of knowing the body (Lupton and Maslen, 2018: 191). Complex assemblages of human-device-data generate new meanings or sense making through digital tracking technologies whereby we discover new information, insights and motivation about their body and its health (Lupton and Maslen 2018; Maslen 2015). Technologies as intermediaries between people to track other bodies show the ways this human technology interface may be rejected or viewed as less appealing or valuable in our interactions with each other. Digital sensors used by parents to track children and are shown to disrupt parental observations and their feelings about their relationships with their child (Maslen 2021). Biomedical implanted bodies include surgically implanted pacemakers regulating heart function, brain implants stimulating neuropathways, dental implants, breast implants, and nets, bands and staples that change and control bodies.

Research on the hybrid brain-machine interface explores the ways a body might function through a machine, computer, brain interface. (Nicolelis 2001). Bodily implants provoke new ways to consider digital proximity and embodied sensorial experiences in order to challenge the concepts of natural and artificial and to consider how cochlear implant experiences offer a window into ‘nature’ becoming something *with* the ‘artificial’ (Lloyd and Bonventre 2020: 312 emphasis in original).

This article explores the ways an implanted deaf and hearing body is enacted through daily practices combining artefacts, technologies, and techniques of hearing through a cochlear implant. The externally worn ‘speech processor’, reliant on a daily regime of recharging and replacing batteries, is connected to the surgically implanted cochlear implant. The implant is paired through blue tooth technology with several other devices including mobile phones, FM receiver, and digital screens that provide shifting levels of proximity. Together these technologies enable active choices in when and how one might engage in social practices. A speech processor may be switched on, or taken off, depending on the situation or circumstance thus providing ways to reflect on the nature of embodiment, sensory perception, and connection to sound and social life (Rice 2013: 9). Connecting to silence is equally meaningful and understood here, drawing on Pagis (2010), not as the consequence of power or oppression ‘as part of a conspiracy of silencing’ (311), but an introspective process or concentration on interior or embodied experiences that might also embrace shared social processes (324). Connections and disconnections are enacted in a fluid and open body that can be different across time and place.

Background: Deafness and The Cochlear implant

Controversy has surrounded cochlear implants from early surgeries with deaf people in the 1980s and more specifically in the 1990s when young children began to be implanted. The device is targeted at ‘profoundly’ deaf children who do not hear at 90 decibels (Blume 2010; Clark 2003; Mauldin 2012, 2016). Globally, the largest consumers of the implant are hearing parents of deaf children (Blume 2010; Friedner 2018; Mauldin 016). A cochlear implant has a surgically inserted internal device and an external part, the ‘speech processor’ that is located behind the ear. A microphone in the speech processor picks up sound and sends it via a transmitter coil that connects magnetically to the head, through the skin and into the internal device that has been surgically implanted under the skin. Sound is transferred to the 22 electrodes that are threaded into the inner ear cochlea and sent as electrical stimulation to the auditory nerve within the brain. The electrodes bypass the damaged or missing hair cells in the inner ear that normally code and transfer sound to the auditory part of the brain (Grayden and Clark 2006). The device allows children who are born deaf to have access to sound and opportunities to learn to hear and speak (Sarant and Naz 2012).

Hearing parents in the developed world were amongst the first to take up the Australian developed multi-channel cochlear implant device when it became available in the early 1990s. There was much debate at that time about the risks and ethical concerns from within the medical community and from society more broadly including from deaf people who largely rejected the device (Blume 2010; Friedner 2018; Mauldin 2016).

A substantial body of research considers the impacts of cochlear implants on language, identity, representations of deafness and the ethics of disability

(Christiansen and Leigh 2010; Friedner and Kusters 2020; Sparrow 2005, 2010; Valente 2011). Assumptions about implants reproduce tensions around notions of deafness that draw on ethical discourses about children's rights, the body and parental decision-making (Blume 2010; Kermit, 2010; Mauldin 2016; Solomon 2010; Sparrow 2010). Parents who embrace cochlear implants for their children are often cast as experiencing deafness through a medical prism drawing them into long-term rehabilitative labour to develop oral communication and erase or render invisible the 'pathological' deafness (Mauldin 2016).

The cochlear implant has been the subject of intense debates: alternatively hailed as a 'miracle cure' and a 'quick fix' that effectively transforms the deaf into hearing people, it is also viewed as a means of 'cyborgizing' deaf children (Valente 2011) and enabling a post human cybernetic sensory future (Chorost 2005; Friedner and Helmreich 2012; Mills 2012). Sign language has been predicted to die a rapid death due to the cochlear implant (Johnston 2006; Solomon 2012), and in the global take up of the device an 'ethnocide' of Deaf Culture is predicted (Edwards, 2012; Humphries and Humphries 2011; Eckert 2010). Parents of deaf children are often given an either-or choice—the implant or sign language—in their early meetings with health professionals and this rhetoric frames deafness as a hearing or deaf, speech or sign binary.

Mauldin (2014) has argued that paediatric cochlear implantation changed deafness from a sensory loss to a neurological processing problem and 'the cochlear implant (CI) has been recast as a device that merely provides access to the brain. The "real" treatment emerges as long-term therapeutic endeavours focused on neurological training. This redefinition brings forth an ensuing responsibility to “train the brain,” subsequently displacing failure from the device onto the individual’s (or their parent’s) ability to train his or her brain (2014: 32). Scientific discourses in neuroplasticity are harnessed in debates about early screening and testing for deafness, and deaf children’s language acquisition and cognitive development (Mauldin 2016; Yoshinago-Itano et al. 2017; Young and Tattersall 2007). There is a shift in understanding the body as suffering from sensory impairment to thinking of it as one that is enhanced by a technological device that requires ongoing maintenance and training. Our paper contributes to this literature through a perspective grounded in the sensorium of an implanted body.

Methods

This article is based on ethically approved, multi-sited ethnographic fieldwork carried out between 2017 and 2018 in an Australian city as previously reported (Harris et al. 2020, 2021). In summary, sixteen months of participant observation was undertaken by the first author in clinical sites including four audiology clinics, two cochlear implant centres and three early intervention services for families with deaf children. In total seventy-eight interlocutors were involved in the study, made up of forty-one parents, ten young adults and twenty-seven health and education professionals. Ethics approval only included people aged over 18 years. Consequently, this paper draws on data from a subset that includes ten young adults who were born deaf and had received cochlear implants when young, and their parents. One young adult had chosen a cochlear implant as teenager after some years of hearing aid use, and another two chose a second cochlear implant for the ear that had not been implanted when the first surgery was undertaken. In addition, during fieldwork one parent, aged in his early 40s and born deaf, had a cochlear implant operation a few months before his infant received his implant.

Qualitative semi-structured, in-depth interviews and guided conversations (Csordas et al. 2010) were undertaken. Parents/carers and young people came from diverse socio-economic backgrounds. Interviews generally took about three hours and occurred in libraries, homes, places of work, in parks and cafes. The first author accompanied interlocutors to audiology appointments at cochlear implant clinics, attended social group programs and was invited to 21st birthday parties. When questioning young adults with cochlear implants the focus was initially on what participants thought about their parents' decisions for cochlear implant surgery when they were young. She also asked about how deafness shaped their sense of self and everyday experiences of living with a cochlear implant. Interviews were guided by interlocutors' everyday experiences of deafness and hearing. Sound and technology, and communication and second implant surgeries, were often the subject of conversations.

Interviews and observations of medical appointments were recorded on a smart phone and later written up verbatim. These transcripts were read and re-read and manually sorted prior to importing into NVivo for a process of line-by-line coding. This initial coding led to the development of ideas and key concepts, which were thematically analysed. Participant observation was recorded through making detailed handwritten field notes in eight notebooks and these provided contextual information, knowledge, and practices about deafness in families with children with cochlear implants. Field notes from the eight notebooks were logged into an Excel document that noted location, people present, date and time, subject of discussions and key observations. Once logged these were sorted and coded for key themes and the document was an important reference for returning to field notes. Adopting elements of a grounded theory approach themes generated from analysis of field notes were cross referenced with interview data and relationships between emergent themes were examined and refined (Charmaz 2006). The lead author has a child who was born deaf and received an implant in the late 1990s. She has other family members who are deaf and for twenty years has lived with a child who hears through technology. All research participants and field sites have been given pseudonyms.

Young adults with cochlear implants

During fieldwork the first author met a group of deaf teenagers and young adults who had cochlear implants and who agreed to be involved in the research. Many knew each other through their membership of a youth social support group, which was established some years before by three young adults who were deaf. Their aim was to provide social support and mentoring for students as they transitioned from primary to secondary school. Each person had very different stories and self-identified as hearing and deaf or something more nuanced that relied not on a sensory or ability/disability categorisation. They identified as people first and often chose to not bring attention to either their deafness or cochlear implant because, as 18-year-old Mitch explained, ‘I don’t want it to define me’. While the cochlear implant was sought by their parents, some research participants chose second implants as they became available from about 2008 onwards.[12] Second surgeries and ensuing therapy evoked discussions about neuroplasticity, the brain's response to auditory stimulation, binaural hearing and discussions about sound location and direction. Participants spoke about being deaf and the sense of hearing, of listening and hearing with the brain, and emphasised sound, silence, and social interactions in their experiences.

For these young people, there was an active engagement between themselves and technology which led to discussions of the ways it enabled perception and connection to the world. This had several elements – connection to the 'natural' world with its elemental forces; social connections with family; and connection to broader social networks. They often discussed their model of cochlear implant and its capabilities: did it connect via blue tooth to screens, music devices, smart mobile phones or did they have an intermediary body worn connector, how often did batteries need recharging or changing, and was it a device that could be worn in water while swimming, did they listen to music while in the bath with their processor on. Despite an everyday familiarity with technology and connectivity the notion of futuristic cyborg capability was either not discussed or rejected by participants. 'I'm not a robot', said Juno, 'I'm a person'.

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[12] From 1990 to approximate 2006, only one ear was implanted. Increasing understandings of directional sound and improved capacity of hearing in background noise encouraged the undertaking of bilateral cochlear implants. In the field site, one of the first infants to have both ears implanted simultaneously, was during 2011.

Some participants spoke of a sense of betwixt and between the hearing and deaf world. They felt a deep connection with their families. This connection came from bonds of kinship and an emphasis on communicating through spoken language, which many attributed to the cochlear implant and therapy with teachers of the deaf and their mothers. They felt connections with other people who had cochlear implants and indeed many of them had known each other since they were very young. Some participants were also connected to the Deaf Community through social groups and their use of Auslan (Australian sign Language).

However, feelings of belonging and acceptance in the broader community were often contingent on how they experienced communication. These experiences were sources of tension for some participants; wishing for greater inclusivity was identified as a theme in data analysis. Connection and acceptance in broader society were perceived as being tied to communication and in particular speech intelligibility. While several participants both signed and spoke, some expressed a desire to 'improve my speech'. Normative ideas about fitting in through 'better speech' were expressed through perceived concerns about communicative practices, access to mainstream culture and employment. Nearly all participants had experienced social exclusion and bullying at school and many of them had come up against the politics that exists in deafness generally through online social media, through deaf social groups, and advocacy organisations. Some talked about criticism directed at them, from deaf people via online social media platforms, about the choices their parents had made with the implication that choosing a cochlear implant for a child was a mistake. Despite this, an overriding theme emphasised during fieldwork was the need for inclusivity, shared humanity and of young people valuing opportunities for employment and social connections that they linked with their cochlear implants.

Deaf and hearing – embracing, valuing and debating technology

18-year-old Juno was visiting his audiologist. His cochlear implant was being upgraded to a newer robust model that had greater Bluetooth connectivity. The implant was being 'Mapped' – a process of connecting the externally worn part of the device to a computer to adjust or fine tune the comfort and threshold levels of the 22 electrodes that were surgically inserted into Juno's snail shaped cochlear inside his inner ear. When the Mapping was finished, he went 'live' with two new programs. Later as we sat in the car, a piece of classical music came on the radio. He listened intently. The first author asked him if it sounded different. He said,

> Yeah, there's more colour. It feels like it's gone from black and white to colour, it's more three dimensional – amazing.

Juno sensed the music as a three-dimensional, embodied phenomenon, but it was not metaphorical; rather a feeling associated with perception of sound. This would indicate a subtle and nuanced experience and the significance of sound. Juno articulates a perception of sound as a bodily process (Merleau-Ponty 2004). Like Melanie, Juno received his implant as an infant and was the only one in his family who was deaf. The first author asked him what that was like, did he feel different being deaf in a hearing family? He smiled and said, "No I'm just a normal human being". He was quiet, thinking, and continued with, "actually I'm just a human being, no one is normal".

Juno had a marked interest in sound and technology. It had spurred the purchase of a series of small speakers that had been positioned on three of his bedroom walls and a sub-woofer that sat at the base of his television. The minutiae of a film or game's sound world drew him in. He had a fascination with sounds from the natural world: rain, wind in trees or birds, and especially after his processors had been 'mapped' and adjusted for sound. He said, 'my senses make me feel connected to the world. I like the wind in the trees'. In conversation with the first author he said,

> A cochlear implant is not like a subwoofer on my head. I don't feel the vibration in my head. I hear the sound and my brain processes it. When I was in two-seater plane, I felt the vibrations in my body but the sound doesn't produce vibrations in my head.

Sound was experienced as a bodily vibration only when it was above 90 decibels, as Juno explained, he felt some vibration through his body when he was next to a speaker at a concert or near a low flying jet engine. Bodily or felt experiences of sound were clearly articulated by a late implanted woman who had been born deaf. When the device was first switched on, she said, lifting off the seat of her chair, 'I feel it, I feel it in the brain.' These feelings in the brain would continue in the early days and weeks of living with a device that sent electrically stimulated sound through her cochlear and into the brain's auditory nerve. For the first few days she, 'felt it in the back of my brain and then it moved forwards to the front of my brain'. These feelings suggesting a moving through as though the brain was being stimulated by a physical touch or vibrotactile experience are different to Juno who felt no vibration or sensation in his head. David, discussed later, who decided to have surgery in his early forties spoke in a similar way about feeling sounds moving through his brain confirming the diversity of sensory experiences for people living with cochlear implants as discussed by Lloyd and Bonventre (2020).

Juno was tuned into sound and engaged in ways that offered countless opportunities for sensory experience. He acknowledged his brain in his experiences of hearing and listening to sound and vibration as an embodied experience. He said, ‘the brain is involved with all my senses, not just hearing’. He told me, with his new speakers, one of the best films he’d recently seen was Bird Box, a film that employed sound and the senses as a means of developing the key theme in this post-apocalyptic, psychological thriller, and that the soundtrack of the film heightened the drama and the action of the film. ‘Senses are skills employed to interpret the world’ (Ingold 2000) and this is productive in thinking about the biotechnic device that allows a deaf person to hear and perceive the auditory world. Somatic work may be performed according to ‘somatic rules’ (Howes 1991) but this shifts when there is a capacity to switch on or off sensory registers.

Relationships with technology and connectivity extended to sourcing devices that enabled blue tooth connectivity across all platforms to the speech processor and cochlear implant. Direct connection and close proximity were created via blue tooth technology with smart mobile phones, gaming computers, music streaming and television viewing. Juno, for example, switched between devices and connectivity but explained that when he walked with people, he always positioned them on his right-hand side because, ‘that ear has got more experience. My left ear is an old radio, and my right ear is an expensive hi-fi system’. His right ear was implanted when he was an infant therefore it ‘had more experience’ than his left ear that was implanted when he was a teenager. He could hear through both cochlear implants although his new ear was like a radio or ‘flat like techno music’. Senses, space, and emotion are constitutive and shape experiences (Dundon and Hemer 2016) and everyday experiences with two implants were significant because distance and direction or location of sound could be better detected thus increasing a sense of agency in navigating time and place.

Connection & disconnection: switching on and off sensory engagement

Vaughn articulated experiences of time and space through his implanted body that sometimes was deaf and sometimes hearing. Vaughn worked in an open plan office. He explained he was born ‘fairly deaf, actually profoundly deaf’, which was diagnosed when he was fifteen months old and although he had hearing aids to begin with, they ‘weren’t doing the job for a profoundly deaf person’. Vaughn was three and half when he received a cochlear implant in the early 1990s. He said,

> Yes, I’m deaf but I live in the hearing world. I don’t know whether I’m glad to be deaf, it’s just the way I am but I am glad to have a cochlear implant. I also live in a world where I can hear and choose to not hear or have no sound.

Vaughn emphasised that deafness was ‘all he knew’; additionally, his cochlear implant was ‘all he knew’, and thus he took for granted his capacity to hear and communicate with his family and to ‘switch off.’ He explained that in the morning he put on his implant when he was getting ready to leave for work and that when he came home, while he initially conversed with his family, he then removed his speech processor to 'relax and enjoy the calm of not hearing'. He explained that 'with silence… I am in my own zone, and I can't be taken out if it when I can't hear'. Having agency over sensory experiences including when to be in 'my zone for going to sleep with less distractions', was valued. This zone was not always perceived as a safe or comforting place because if he was home alone or in a hotel, he sometimes worried about not hearing alarms at night in case of an emergency.

Vaughn wore his speech processor when leaving his house and said, 'I don't know if there is a psychological element to this but once I leave the house, I'm part of the world and it stays on'. His cochlear implant was switched on when he was outside his home as he had 'always known hearing' and connected with other people and conversations. He spoke about going to work in a noisy, open plan office. Vaughn found being in noise and listening, an exhausting experience, but he chose not to take his implant off in the workplace. This was not a time for being in his own zone, he explained, the people he worked with 'think it's a bit rude or they might be talking about me, I might miss out on a conversation'. In the space of work, he felt a need to keep the processor on as a way of maintaining his sense of connection with people and the social world.

A sense of self and 'bodily modes of knowing' (Howes 1991 p. 3) are reflected in the ways Vaughn and other interlocutors chose to engage with sensory experience of hearing and listening. Vaughn had a sense of control or agency in experiences of time and space, which he could exercise in ‘his own zone’ or in the external world. He generally slept with the processor off. ‘This is the best thing about being deaf and I really do feel that hearing people are missing out. I can’t imagine not sleeping in silence, so this is an absolute advantage. I couldn’t ever imagine listening to other people snore’, he said. It was difficult for him to explain what silence was like, but it was highly valued. Without his implant on he sometimes sensed vibrations in his body, but he heard ‘absolutely nothing’. We draw on Pagis, (2010) who argues that shared or group situational silence, through meditation practices, evoke interactive, social, and intersubjective experiences. Considering sensory connections and disconnections through technology is not to construe silence as alienating, but rather to understand silence as meaningful and as a ‘constitutive mechanism that allows for certain experiences to surface’ (313). Experiences of silences occur in everyday practices that that are infused by non-verbal, silent experiences including art, dance, romantic love (324) and we argue also through disconnecting technology.

The concept of being in one’s own zone by actively choosing to be in the peace of a silent environment, or to nullify a distracting auditory world, has significance for people with cochlear implants. There was an acknowledgement in interviews that listening was often tiring and at the end of the day it was relaxing to hear no sounds and an embodied ‘letting go’ was experienced. There were other situations when participants would choose to remove their speech processors. Mitch said he couldn’t stand the noise of crying babies, and if he met one, he would often take off his processor to cancel the auditory intrusion: a form of disconnection. The cochlear implant, deafness, and hearing draw together in fluid sensory socialites. These experiences challenge the notion that 'hearing is captive' (Le Breton 2017: 71) and a person is 'defenceless against the intrusion of the external world' (71)[13]. The sense of hearing is mediated; the cochlear implant trumps the best state of the art noise-cancelling headphones available to a 'normal' hearing person. While participants chose to be hearing when they were outside the house and 'in the world', which led to feeling 'part of the world' to quote Juno, and 'secure' in navigating and locating themselves in relation to time and space, and other people or objects in the world, the device is also called on to annul auditory intrusion.

Unlike other participants who had lived with their implants from a time before they could remember, David, introduced earlier, received an implant as an adult although he was born profoundly deaf and wore hearing aids as a child. His process of accepting and discovering living with this new body part was a curious experience of understanding sounds and senses with his cochlear implant. When his implant was first 'switched on' it felt like a physical sensation moving through and in his head. He and the first author had been talking about neuroplasticity and the assumption that an implant enabled immediate hearing: the 'miracle cure'. He said,

> First, I was feeling sounds in one side of my brain, and they went deeper into my brain as time went on. Then I was hearing the sounds, but they had no meaning. I'm learning what they mean – the sound of the kettle, the tap running, the indicator in the car. I didn't have a database to connect the sounds to.

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[13] This is complicated for people who are held captive by tinnitus, commonly called 'ringing in the ears'. Some people who experience tinnitus say their cochlear implant helps ameliorate the auditory intrusion.

This process of identifying and locating sounds in space shifted his understanding and sensory experiences of himself, the world, and other people. Hearing the sound of his own breathing through the cochlear implant, was a revelatory and embodied phenomenon where the 'ephemeral materialization of the air at the interface of body and world, engages with and alters the quality of both' (Oxley and Russell 2020: 3). Sensing the border between the interior and external body is experienced at yet another degree, the first author was told, by the recipients of a new cochlear implant where the device is entirely surgically implanted. These devices, at early development, gave an unintended visceral sense of hearing and feeling the internal workings of the ear and blood moving through the head.

For David, learning that he could 'tune out the sounds in my brain that are not relevant' was equally significant to hearing his breath. He experienced a dislocation between sounds 'that I didn't have a vocabulary for' like the sound of rain on a tin roof and to what he knew about the world from reading books. Discovering a wall clock in his house made a repeated ticking noise 'blew me away'. He said, 'I had no idea that a clock without a second hand would make a noise. I learnt things from books, and you learn that a clock with a second-hand ticks!' Hearing sounds became an embodied sensation that involved locating the source, finding its meaning, which changed understandings and everyday experiences of living in the world as a deaf and hearing man. As each day progressed, he added new sounds to his internal database. Profound sensory experiences generated a dynamic and complex process of interpretation, perception and sense making.

Making active choices

Making choices about when and how to engage with the auditory world was varied and situational. This was evidenced in the ways speech processors were used in everyday lives and also by the choices to have second cochlear implants. With increasing recognition of bilateral implants offering access to sound direction and location and improved hearing in noisy backgrounds, many young people chose second surgeries. Outcomes varied. Eighteen-year-old Mitch was disappointed with his second cochlear implant. He could hear sounds but was not able to identify or discern what they were. He thought the sounds or understanding of the sounds was coming from the other side of his head and the sense making was ‘mixing in my head’, which he demonstrated by waving his hand over the top of his head.

Amber, like Vaugh discussed above, often wanted to take off her speech processor to block out the noise at work. This capacity to remove oneself from a situation or to cut off external conversation or noise was considered in a recent Facebook discussion group for people with cochlear implants. People shared their experiences of taking their processors off to not hear arguments, excessive noise, or pointless conversation. One woman recalled being asked why she wasn’t ‘listening’, and she would say, ‘sorry I turned my ears off, nothing you were saying was worth my batteries’. A series of amusing posts from other CI recipients appeared and there was a general endorsement of the phrase ‘are you worth my batteries?’

Parents in this project talked about living with children with cochlear implants, the ways they might tune in and out by switching off their processors, and the varieties of practices within a family. Mary had three young children with bilateral cochlear implants, which involved a precision management of overnight recharging batteries for six speech processors and three FM systems for use in the classroom. She said,

> Our everyday is that the kids will at least put on one processor in the morning. They don't put them on right away. We are the ones that get at least one on in the morning as it's much easier to help get ready. Frankie will usually be the last to get one on and sometimes not until just walking out the door for school. Maeve will want hers on -we still help her to put it on - when she wants to converse with someone or if she wants to hear the TV or iPad or similar.

While Mary's children tune into a sensory perception of hearing they choose the point or time of entry. Only one child used the FM system for both processors and only one child used the aqua accessory so that he could wear his speech processor and hear while swimming. The other two children were 'happy to not have them on', preferring an embodied sensory experience of quiet immersion in water.

Several months after David's cochlear implant had become more familiar to him, he sent the first author an email and said,

> My cochlear has been going well, it's very much a part of my life now. I am finding it much easier to communicate with people. I've been engaging with people much more readily at work this year and taking on a more conflict

> resolution approach rather than conflict avoidance. While I can't recognise speech with the CI it is still invaluable with so many cues that make up conversational speech in choosing the right times to listen and to talk. I certainly feel that sense of having two bodies. I wear it all day and feel really strange when I remove it, like something is missing. But I wear it from morning to night and have come to accept it all, the good and the bad. It's a much richer experience than I had before.

For David, choosing to be implanted meant noticing cues that allowed him to be connected more readily to others, rather than to hear speech – an experience that made life 'richer' for him.

Conclusion

We have considered how cochlear implants generate sensory experiences that value both deaf and hearing ways of being. This is productive in thinking about how cochlear implants generate engagement more broadly with the sensorium. Narratives from young adults with cochlear implants contest the persuasive framing of people with implants through a medical lens to reveal the significances of being deaf and hearing through technology. Diverse sensory socialites and nuanced ways of being deaf are illustrated through a relational sensory perception and technological capacity to switch on and switch off; to reconfigure sense making, which challenge framing the cochlear implant as a technology 'that seeks to remediate deafness itself…' (Friedner and Kusters 2020: 40).

Deaf experiences and understandings of the term are highly relational and socially situated (Berger 2010; Friedner and Kusters 2020; Ginsburg and Rapp 2013a; Ladd and Lane 2013; Lane 2005). As communities aligned through common experiences and beliefs, Lane argues for a 'Deaf-World' (2005: 91) and this 'twenty-first-century view rests on a history of struggle against widespread discrimination' (Ginsburg and Rapp 2013a: 8). In a similar binary vein is the notion that parents of deaf children, of whom over 90 per cent are hearing, want to re-make their children to be like them, as hearing individuals, and so seek medical and rehabilitative interventions to develop auditory neural pathways (Maudlin 2016; Sparrow 2010). In contrast we have shown how these experiences represent a unique sensorial engagement with the world through implanted bodies that is not like hearing parents at all.

Furthermore, deafness exists in an ambiguous zone of disability and 'not disability' (Park, Fitzgerald and Legge 2015) and there are many ways to be deaf as contemporary contributions to deaf anthropology demonstrate (Friedner and Kusters 2020; Monaghan et al. 2003). 'Disability is a profoundly relational category, always created as a distinction from cultural ideas of normality…not simply lodged in the body but created by the social and material conditions that 'dis-able' the full participation of a variety of minds and bodies' (Ginsburg and Rapp 2013a: 54). Interlocutors in this study, who were amongst the first generation of infants implanted in the 1990s, and are now young adults, challenge notions of disability and offer unique deaf ontologies through their everyday practices of living with bodies embedded with technology.

Embodied sensory experiences of hearing and deafness, as augmented by technology, embrace a human diversity or alterity that cuts across binary notions of normality versus what it is to be deaf. This technological capability is intimately interconnected with sensory and bodily experiences, to ways of knowing and ways of being. Complex, distinct, and insightful meanings are embedded in everyday practices of always knowing and living in a body that has included a biotechnological surgically implanted device. Bodily articulations where sense making boundaries permeate between body and brain, hearing and listening, silence and sound, and can be switched on or off, reveal rich signification and offer new deaf epistemologies and ontologies. We argue, furthermore, that the device has an intrinsic value through enabling hearing while not removing deafness. It is a conduit to communication and relationships in the world, which is valued in being deaf within a hearing family, while at the same time the sensory experience of deafness is also held as significant.

Our ethnography challenges assumptions about the body and sensory articulations through presenting a body that is fluid and agential in every day lived experiences of sensory connection and disconnection. The assumption that hearing is a binary opposite to deafness negates the subtlety and nuanced significances of these ways of being simultaneously deaf and hearing. Interlocutors in this study valued their deafness, seeing it as inherently part of who they were. Their everyday practices of living with a cochlear implant provide a window into varied sensory and social experiences including moments of silence ‘when we are alone and together at the same time’ (Pagis 2010: 324). Interlocutors simultaneously acknowledged their cochlear implants as integral to who they were and to their ways of engaging with the senses, with sounds, with communication and with socialisation. Further ethnographic research with families with deaf children and young adults with cochlear implants is called for to gain insight into living in and through a body implicated with technology and sensory fluidity and in valuing multiple and diverse ways of being deaf in the world.

Chapter 8: Conclusions

> I guess I'm disappointed with policy makers. They listen to so-called experts, maybe some ENT surgeon or some educators but I don’t think the educators, or the specialists really understand the life of a hearing-impaired children's family. They would never be able to represent the parents and the children: they could never. I decided very early on we needed to support each other and share our life experience with other families. And we also learned a lot from other parents as well as being in that community.
>
> (Florence, mother of a 20-year-old daughter who has cochlear implants)

This ethnographic thesis has provided insights and knowledge about everyday practices and experiences of deafness from the point of view of parents of deaf children, and young people with cochlear implants. I have examined parents’ experiences through considering reactions to the diagnostic process and to processes of decision making in a complex referral pathway. I have probed parents’ emotional reactions to childhood deafness and their interactions with health and education professionals, which were often ambiguous and challenging. As well, I have presented analysis of everyday practices of young adults to examine the implications that technology, namely the cochlear implant, had in their lives. These young adults were some of the first infants to receive cochlear implants after they were approved for use in Australia, and this thesis elucidates the value and signification of embodied experiences of deafness and hearing for this cohort. Deafness is often framed as a medical experience that embraces a social imaginary of ‘normal’, but this thesis offers a subtler understanding to illustrate the ways that difference and multiplicity are generated through diverse deaf experiences. Paying close attention to interlocutor's lived experiences, I illustrate the ways that deafness is perceived, experienced, and navigated to argue against the common view that the key goal of medicalisation and the cochlear implant is to 'render (deafness) as invisible as possible' (Mauldin 2016: 156). This thesis demonstrates the complexity and richness of deaf experiences to challenge restrictive binary concepts and representations of deafness.

Parents' experiences of childhood deafness

In examining parents' reactions to a diagnosis of childhood deafness, and to uncertainty in diagnosis and prognosis, I have shown how socially situated concepts of emotion become intrinsically entangled in clinical practices, which resulted in parents and more specifically, women, often being perceived as overwhelmed by the very idea of deafness. Findings from this thesis concur with other findings regarding the diagnostic moment and referral journey as emotional experiences for parents; feelings of grief, maternal guilt, anxiety, worry and stress, hope and future-looking are intertwined. The diagnosis reverberates with how men and women perceive their role as parents. Furthermore, men and women's reactions in the clinical setting demonstrate the ways that emotion inherently contributes to how we negotiate and understand the world (Davidson, Bondi & Smith 2005; Lutz 1998, 2017). Emotion is complicated in clinical settings, and men and in particular women are characterised in certain gendered ways within these settings.

I have shown how, contrary to what is often reported in the literature, parents had knowledge or prior experience of deafness and so this notion that they were ‘unknowing’ in their initial encounters with deafness may not be so certain. Much literature on hearing parents of deaf children rests on this assumption that parents know nothing about deafness when their child is diagnosed, and that this ‘knowing nothing’ state of being, compounds their experiences of deafness and their emotional reactions. I argue instead that knowledge and experience of deafness are drawn from other family members, from childhood experiences, through association with older people, from representations in media, broadly public culture: film and television programs, social media content including videos, blogs, and support pages, and through observations of deaf interpreters on news reporting and at a myriad of cultural events.

I show how parents’ experiences of deafness and the decisions that they made for their infants were often influenced by their understandings of their positions as parents, their relationships with their children and their ideas about deafness and disability. Parents’ desire to communicate with their child, in ways that match what they perceived to be the culture of their family – often about the choice of speech – was a shared value and held significance and meaning for parents. That this speech might be idiosyncratic was embraced by parents as they effectively complicated or rejected notions of ‘normal’ with their children. This calls into question notions about culture and deafness and challenges the over determined and reductive binaries in deafness to offer new insights into deafness.

Parent’s experiences are shaped by the ways that deafness is both represented and constructed within clinical and early intervention settings and more broadly in society.

Interrogating the ways that discourse, knowledge, and social practices are constituted in people's every day lived experiences of deafness, I put forward that many parents were less perturbed by their child's deafness and more by the contested nature of the field that included their relationships with health and education professionals, siloed services, competing services, oppositional ideas about what was 'best' for a deaf child, and stakeholders with agendas. In considering the ways that historic deaf discourses have created meaning and a kind of accepted currency for practices, I have shown also how alternative concepts about deafness, drawn from lived experiences of parents and deaf people, offer resistance and potential avenues for change. Parents were highly motivated and focused on their child's future, which propelled them into sometimes complex relationships within assemblages of care. Moreover, assumptions about parents' emotional responses and about what was best for a deaf child and their family, were sometimes experienced by parents as counterproductive to good care. Mol, Moser and Pols argue, 'While observing care practices we ask what is sought, fostered and hoped for, then and there: what is performed as a good' (2010: 12). It was often the complex referral pathway and roles of stakeholders, experienced by parents as both positive and negative, that created tensions and ambiguity for parents and in some cases complicated the navigation of their 'deaf journey'.

This thesis offers an alternative to recent work about parents, childhood deafness, and the cochlear implant. While a science and technology lens, such as that employed by Laura Mauldin (2016), provides insights into the ways that the medical technology is harnessed alongside neuroscientific scripts about the listening brain, my findings challenge the idea that women are co-opted into anticipatory structures in deaf clinical spaces and held responsible for the efficacy of the device by years of maternal labour. I argue women have their own future looking trajectories. These may work in tandem with anticipatory structures within a clinic, but they signal parents' agency. Parents, in this research, were thinking about, considering, hoping, and planning for their child's future; they were agential in advocating and seeking treatment for their children. What emerged as problematic were the ways that tensions between different agencies and sectors in this setting reignited old debates about communication methodologies and raised concerns about other issues including age and eligibility of implantation, the quality and training of therapists and audiologists, how parents were referred into early intervention programs and the ways that services positioned and valued parents. Parent agency, choice and empowerment were also central in understandings of the navigations and negotiations in clinical and early intervention contexts. Questions about power were central as were discussions about the ways that it proliferated through the field site between interlocutors, competing organisations, ideas, and discourses about deafness.

Experiencing the cochlear implant

Drawing on evidence of the ways in which young people experience, think, and feel about deafness in their quotidian lives, I present understandings of the subtle, complex, and ambiguous relationships between people, technology, and the senses and emotions, to reveal distinct meanings and significations of deafness. Disability is socially understood as an impairment that departs from so-called 'normal' human functioning. Furthermore, deafness is broadly recognised as a phenomenon that draws contested and passionate opinion and debate. My analysis departs from the binary and often reductive way that deafness is interpreted to contribute greater understandings to scholarship about parents, young adults, and deafness. I have shown that while parents are offered biomedical resolutions for deafness in their children, in line with many other medical choices parents make for themselves or their children, the ways that deafness is complicated across different settings or contexts, confounds both the process and understandings of this sensory phenomena.

This calls into question how the cochlear implant is perceived. Parents with lived experience of raising children with cochlear implants grasp that it is not a panacea for deafness, and long-term fieldwork with families with deaf children contributes to the research on the ways that families embrace human variability. I argue the cochlear implant is not about erasure of deafness or the creation of a substitute hearing child; rather, the complexity and variability of experiences of deafness are highlighted. Anthropologists working in deafness do not often explicitly address the forty percent of deaf children who also have other health issues that complicate lived experiences, but which are worth noting when views are presented about the efficacy of this surgical implant, and in discussions and reflections on the notion of disability. Parents and young adults are creating new meanings about personhood and human variability through their intimate and everyday experiences of deafness and cochlear implants that challenge notions of normativity.

In considering experiences of young adults with cochlear implants I have focused on their lived experiences and intersections and connections between the human, technology, and the sensorium. I have demonstrated how the cochlear implanted body encompasses a fluid and open sensory engagement that generates possibilities for connection and disconnection, for turning off and on sensory and social engagement. The cochlear implanted body affords insights into the workings of perception, sensory experiences, and the ways that agency and possibilities for acoustic and temporal and spatial navigation are experienced. Furthermore, these findings offer understandings of how people with cochlear implants value and are open to both deaf and hearing ways of being. More broadly the research offers ways of understanding lived implanted bodies through human and sensory connections to diverge from prevalent cyborg or more-than-human analysis. Young adults, included in this study, who had received cochlear implants as infants, experienced the device not through a cyborg lens, or a more than human or artificial or natural dichotomy. Deafness and their cochlear implant were fundamentally who they were; to their way of being in and of, the world.

Emotion in clinical spaces and as a motivator

In the context of the audiological and early intervention space, I have shown how parents' and professionals' reactions to diagnosis and medical uncertainty are intrinsically tied to cartesian concepts about emotion and socially situated ideas about parenthood and gender. Concepts of maternal connection to newborns, and developing infants, link hearing and audition with a perceived capacity for the mother to connect through speaking, singing, storytelling and a process professionals call 'motherese' wherein a parent creates an auditory soundtrack that connects, calms, and communicates with her baby. For many hearing parents, deafness interrupts these perceived concepts of maternal or paternal connection. This finding is about hearing parents, who were 99% of my research participants and I am aware that for a parent who is deaf the diagnosis may not evoke such emotions.

A key result of this thesis centres on emotion and the way it is constructed and evoked within medical settings and more specifically within the context of deafness. Through examining parents' responses to their child's diagnosis and to medical uncertainty, I have shown that emotion, continues to be conceived through a cartesian lens that splits a rational mind from a feeling heart. Assumptions and tacit understandings about emotion are often reductive. Reason is positioned in opposition to emotions. Data from women in this research actively challenges this outdated view. Rather than separating logical thinking from emotional responses, women harnessed their emotions to help them digest new medical information and knowledge about deafness. While strong emotions were no doubt very real experiences for women and men, parents did not perceive these to impair their judgement or disable decision making about their own or their child's futures. Assumptions about gender and emotion shape parent's experiences in the clinic, and I demonstrate more broadly the ways that space, place, and emotions are co-constitutive in this setting, which has implications for other clinical and diagnostic contexts.

Politics of deafness and disability

In examining experiences of childhood deafness in an Australian context, the politics, and divisions between different models of deafness and ideas about disability and communication were unavoidable. In this thesis I have argued that framing parents' and young people's experiences of deafness through a binary medical-cultural lens is a reductive analysis. I have shown that the persistent binary modelling of deafness as shaped by either cultural or medical experiences closes avenues of enquiry. Classifying some kinds of deaf people and their experiences, as ‘medical’, and other deaf people as invested with cultural capital, continues to separate deaf people and their families. This research indicates the ways that professionals’ ideas about what is best for deaf children and arguments about oral language versus signed language reiterate historical discourses that entangle deafness in a politics of language.

My research has interrogated the contested nature of the field to illustrate how it is shaped by policies in health and disability care that have changed the way funding is channelled into the sector. New services, which emerged to meet growing demand, were often seen as being below par by the established early intervention organisations, which caused friction and increased competition for family enrolments and funding between these organisations and the new emergent services. This competition sits over an historical layer of contestation fundamentally about teaching and communication methodologies. Many families found the overlay and complexity of these factors stressful and navigating services and the ‘medical merry-go-round’ was difficult.

Reflecting on my fieldwork journey, I also experienced these complexities and complications and a flow on effect during the writing of the thesis. The decision to undertake a PhD by publication, rather than by exegesis through the making of a documentary film, brought an additional complexity to the practice and another encounter with the politics of deafness. In the process of choosing journals to submit articles to, I met a bias in understandings of deafness. I began to question whether some voices were given more space than others. This became frustrating particularly when assumptions about language and communication and ‘different kinds’ of deaf people would reappear. There might be hostility in some quarters to sign language, but there is also hostility to cochlear implants and to so called oralism. A core finding of this study is that parents want their children to hear and speak, and so actively choose interventions and therapies in a bid to make this happen. Some parents also chose sign language. However, because a parent does not choose sign, this does not equate to hostility to it. Some parents are not interested, and others do not have the time, inclination, or confidence to learn a new language. Parents’ understandings and knowledge about deafness and their children are much more complicated and nuanced than is often presented in literature. This applies to young adults with cochlear implants. Parents employed the phrase ‘to have a normal life’, when referring to the choices they made for their children, while also speaking about ‘disability’; these concepts were not mutually exclusive. Davis notes the complex ironies and historic specificities of the term normal as he articulates, ‘not one of us is, or can be, normal, nor can anyone describe what a normal person is’ (Davis 2006: 18), echoed succinctly earlier by one of my interlocutors: ‘I’m just a human being, no one is ‘normal’.

The value of this ethnography

A central aim of this thesis has been to explore how parents and young people experience deafness in an Australian setting. I focused on the ways that clinical services and policies were implemented and practiced in this setting and how parents responded and made decisions within a paediatric deaf referral pathway. Drawing on a phenomenological analysis of ethnographic data collected over sixteen months, the results of this research demonstrate the ways that deafness both generates and is generated by knowledge and practices of this sensory phenomena.

This thesis explored experiences of parents through following families and babies on their journeys and therefore the research has not been confined to one clinical space. This multisite approach to fieldwork enabled a deep immersive insight into ordinary practices and significations in deafness. In grappling with how to manage a complex multi-sited field work I decided to undertake a 'follow the baby' approach, drawing on Marcus's notion of 'follow the thing' as a way through complex systems, 'strategies of quite literally following connections, associations, and putative relationships are thus at the very heart of designing multi-sited ethnographic research' (Marcus 1995: 97). By following the baby, often responding at short notice to parent's text messages about medical or therapy appointments, I experienced parents' interaction with multi layers of different agencies involved in their child's interventions. Following the connections, links, relations and 'putative relationships' (199597) I experienced parents' routine processes of navigating the complexities of repeated and numerous interactions and appointments with clinicians, other parents, therapists and family members. A strength of this ethnographic approach, of following interlocutors from the process of diagnosis through a journey of decision making, were the valuable insights gained from regular or daily engagement with research participants and their families. Rather than a snapshot vision gained from an interview or a retrospective view of reactions to childhood deafness, I was able to capture and observe in the moment, which added a layer of immediacy and signification. My ethnographic method was not restricted to the follow the baby approach; it also included periods of time spent observing and participating at several clinical organisations. Furthermore, this ethnography has been shaped by archival research, which gave access to the texts, news and government reports, images, artefacts, and materiality of the history of my field site.

Immersion in the deaf referral pathway was an invaluable method and access to accompany parents on their journey of diagnosis, referral, and decision making. This ethnographic research process of ‘following the baby’ afforded a deep examination of the connections between cultural meanings, discourse, material objects and senses and emotions as they dispersed through space and time in this deaf context. It gave me, as researcher, a way to observe and participate from the parents’ point of view. I am also a parent, so this gave the double complication and benefit of holding an insider/outsider perspective. I believe it provided insight into the perspectives and perceptions of parents and thus generates new meaning and understanding about childhood deafness. This intimate insider view of parents’ daily practices was my intended focus including the interactions and generative potential of space, place and the emotions and sensorium.

Contribution

Findings presented in this study are significant to the research on parents with deaf children who are an understudied cohort in anthropology and the social sciences more generally. There is a lack of anthropological studies in the area in Australia. The findings aim to break down the binary assumptions that are found in deaf studies and health sciences to offer a more subtle view of deafness and of families with deaf children. The findings also offer understandings for medical practice through demonstrating that the politics in deafness is an issue not just for parents but also for health and medical professionals working in the field. My research offers valuable insights into the experiences of young adults with cochlear implants who have received limited attention from the social sciences. Oralism versus sign language debates in deafness offer discourses about cultural loss and the importance of maintaining cultural diversity through signed language. The findings from this study would indicate it is time to broaden the frame and consider other deaf experiences also as cultural experiences, which may mitigate the ways that deaf people have become problematic to each other.

Findings include the need for more research on the concept of culture as applied to deaf people. Persisting with the medical-cultural binary and other cultural constructions about deafness and deaf experiences will maintain the status quo. In a similar vein, continuing to see the medical model of deafness as a deficiency model strangleholds enquiry. Deafness may be augmented by technology in the same way that human life is augmented by other technologies and devices. Instead of dismissing this as a clinical experience, a more interesting approach might consider how these practices are experienced and what meanings and values they hold for people in their everyday lives.

Future research on the ways that parents support and inform each other and the clinical practices that they are engaged in is warranted. This would open ways for change in how parents experience childhood deafness – to acknowledge that parents and young adults are key stakeholders and as such their experience demands greater involvement in the ways that medical and education practices and policies are shaped. The establishment of the NDIS in Australia seems to have localized disability and choice individually within a family, which in some ways is to be applauded, but research is called for to understand how parents experience the process.

Experiences of siblings in families with children who are deaf warrants research to consider the dynamics in family life of complex and long-term engagement with medical and education networks. Siblings are often neglected in deaf research, yet they are integral to the quotidian experiences and social practices of families with children who are deaf or have disabilities. Additional research with young people and adults who are deaf and have cochlear implants is called for, as this technology continues to change. Moreover, cochlear implant recipients’ input is increasingly sought in design and function development, so that this is not a fixed or constant social field but rather one that is fluid and shifting.

The study’s limitations are reflected in the fieldwork site being restricted to research in one Australian city. Broadening the scope to consider other city or state locations may have revealed differences in the diagnostic referral processes, with, for example, the addition of counsellors or psychologists. I had considerable ground to cover in a multi sited field in one location and attempting to observe experiences in more than one city was beyond the range of the fieldwork duration. I have not focused on the Deaf Community or on health and education professionals. While audiologists, surgeons, cochlear implant and other technology providers and early intervention workers have been included in this study, they have not been at the centre of attention.

While families from rural and regional areas were included as research participants, I was situated in the metropolitan area, so interviews and observations of their meetings with doctors and audiologists were for the most part undertaken in the context of the family coming to the city for their appointments. I made several visits as day trips to families who were living in country areas and spoke with and interviewed by telephone parents in rural areas. I also had opportunities to observe online Skype and Zoom sessions with remote families and their city-based therapists, and to travel with a team of audiologists to a rural location to observe as they tested several infants. Many families spoke to me about the challenges of life in rural areas, and the lack of access to information and advice. They felt the strain of this and of repeated long travel to attend city-based meetings. More insights might have been gained into these families' experiences had I been able to spend an extended period situated with them in rural or remote locations.

In conclusion, I contend that parents' and young adults' experiences of deafness are often complicated by assumptions about deafness and emotion in clinical spaces and by enduring binary concepts of deafness that frame people through either a medical or cultural model. I argue these models are reductive ways of thinking, which close avenues for enquiry. Interlocutors understand deafness in more subtle and complex ways that open to possibilities, and nuanced ways of experiencing a sensory engagement that embraces deaf and hearing ways of being. Parents of deaf children and young adults with cochlear implants challenge medical and cultural views of deafness and their experiences warrant a broader view of this sensory phenomena.

Figure 11: A small child, tired of waiting for his parents and the audiologist, removes his speech processor, the externally worn part of his cochlear implant, and hangs it on the audiologist's door.

References

Agnew, J. (2005) ‘Space Place,’ Ch. 5 in Cloke, P. J. & Johnston, R. (eds) *Spaces of geographic thought: deconstructing human geographies binaries*, Sage: London.

Ahmed, S. (2014) *The cultural politics of emotion*, Edinburgh University Press: Edinburgh.

Bachelard, G. (1964) *The poetics of space*, Orion Press: New York.

Barkham, L.F. (1974) *The story of Townsend House, 1874-1974: the South Australian Institution for Deaf and Blind Incorporated*, South Australian Institute for the Deaf and Blind: Adelaide.

Baumen, H.-D. L. & Murray, J. J. (2012) ‘Deaf studies in the 21st century: ‘Deaf-gain’ and the future of human diversity,’ in Marschark, M. & Spencer, P. E. (eds) *The Oxford handbook of deaf studies, language, and education*. Vol 2. Oxford University Press.

Beatty, A. (2013) ‘Current emotion research in anthropology: reporting the field,’ *Emotion Review*, 5(4): 414-422.

Beatty, A. (2014) ‘Anthropology and emotion,’ *Journal of the Royal Anthropological Institute*, 20(3): 545-563.

Berger, J. (2010) ‘Uncommon Schools: Institutionalizing Deafness in Early- Nineteenth-Century America,’ pp: 153-171 in Tremain, S. (ed), *Foucault and the government of disability*, University of Michigan Press: Ann Arbour, US.

Bianco, J.L. (1987) *National policy on languages*, Australian Government Publishing Service: Canberra.

Bier, S. (2018) *Bird Box*, Bluegrass Films, Chris Morgan Productions, Netflix.

Blackman, L. (2008) *The body: the key concepts*, Oxford: Berg.

Blackman, L. (2010) ‘Bodily integrity,’ *Body and Society*, 16(3), pp.1-9.

Blume, S. (2010) *The Artificial ear: cochlear implants and the culture of deafness*, Rutgers University Press: New Brunswick, N.J.

Bondi, L. (2014) ‘What’s in a name? Secrets, haunting, and family ties,’ Ch. 7, pp: 43-48 in Wyatt, J. & Adams, T. E. (eds) *On (writing) families: autoethnographies of presence and absence, love and loss*, Sense Publishers: Rotterdam, Netherlands.

Bosteels, S., Van Hove, G. & Vandenbroeck, M. (2012) ‘The roller-coaster of experiences: becoming the parent of a deaf child,’ *Disability and Society*, 27(7): 983-996.

Brabers A. E. M., Rademakers J.J.D.J.M., Groenewegen P.P., van Dijk L. & de Jong J.D. (2017) ‘What role does health literacy play in patients’ involvement in medical decision-making?’ *PLoS ONE*, 12(3), https://doi.org/10.1371/journal.pone.0173316.

Brannick, T. & Coghlan, D. (2007) ‘In defense of being ‘native’: the case for insider academic research,’ *Organizational Research Methods*, 10(1): 59-74.

Bruin M., & Nevøy A. (2014) ‘Exploring the discourse on communication modality after cochlear implantation: a Foucauldian analysis of parents’ narratives,’ *Journal of Deaf Studies and Deaf Education*, 19(3): 385-399, https://doi.org/10.1093/deafed/enu003.

Burns, E., Fenwick, J., Schmied, V., & Sheehan, A. (2012) ‘Reflexivity in midwifery research: the insider/outsider debate,’ *Midwifery*, 28(1): 52-60.

Bury, M. R. (1982) ‘Chronic illness as biographical disruption,’ *Sociology of Health and Illness*, 4(2): 167-182.

Bussé, A., Mackey, A., Carr, G., Hoeve, H., Uhlén, I., Goedegebure, A., Huibert, J. & Simonsz, H. (2021) 'Assessment of hearing screening programmes across 47 countries or regions III: provision of childhood hearing screening after the newborn period,' *International Journal of Audiology*, 60(11): 841-848, DOI: 10.1080/14992027.2021.1897170.

Butler, J. (1990) *Gender trouble*, Routledge: New York.

Cardon, G. & Sharma, A. (2013) 'Central auditory maturation and behavioral outcome in children with auditory neuropathy spectrum disorder who use cochlear implants', *International Journal of Audiology*, 52(9): 577-586.

Carolan, M. (2003) 'Reflexivity: a personal journey during data collection,' *Nurse Researcher*, 10(3): 7-41.

Cascio, M. A. (2017) 'Operationalizing new biopolitical theory for anthropological inquiry,' *Anthropological Quarterly*, 90(1): 193-224.

Charles, C., Gafni, A., & Whelan, T. (1997) 'Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango),' *Social Science & Medicine*, 44(5): 681-692, https://doi.org/10.1016/s0277-9536(96)00221-3.

Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis*, Sage: London.

Ching, T.Y., Crowe, K., Martin, V., Day, J., Mahler, N., Young, S., Street, L., Cook, C. & Orsini, J. (2010) 'Language development and everyday functioning of children with hearing loss assessed at 3 years of age,' *International Journal of Speech-Language Pathology*, 12(2): 124-131.

Ching, T.Y., Dillon, H., Day, J., Crowe, K., Close, L., Chisholm, K. & Hopkins, T. (2009) ‘Early language outcomes of children with cochlear implants: interim findings of the NAL study on longitudinal outcomes of children,’ *Cochlear Implants International*, 10(S1), pp.28-32.

Ching, T.Y., Dillon, H., Marnane, V., Hou, S., Day, J., Seeto, M., Crowe, K., Street, L., Thomson, J., Van Buynder, P. & Zhang, V. (2013) ‘Outcomes of early-and late-identified children at 3 years of age: findings from a prospective population-based study,’ *Ear and Hearing*, 34(5): 535-552.

Chorost, M. (2005) *Rebuilt: how becoming part computer made me more human*, Houghton Mifflin Publishers: New York.

Christiansen, J. & Leigh, I. (2010) ‘Cochlear implants and deaf community perceptions,’ in Paludneviciene, R. & Leigh, I. (eds) *Cochlear implants: evolving perspectives*, Gallaudet University Press: Washington, DC.

Clark, G. (2003) *Cochlear implants: fundamentals and applications*, Springer: New York.

Classen, C. (1997) ‘Foundations for an anthropology of the senses,’ *International Social Science Journal*, 49(153): 401-412.

Collyer F. M., Willis K. F. & Lewis S. (2017) ‘Gatekeepers in the healthcare sector: knowledge and Bourdieu’s concept of field,’ *Social Science and Medicine*, 186: 96-103, https://doi.org/10.1016/j.socscimed.2017.06.004.

Coulter, A. & Collins, A. (2011) *Making shared decision-making a reality: no decision about me, without me*, The King’s Fund Publishing: London.

Cresswell, T. (2015) *Place: an introduction*, John Wiley and Sons Ltd: Chichester, West Sussex.

Crowe, K., Fordham, L., McLeod, S. & Ching, T. Y. C. (2014) '"Part of our world": influences on caregiver decisions about communication choices for children with hearing loss,' *Deafness and Education International*, 16(2): 61-85, https://doi.org/10.1179/1557069X13Y.0000000026.

Csordas, T. J. (1990) 'Embodiment as a paradigm for anthropology,' *Ethos Journal of the Society of Psychological Anthropology*, 18(1): 5-47.

Csordas, T.J., C. Dole, A. Tran, M. Strickland, & Storck, M. (2010) 'Ways of asking, ways of telling,' *Culture, Medicine and Psychiatry*, 34(1):29-55, https://doi.org/10.1007/s11013-009-9160-4.

Cytowic, R. (2010) 'Our hidden superpowers', *New Scientist,* 206(2757): 46.

Dahl, H-H. M., Ching, T. Y. C., Hutchison, W., Hou, S., Seeto, M. & Sjahalam-King, J. (2013) 'Etiology and audiological outcomes at 3 years for 364 children in Australia,' *PloS One*, 8(3): e59624–e59624, DOI: 10.1371/journal.pone.0059624.

Davidson, J. Bondi, L & Smith, M. (2005) *Emotional geographies*, Ashgate Publishing: Aldershot, England.

Davis, C. (2011) *Reflexive ethnography: a guide to researching selves and others*, Routledge: London.

Davis, L. J. (2016) *The disability studies reader*, Routledge: London.

De Leon, J. P. & Cohen J. H. (2005) 'Object and walking probes in ethnographic interviewing,' *Field Methods*, 17(2): 200-204, DOI: 10.1177/1525822X05274733.

Dettman, S.J., Pinder, D., Briggs, R.J., Dowell, R.C. & Leigh, J.R. (2007) ‘Communication development in children who receive the cochlear implant younger than 12 months: risks versus benefits,’ *Ear and Hearing*, 28(2): 11S-18S.

Dettman, S., Choo, D., Au, A., Luu, A. and Dowell, R. (2021) ‘Speech perception and language outcomes for infants receiving cochlear implants before or after 9 months of age: use of category-based aggregation of data in an unselected pediatric cohort,’ *Journal of Speech, Language, and Hearing Research*, 64(3): 1023-1039.

Devlieger, C. (2018) ‘Disability,’ in Stein, F., Lazar, S., Candea, M., Diemberger, H., Robbins, J., Sanchez, A., & Stasch, R. (eds) *The Cambridge encyclopedia of anthropology*, http://doi.org/10.29164/18disab.

Dillehay, J. (2011) ‘Genetic research, bioethical issues and cochlear implants: an overview of the issues affecting the deaf community,’ in Paludneviciene, R. & Leigh, I. W. (eds) *Cochlear implants: evolving perspectives*, Gallaudet University Press: Washington, DC.

Disability Discrimination Act, 1992, https://humanrights.gov.au/our-work/employers/disability-discrimination

Doidge, N. (2007) *The brain that changes itself*, Viking, 6: New York.

Drought, T.S. & Koenig, B. A. (2002) ‘“Choice” in end-of-life decision making: researching fact or fiction?,’ *The Gerontologist*, 42(Special Issue III): 114-128.

Duchan, J. F. & Kovarsky, D. (2005) *Diagnosis as cultural practice*, Mouton de Gruyter: Berlin.

Duncan, J. (2009) ‘Parental readiness for cochlear implant decision-making,’ *Cochlear Implants International*, 10(S1): 38-42, DOI: 10.1002/cii.384.

Duncan, J. (2011) ‘Application of auditory (re) habilitation teaching behaviors to a signed communication education context,’ pp: 229-241 in Paludneviciene, R. & Leigh, I. W. (eds) *Cochlear implants: evolving perspectives*, Gallaudet University Press: Washington, DC.

Dundon, A. & Hemer, S. (2016) ‘Ethnographic intersections: emotions, senses and spaces’ in Hemer, S. & Dundon, A. (eds) *Emotions, senses, spaces: ethnographic engagements and intersections*, University of Adelaide Press.

Edwards, R.A. (2012) *Words made flesh*, New York University Press: New York.

Estabrooks, W. MacIver-Lux, K. & Rhoades, E A. (2016) *Auditory-verbal therapy for young children with hearing loss and their families, and the practitioners who guide them*, 1st edition, Plural Publishing, Inc.: San Diego, California.

Fjord, L. (2001) ‘Ethos and embodiment: the social and emotional development of deaf children,’ *Scandinavian Audiology*, 30(2): 110–115.

Fjord, L. (2003) ‘Contested signs: discursive disputes in the geography of the pediatric cochlear implant, language, kinship, and expertise,’ ProQuest Dissertations Publishing.

Flaherty, M. (2015) ‘What we can learn from hearing parents of deaf children,’ *Australasian Journal of Special Education*, 39(1): 67-84, DO1:10.1017/jse.2014.19.

Flexer, C. (2011) ‘Cochlear implants and neuroplasticity: linking auditory exposure and practice,’ *Cochlear Implants International*, 12(sup1): S19-S21, DOI: 10.1179/146701011X13001035752255.

Foucault, M. (1978) *The history of sexuality: volume 1, the will to knowledge*, Penguin Random House: New York.

Foucault, M. (1989) *The birth of the clinic: an archaeology of medical perception*, Routledge: London.

Foucault, M. (2001) *Madness and civilization: a history of insanity in the age of reason*, Routledge: London.

French, S. (1993) 'Disability, impairment or something in between,' in Swain, J., French, J., Barnes, C. & Thomas, C. (eds) *Disabling barriers, enabling environments*, Sage: London.

Friedner, M. (2013) 'Producing "silent brewmasters": deaf workers and added value in India's coffee cafés,' *Anthropology of Work Review*, 34(1): 39-50.

Friedner, M. (2014) 'The church of deaf sociality: deaf churchgoing practices and "sign bread and butter" in Bangalore, India,' *Anthropology and Education Quarterly*, 45(1): 39-53.

Friedner, M. (2015) *Valuing deaf worlds in urban India*, Rutgers University Press: New Brunswick, NJ.

Friedner, M. (2018) 'Sign language as virus: stigma and relationality in urban India,' *Medical Anthropology*, 37(5): 359-372, https://doi.org/10.1080/01459740.2017.1371151.

Friedner, M. & Helmreich, S. (2012) 'Sound studies meets deaf studies,' *The Senses and Society*, 7(1): 72-86.

Friedner, M. & Kusters, A. (2020) 'Deaf anthropology,' *Annual Review of Anthropology*, 49(1): 31-47, https://doi.org/10.1146/annurev-anthro-010220-034545.

Gale, E., Berke, M., Benedict, B., Olson, S., Putz, K. & Yoshinaga-Itano, C. (2019) ‘Deaf adults in early intervention programs,’ *Deafness and Education International*, 1–22, https://doi.org/10.1080/14643154.2019.1664795

Garate, M. (2011) ‘Educating children with cochlear implants in an ASL/ English bilingual classroom,’ pp: 206-228 in Paludneviciene, R. & Leigh, I. W. (eds) *Cochlear implants: evolving perspectives,* Gallaudet University Press: Washington, DC.

Geers, A. E. (2006) ‘Factors influencing spoken language outcomes in children following early cochlear implantation,’ *Cochlear and Brainstem Implants: Advances in Otorhinolaryngol*, 64: 50-65, DOI: 10.1159/000094644.

Geers, A. E., Moog, J.S., Biedenstein, J., Brenner, C. & Hayes, H. (2009) ‘Spoken language scores of children using cochlear implants compared to hearing age-mates at school entry,’ *The Journal of Deaf Studies and Deaf Education*, 14(3): 371-385.

Geers A., Mitchell C. M., Warner-Czyz A, Wang, N-Y. & Eisenberg, L. S. (2017) ‘Early sign language exposure and cochlear implantation benefits’, *Pediatrics (Evanston)*, 140(1): e20163489, https://doi.org/10.1542/peds.2016-3489.

Gilliver, M., Ching, T. & Sjahalam-King, J. (2013) ‘When expectation meets experience: parents’ recollections of and experiences with a child diagnosed with hearing loss soon after birth,’ *International Journal of Audiology*, 52(Supp.2): S10-S16.

Ginsburg, F. & Rapp, R. (2013a) ‘Disability worlds,’ *Annual Review of Anthropology*, 42(1): 53-68.

Ginsburg, F. & Rapp, R. (2013b) ‘Entangled ethnography: imagining a future for young adults with learning disabilities,’ *Social Science and Medicine*, 99: 187-193, https://doi.org/10.1016/j.socscimed.2013.11.015.

Ginsburg, F. & Rapp, R. (2020) ‘Disability/anthropology: rethinking the parameters of the human: an introduction to supplement 21,’ *Current Anthropology*, 61(S21): S4-S15.

Goodley, D. (1999) ‘Disability research and the ‘researcher template’: reflections on grounded subjectivity in ethnographic research,’ *Qualitative Inquiry*, 5(1): 24-46.

Grayden, D.B. and Clark, G.M. (2006) ‘Implant design and development’, in Cochlear implants: A practical guide’, Cooper H.R. & Craddick, L. C. (Eds) Whurr Publishing London & Philadelphia.

Green, S. E. (2007) ‘“We’re tired, not sad”: benefits and burdens of mothering a child with a disability,’ *Social Science and Medicine*, 64(1): 150-163.

Gregg, M. & Seigworth, G. J. (2010) *The affect theory reader*, Duke University Press: Durham, NC.

Hall, M. L., Hall, W. C., & Caselli, N. K. (2019) ‘Deaf children need language, not (just) speech,’ *First Language*, 39(4): 367-395, https://doi.org/10.1177/0142723719834102.

Haraway, D. (1991) *Simians, cyborgs and women: the reinvention of nature*, Free Association: London.

Hardonk, D. (2013) ‘Analysing care-related decisions in parents of congenitally deaf children: introduction of an explanatory model,’ *Scandinavian Journal of Disability Research*, 15(3): 264-281, https://doi.org/10.1080/15017419.2012.703966.

Harris, A. & Guillemin, M. (2012) ‘Developing sensory awareness in qualitative interviewing: a portal into the otherwise unexplored,’ *Qualitative Health Research*, 22(5): 689-699.

Harris, C., Hemer, S.R. & Chur-Hansen, A. (2020) '"It's an emotional rollercoaster" the spatial and temporal structuring of affect in diagnosing childhood hearing loss,' *Emotion, Space and Society*, 37: 100729.

Harris, C., Hemer, S. & Chur-Hansen, A. (2020) 'Emotion as motivator: parents, professionals and diagnosing childhood deafness,' *Medical Anthropology*, 40(3): 254-266.

Harris, C., Hemer, S.R. & Chur-Hansen, A. (2021) 'Informed choice and unbiased support: Parents' experiences of decision-making in paediatric deafness,' *SSM-Qualitative Research in Health*, 1: 100022.

Henner, J., & Robinson, O. (2021, July 8) *Unsettling languages, unruly bodyminds: imaging a crip linguistics,* https://doi.org/10.31234/osf.io/7bzaw.

Heritage, M. & Maynard, D. W. (2006) 'Problems and prospects in the study of physician-patient interaction: 30 years of research,' *Annual Review of Sociology,* 32(1): 351-374, https://doi.org/10.1146/annurev.soc.32.082905.093959.

Hoad, T.F. (2013) *The concise Oxford dictionary of English etymology*, Oxford University Press: Oxford, UK.

Hochschild, A. R. (1979) 'Emotion work, feeling rules, and social structure,' *The American Journal of Sociology*, 85(3): 551-575.

Hochschild, A. R. (2012) *The managed heart: commercialization of human feeling*, University of California Press: Berkeley.

Holland, D. & Leander, K. (2004) 'Ethnographic studies of positioning and subjectivity: an introduction,' *Ethos*, 32(2): 127-139, https://doi.org/10.1525/eth.2004.32.2.127.

Howes, D. (1991) *The varieties of sensory experience: a sourcebook in the anthropology of the senses*, University of Toronto Press: Toronto.

Howes, D. (2003) *Sensual relations: engaging the senses in culture and social theory*, University of Michigan Press: Ann Arbor.

Howes, D. (2006) *Charting the sensorial revolution*, Berg Publishers: UK.

Hubert, J. (2000) *Madness, disability, and social exclusion: the archaeology and anthropology of 'difference',* Routledge: New York.

Humphries, J. & Humphries, T. (2011) 'Deaf in the time of the cochlear,' *Journal of Deaf Studies and Deaf Education,* 16(2): 153-163.

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Padden, C., Rathmann, C. & Smith, S. (2016) 'Language Choices for Deaf Infants: Advice for Parents Regarding Sign Languages,' *Clinical Pediatrics*, 55(6): 513-517, https://doi.org/10.1177/0009922815616891.

Humphries T., Kushalnagar P., Mathur G., Napoli D. J., Padden C., Rathmann, C., & Smith, S. (2016) 'Avoiding Linguistic Neglect of Deaf Children,' *Social Service Review*, https://doi.org/10.1086/689543.

Huiracocha, L., L. Brito, M.E. Peréz, R., Clavijo, S., Sempertegui, S.K., Huiracocha, S K. & S. Blume (2015) ''Su guagua no escucha nada': Ecuadorian families confronting the deafness of a child,' *Disability and Society*, 30(4): 556-568.

Huiracocha-Tutiven, L., Orellana-Paucar, A., Brito, L., & Blume, S. (2017) 'Parents and grandparents of deaf children in Ecuador: concerns and expectations,' *Disability and Society*, 32(10): 1555-1569, DOI: 10.1080/09687599.2017.1358603.

Hutchins, J. & Hutchins, E. (1995) *To hear is to speak*, Cora Barclay Centre: Gilberton, South Australia.

Hyde, M., Punch, R., & Komesaroff, L. (2010) 'Coming to a decision about cochlear implantation: parents making choices for their deaf children,' *Journal of Deaf Studies and Deaf Education*, 15(2): 162-178, https://doi.org/10.1093/deafed/enq004.

Ingold, T. (2000) *The perception of the environment: essays on livelihood, dwelling and skill*, Routledge: London.

Jackson, M. (1989) *Paths towards a clearing, radical empiricism and ethnographic enquiry*, Indiana University Press: Bloomington.

Jackson, M. (1996) *Things as they are: new directions in phenomenological anthropology*, Indiana University Press: Bloomington.

Johnston, T. (2006) 'W(h)ither the deaf community? population, genetics, and the future of Australian sign language,' *Sign Language Studies*, 6(2): 137-173.

Joint Committee on Infant Hearing, American Academy of Pediatrics & American Speech-Language-Hearing Association (2000) 'Year 2000 position statement: principles and guidelines for early hearing detection and intervention programs,' *Pediatrics*, 106(4): 798-817.

Joint Committee on Infant Hearing, American Academy of Pediatrics & American Speech-Language-Hearing Association (2007) 'Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs,' *Pediatrics*, 120(4): 898-921, DOI: 10.1542/peds.2007-2333.

Joint Committee on Infant Hearing of the American Academy of Pediatrics, Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., Brookhouser, P. E., Epstein, S., Buchman, C., Mehl, A., Vohr, B., Moeller, M. P., Martin, P., Benedict, B. S., Scoggins, B., Crace, J., King, M., Sette, A. & Martin, B. (2013) ‘Supplement to the JCIH 2007 position statement: principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing,’ *Pediatrics*, 131(4): e1324–e1349, https://doi.org/10.1542/peds.2013-0008.

Jutel, A. & Conrad, P. (2011) *Putting a name to it: diagnosis in contemporary society*, John Hopkins University Press: Baltimore.

Jutel, A. & Nettleton, S. (2011) ‘Towards a sociology of diagnosis: reflections and opportunities,’ *Social Science and Medicine,* 73(6): 793-800.

Jutel, A. & Jutel, T. (2014) ‘‘Deal with it. name it’: the diagnostic moment in film,’ *Medical Humanities*, 43(3): 185-191.

Kecman, E. (2018) ‘Old challenges, changing contexts: reviewing and reflecting on information provision for parents of children who are deaf or hard-of hearing,’ *Deafness & Education International*, 21(1): 3-24, https://doi.org/10.1080/14643154.2018.1506072.

Kermit, P. (2010) ‘Choosing for the child with cochlear implants: a note of precaution,’ *Medicine, Health Care, and Philosophy*, 13(2): 157-167, DOI: 10.1007/s11019-010-9232-9.

Kleinman, A. (1995) *Writing at the margin: discourse between anthropology and medicine,* University of California Press: Berkeley.

Kleinman, A. (1997) *Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine and psychiatry,* University of California Press: Berkeley.

Kovarsky, D., L.K. Snelling & Myer, E. (2005) ‘Emotion and objectivity in medical diagnosis,’ pp: 179-200 in Duchan, J.F. & Kovarsky, D. (eds) *Diagnosis as cultural practice*, Mouton de Gruyter: Berlin.

Knoors, H. & Marschark, M. (2012) ‘Language planning for the 21st century: revisiting bilingual language policy for deaf children,’ *Journal of Deaf Studies and Deaf Education*, 17(3): 291-305, https://doi.org/10.1093/deafed/ens018.

Kral, A. & Lenarz, T. (2015) ‘How the brain learns to listen: deafness and the bionic ear,’ *Neuroforum*, 21(1): 21-28.

Krassnitzer, L. & Willis, E. (2016) ‘The public health sector and Medicare,’ pp: 17-34 in *Understanding the Australian health care system*, 3rd edition, Elsevier Australia.

Kurtzer-White, E. & Luterman, D. (2003) ‘Families with children with hearing loss: grief and coping,’ *Mental Retardation and Developmental Disabilities Research Reviews*, 9(4): 232-235.

Kusters, A. (2012) ‘“The Gong was beaten” – Adamorobe: A “deaf village” in Ghana and its marriage prohibition for deaf partners,’ *Sustainability*, 4(10): 2765-2784.

Kusters, A. (2015) *Deaf space in Adamorobe: an ethnographic study of a village in Ghana,* Gallaudet University Press: Washington, DC.

Ladd, P. (2003) *Understanding deaf culture: in search of deafhood,* Multilingual Matters: Clevedon.

Ladd, P. (2007) ‘Cochlear implantation, colonialism, and deaf rights,’ p. 129 in in Komesaroff L. (ed.) *Surgical consent: Bioethics and cochlear implantation,* Gallaudet University Press: Washington, DC.

Ladd, P. & Lane, H. (2013) ‘Deaf ethnicity, deafhood, and their relationship,’ *Sign Language Studies*, 13(4): 565-579.

Laing, P. (2006) ‘Migrating to a deaf world: a model for understanding the experiences of hearing parents of deaf children,’ *Journal of Social Anthropology and Cultural Studies,* 3(1): 75-99, DOI: 10.11157/sites-vol3iss1id41.

Landsman, G. (1998) ‘Reconstructing motherhood in the age of perfect babies,’ *Signs*, 24(1): 69-99.

Landsman, G. (2008) *Reconstructing motherhood and disability in the age of perfect babies*, 1st edition, Routledge: New York, https://doi.org/10.4324/9780203891902.

Lane, H. (1995) ‘Constructions of deafness,’ *Disability and Society*, 10(2): 171-190.

Lane, H. (2005) ‘Ethnicity, ethics, and the deaf-world,’ *The Journal of Deaf Studies and Deaf Education*, 10(3): 291-310.

Lane, H., Pillard, R.C. & Hedberg, U. (2011) *The people of the eye: deaf ethnicity and ancestry*, Oxford University Press: New York.

Latimer, J. (2007) ‘Diagnosis, dysmorphology, and the family: knowledge, motility, choice,’ *Medical Anthropology*, 26(2): 97-138.

Latimer, J. (2013a) ‘Unsettling conditions? Motility, human division and (post) human imperatives,’ *Plenary, Australian Anthropology Association’s Annual Conference*, The Human in the World, the World in the Human, Canberra, Nov. 6-8, 2013.

Latimer, J. (2013b) *The gene, the clinic and the family: diagnosing dysmorphology, reviving medical dominance*, Routledge: London.

Le Breton, D. (2017) *Sensing the world: an anthropology of the senses*, Bloomsbury: London.

Leigh, J., Dettman, S., Dowell, R. & Briggs, R. (2013) 'Communication development in children who receive a cochlear implant by 12 months of age,' *Otology and Neurotology*, 34(3): 443-450.

Leiter, V. & Wyngaarden Krauss, M. (2004) 'Claims, barriers, and satisfaction: parents' requests for additional special education services,' *Journal of Disability Policy Studies*, 15(3): 135-146, https://doi.org/10.1177/10442073040150030201.

Leiter, V. (2012) *Their time has come: youth with disabilities entering adulthood,* Rutgers University Press: New Brunswick, N.J.

Lende, D.H. & Downey, G. (2012) *The encultured brain: an introduction to neuroanthropology,* MIT Press: Cambridge Mass.

Lock, N. & Nguyen, V-K. (2018) 'An anthropology of biomedicine,' in *An anthropology of biomedicine*, John Wiley & Sons, Incorporated: Malden, Mass.

Lloyd, S. & Bonventre, C. (2020) 'When the artificial is natural: reconsidering what bionics and sensoria do,' *Ethos*, 48(3): 295-316.

Long, D., Hunter, C. & van der Geest, S. (2008) 'When the field is a ward or a clinic: hospital ethnography,' *Anthropology and Medicine*, 15(2): 71-78.

Lupton, D. (1994) *Medicine as culture: illness, disease and the body in western societies*, Sage: London.

Lupton, D. (2012) *Medicine as culture: illness, disease and the body,* Sage: Los Angeles.

Lupton, D. & Maslen, S. (2018) 'The more-than-human sensorium: sensory engagements with digital self-tracking technologies,' *The Senses and Society*, 13(2): 190-202, DOI: 10.1080/17458927.2018.1480177.

Luterman, D. (2004) ‘Counselling families of children with hearing loss and special needs,’ *Volta Review*, 10(4): 215-220.

Lutz, C. (1998) *Unnatural emotions: everyday sentiments on a Micronesian atoll and their challenge to western theory*, University of Chicago Press: Chicago, IL.

Lutz, C. (2002) ‘Emotions and feminist theories,’ pp: 104-121 in Kasten I., Stedman G. & Zimmermann, M. (eds) *Querelles: Jahrbuch für Frauenforschung 2002*. J.B. Metzler, Stuttgart https://doi.org/10.1007/978-3-476-02869-3_6.

Lutz, C. (2017) ‘What matters,’ *Cultural Anthropology*, 32(2): 181-191.

Lutz, C. & L. Abu-Lughod, L. (1990) *Language and the politics of emotion*, Cambridge University Press: Cambridge.

Lutz, C. & White, M. W. (1986) ‘The anthropology of emotions,’ *Annual Review of Anthropology*, 15: 405-436.

Lyness, C. R., Woll, B., Campbell, R. & Cardin, V. R. (2013) ‘How does visual language affect crossmodal plasticity and cochlear implant success?,’ *Neuroscience and Biobehavioral Reviews,* 37(10): 2621-2630.

Marcus, G. E. (1995) ‘Ethnography in/of the world system: the emergence of multi-sited ethnography,’ *Annual Review of Anthropology*, 24(1): 95-117.

Marcus, G. E. (2002) ‘Beyond Malinowski and after writing culture: on the future of cultural anthropology and the predicament of ethnography,’ *The Australian Journal of Anthropology*, 13(2): 191-199.

Marschark, M., Spencer, P., Adams, J. & Sapere, P. (2011) ‘Evidence-based practice in educating deaf and hard-of-hearing children: teaching to their cognitive strengths and needs,' *European Journal of Special Needs Education*, 26(1): 3-16, DOI: 10.1080/08856257.2011.543540.

Mascia-Lees, F. E. (2011) *A Companion to the anthropology of the body and embodiment,* Wiley-Blackwell: Oxford.

Maslen, S. (2015) 'Researching the senses as knowledge: a case study of learning to hear medically,' *The Senses and Society*, 10(1): 52-70.

Maslen, S. (2021) '(Dis)connected parenting: other-tracking in the more-than-human sensorium,' *The Senses and Society*, 16(1): 67-79.

Matthijs, L., Hardonk, S., Sermijn, J., Puyvelde, M. V., Leigh, G., Van Herreweghe, M. & Loots, G. (2017) 'Mothers of deaf children in the 21st century: dynamic positioning between the medical and cultural–linguistic discourses,' *Journal of Deaf Studies and Deaf Education*, 22(4): 365-377.

Mattingly, C. & Garro, L. C. (2000) *Narrative and the cultural construction of illness and healing*, University of California Press: Berkeley.

Mauldin, L. (2012) 'Parents of deaf children with cochlear implants: a study of technology and community,' *Sociology of Health and Illness*, 34(4): 529-543.

Mauldin, L. (2014) 'Precarious plasticity: neuropolitics, cochlear implants, and the redefinition of deafness,' *Science, Technology and Human Values*, 39(1): 130-153.

Mauldin, L. (2016) *Made to hear: cochlear implants and raising deaf children*, University of Minnesota Press: Minneapolis.

Mauldin, L. (2019) 'Don't look at it as a miracle cure: contested notions of success and failure in family narratives of pediatric cochlear implantation,' *Social Science and Medicine*, 228: 117-125.

McCann, D., Bull, R. & Winzenberg, T. (2012) 'The daily patterns of time use for parents of children with complex needs: a systematic review,' *Journal of Child Health Care*, 16(1): 26-52, DOI:10.1177/1367493511420186.

McCracken, W. & Turner, O. (2012) 'Deaf children with complex needs: parental experience of access to cochlear implants and ongoing support,' *Deafness & Education International*, 14(1): 22-35.

McDaid, D., Park, A. L. & Chadha, S. (2021) 'Estimating the global costs of hearing loss,' *International Journal of Audiology*, 60:3, 162-170, DOI: 10.1080/14992027.2021.1883197.

Mechanic, D. (1978) *Medical sociology*, The Free Press, Macmillan: New York.

Mechanic D. (1995) 'Emerging trends in the application of the social sciences to health and medicine,' *Social Science and Medicine*, 40(11): 1491-1496, https://doi.org/10.1016/0277-9536(95)00024-2.

Mehl, A. L. & Thomson, V. (1999) 'Newborn hearing screening: the great omission,' *Pediatrics*, 101(1): 1-6.

Merleau-Ponty, M. (1962) *Phenomenology of perception*, translated by Colin Smith, Routledge and Kegan Paul Ltd: London.

Merleau-Ponty, M. (2004) *The world of perception*, Routledge: London.

Miller, P. (2006) 'Toward truly informed decisions about appearance-normalizing surgeries,' Ch. 14, pp: 211-226 in Parens, E. (ed.) *Surgically shaping children technology, ethics, and the pursuit of normality*, Johns Hopkins University Press: Baltimore, available at SSRN: https://ssrn.com/abstract=1202702.

Mills, M. (2012) ‘Do signals have politics? inscribing abilities in cochlear implants,’ in *The Oxford handbook of sound studies*, vol. 1, Oxford University Press.

Mills, M. (2015) ‘Deafness,’ pp: 45-58 in Novak, D. & Sakakeeny, M. (eds) *Keywords in sound*, Duke University Press: London.

Milton, K. & Svasek, M. (2005) *Mixed emotions anthropological studies of feeling*, Berg: Oxford, UK.

Mishler, E. G. (1984) *The discourse of medicine: dialectics of medical interviews*, Ablex: Norwood, NJ.

Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, H. (2013) ‘Best practices in family-centered early intervention for children who are deaf or hard of hearing: an international consensus statement,’ *Journal of Deaf Studies and Deaf Education*, 18(4): 429-445.

Mol, A. (2008) *The logic of care: health and the problem of patient choice,* Routledge: London.

Mol, A., Moser, I. & Pols, J. (2010) *Care in practice: on tinkering in clinics, homes and farms,* Transcript, Bielefeld.

Monaghan, L., Schmaling, C., Nakamura, K. & Turner, G. H. (2003) *Many ways to be deaf: international in deaf communities*, Gallaudet University Press: Washington DC.

Morris, J. (1991) *Pride against prejudice: a personal politics of disability*, Women’s Press: London.

Munn, N.D. (1992) ‘The cultural anthropology of time: a critical essay,’ *Annual Review of Anthropology*, 21(1): 93-123.

Murray, J. J., Marschark, M., Bauman, H.-D. L. & Spencer, P. E. (2010) ‘Deaf studies in the 21st century: “deaf-gain” and the future of human diversity,’ in *The Oxford handbook of deaf studies, language, and education*, Vol. 2 (Vol. 1), Oxford University Press, https://doi.org/10.1093/oxfordhb/9780195390032.013.0014.

Nakamura, K. (2006) *Deaf in Japan: signing and the politics of identity*, Cornell University Press: New York.

Nettleton, S. (2013) *The sociology of health and illness,* 3rd edition, Polity: Cambridge.

Neumann, B. (2010) ‘Being prosthetic in the First World War and Weimar Germany, *Body and Society*, 16(3): 93-126.

Nickbakht, M., Meyer, C., Scarinci, N. & Beswick, R. (2020) ‘Family-centered care in the transition to early hearing intervention,’ *Journal of Deaf Studies and Deaf Education*, 26(1): 21-45, https://doi.org/10.1093/deafed/enaa026.

Nicolelis, M. A. (2001) ‘Actions from thoughts,’ *Nature*, 409(6818): 403-407.

Nishimura, H., Hashikawa, K., Doi, K., Iwaki, T., Watanabe, Y., Kusuoka, H., Nishimura, T. & Kubo, T. (1999) ‘Sign language ‘heard’ in the auditory cortex,’ *Nature*, 397(6715): 116-116.

Oakley, A. (2016) ‘Interviewing women again: power time and the gift,’ *Sociology*, 50(1): 195-213.

Okubo, S., Takahashi, M. & Kai, I. (2008) ‘How Japanese parents of deaf children arrive at decisions regarding pediatric cochlear implantation surgery: a qualitative study,’ *Social Science and Medicine (1982)*, 66(12): 2436-2447, https://doi.org/10.1016/j.socscimed.2008.02.013.

Orfali, K. (2004) ‘Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units,’ *Social Science and Medicine*, 58 (10): 2009-2022.

Oxley, R. & Russell, A. (2020) ‘Interdisciplinary perspectives on breath, body and world,’ *Body and Society*, 26(2): 3-29.

Ozyurek, A. & Woll, B. (2019) ‘Language in the visual modality: cospeech gesture and sign language,’ pp: 67-83 in Hagoort, P. (ed) *Human language: from genes and brain to behavior*, MIT Press: Cambridge, Mass.

Padden, C. & Humphries, T. (2006) ‘Deaf people: a different center,’ pp: 331-338 in Davis, L. (ed) *The disability studies reader*, 2nd edition, Routledge: London.

Pagis, M. (2010) ‘Producing intersubjectivity in silence: an ethnographic study of meditation practice,’ *Ethnography, 11*(2): 309-328.

Paludneviciene, R. & Leigh, I. W. (2011) *Cochlear implants: evolving perspectives*, Gallaudet University Press: Washington, DC.

Parens, E. (2006) *Surgically shaping children: technology, ethics, and the pursuit of normality*, Johns Hopkins University Press: Baltimore, Md.

Park, J., Fitzgerald, R. & Legge, M. (2015) ‘The Predicament of d/Deaf: towards an anthropology of not-disability,’ *Human Organization*, 74(2): 154-163.

Parker, M. & Bitner-Glindzicz, M. (2015) ‘Genetic investigations in childhood deafness,’ *Archives of Disease in Childhood*, 100(3): 271-278.

Parrish, R.N. (2010) *Mothers’ experiences raising children who have multiple disabilities and their perceptions of the chronic sorrow phenomenon*, PhD dissertation, Department of Education, University of North Carolina, Greensboro.

Pfister, A. (2015) *Myths and miracles in Mexico City: treatment seeking, language socialization, and identity among deaf youth and their families*, PhD dissertation, University of South Florida, Florida.

Pfister, A. (2017) 'Forbidden signs: deafness and language socialization in Mexico City,' *Ethos*, 45(1): 139-161.

Pfister, A. (2019) 'Predicament and pilgrimage: hearing families of deaf children in Mexico City,' *Medical Anthropology*, 38:3, 195-209,
DOI: 10.1080/01459740.2018.1540617.

Pfister, A. & Vindrola-Padros, C. (2018) 'Fluid and mobile identities: travel, imaginaries, and practices of caregiving among families of deaf children in Mexico City,' in *Healthcare in motion: immobilities in health service delivery and access*, Berghahn Books: New York.

Picard, M. (2004) 'Children with permanent hearing loss and associated disabilities: revisiting current epidemiological data and causes of deafness,' *The Volta Review*, 104(4): 221-236.

Pink, S. (2010) 'The future of sensory anthropology/ the anthropology of the senses, *Social Anthropology,* 18(3): 331-333, DOI:10.1111/j.1469-8676.2010.00119. x.

Poltorak, M., Leach, M., Fairhead, J. & Cassell, J. (2005) ''MMR talk' and vaccination choices: an ethnographic study in Brighton,' *Social Science and Medicine*, 61(3): 709-719, https://doi.org/10.1016/j.socscimed.2004.12.014.

Porter, A. & Edirippulige, S. (2007) 'Parents of deaf children seeking hearing loss-related information on the internet: the Australian experience,' *Journal of Deaf Studies and Deaf Education*, 12(4): 518-529, DOI:10.1093/deafed/enm009.

Porter, C., Creed, P., Hood, M. & Ching, T. (2018) ‘Parental decision-making and deaf children: a systematic literature review,’ *Journal of Deaf Studies and Deaf Education*, 23(4): 295-306, https://doi.org/10.1093/deafed/eny019.

Porter, A., Sheeran, N., Hood, M. & Creed, P. (2021) ‘Decision-making following identification of an infant’s unilateral hearing loss: parent and professional perspectives,’ *International Journal of Pediatric Otorhinolaryngology*, 148: 110822-110822.

Postill, J. (2002) ‘Clock and calendar time: a missing anthropological problem,’ *Time and Society*, 11(2/3): 251-270.

Power, D. (2005) ‘Models of deafness cochlear implants in the Australian daily press,’ *Journal of Deaf Studies and Deaf Education*, 10(4): 451-459.

Pray, J. L. & Jordan, I. K. (2010) ‘The deaf community and culture at a crossroads: Issues and challenges,’ *Journal of Social Work in Disability and Rehabilitation*, 9(2-3): 168-193.

Rapp, R. & Ginsburg, F. (2001) ‘Enabling disability: rewriting kinship, reimagining citizenship,’ *Public Culture*, 13(3): 533-556.

Rapp, R. & Ginsburg, F. (2011) ‘Reverberations: disability and the new kinship imaginary,’ *Anthropological Quarterly*, 84(2): 379-410, https://doi.org/10.1353/anq.2011.0030.

Rhoades, E. A. & Duncan, J. (2010) *Auditory-verbal practice: towards a family centred approach*, Charles C. Thomas Publisher: Springfield, Illinois, US.

Rice, T. (2013) *Hearing and the hospital: sound, listening, knowledge and experience,* Sean Kingston Publishing, Canon Pyon.

Richard C. E. (2010) ‘Toward a theory of deaf ethnos: Deafnicity = D/deaf (Homaemon Homoglosson Homothreskon),’ *Journal of Deaf Studies and Deaf Education*, 15(4): 317-333.

Robinson, O. & Henner, J. (2018) ‘Authentic voices, authentic encounters: cripping the university through American sign language,’ *Disability Studies Quarterly*, 38(4), DOI: http://dx.doi.org/10.18061/dsq.v38i4.6111.

Roberts, R. M., Sands, F., Gannoni, A. & Marciano, T. (2015) ‘Perceptions of the support that mothers and fathers of children with cochlear implants receive in South Australia: a qualitative study,’ *International Journal of Audiology*, 54(12): 942-950.

Rosaldo, M. (1980) *Knowledge and passion: Ilongot notions of self and social life*, Cambridge University Press: Cambridge.

Rose, N. (2007) *The politics of life itself: biomedicine, power, subjectivity in the twenty-first century*, Princeton University Press: Princeton, NJ.

Ross, M. (2004) ‘The audiogram: explanation and significance,’ *Hearing Loss Association of America*, 25(3): 29-33.

Sacks, O. (1989) *Seeing voices: a journey into the world of the deaf*, University of California Press: Berkeley.

Salih, S. (2002) *On Judith Butler*, Routledge: London.

Sallis, J. (1981) *Merleau-Ponty, perception, structure, language: a collection of essays,* Humanities Press: Atlantic Highlands, N.J.

Sarant, J. (2012) *Cochlear Implants in Children: A Review, Hearing Loss,* Dr. *Sadaf Naz (Ed.)*.

Savage, J. (2006) 'Ethnographic evidence the value of applied ethnography in healthcare,' *Journal of Research in Nursing*, 11(5): 383-393, DOI: 10.1177/ 1744987106068297.

Scheper-Hughes, N. (1993) *Death without weeping: the violence of everyday life in Brazil*, University of California Press: Berkeley.

Scheper-Hughes, N. (1995) 'The primacy of the ethical: propositions for a militant anthropology,' *Current Anthropology*, 36(3): 409-440.

Senghas, R. J. & Monaghan, L. (2002) 'Signs of their times: deaf communities and the culture of language,' *Annual Review of Anthropology*, 31(1): 69-97.

Shakespeare, T. & Watson, N. (2001) 'The social model of disability: an outdated ideology?,' pp: 9-28 in Altman, B. M. & Barnartt, S. N. (eds) *Exploring theories and expanding methodologies: where we are and where we need to go*, Emerald Group Publishing Limited.

Shakespeare, T. (2006) 'The social model of disability,' pp: 197-204 in Davis, L. J. (ed) *The disability studies reader*, 2nd edition, Routledge: London.

Shakespeare, T. (2013) *Disability rights and wrongs revisited*, 2nd edition, Routledge: New York, https://doi.org/10.4324/9781315887456.

Shuttleworth, R. (2012) 'Multiple roles, statuses, and allegiances: exploring the ethnographic process in disability culture,' Ch.4, pp: 46-58 in Hume, L. & Mulcock, J. (eds) *Anthropologists in the field: cases in participant observation*, Columbia University Press: New York.

Simon, M., Campbell, E., Genest, F., MacLean, M. W., Champoux, F. & Lepore, F. (2020) 'The impact of early deafness on brain plasticity: a systematic review of the white and gray matter changes,' *Frontiers in Neuroscience*, 14: 206-206.

Smith, R. J. H., Bale, J. F. & White, K. R. (2005) ‘Sensorineural hearing loss in children,’ *The Lancet*, 365(9462): 879-890, https://doi.org/10.1016/S0140-6736(05)71047-3.

Snell, L. (2015) ‘Documenting the lived experiences of young adult cochlear implant users: ‘feeling’ sound, fluidity, and blurring boundaries,’ *Disability and Society*, 30(3): 340-352.

Solomon, A. (2010) ‘Few words provoke a more passionate response in deaf people than ‘cochlear implant’, available at: http://andrewsoloman.com/articles/defiantly-deaf/ (accessed 7 April 2016).

Solomon, A. (2012) *Far from the tree*, Simon and Schuster: UK.

Sparrow, R. (2005) ‘Defending deaf culture: the case of cochlear implants,’ *The Journal of Political Philosophy*, 13(2): 135-52.

Sparrow, R. (2010) ‘Implants and ethnocide: learning from the cochlear implant controversy,’ *Disability and Society*, 25(4): 455-466.

Spinnewijn, L., Aarts, J., Verschuur, S., Braat, D. D., Gerrits, T. & Scheele, F. (2020) ‘Knowing what the patient wants: a hospital ethnography studying physician culture in shared decision making in the Netherlands,’ *BMJ Open*, 10(3): e032921-e032921.

Spradley, T. & Spradley J. P. (1985) *Deaf like me*, Gallaudet University Press: Washington, DC.

Sterponi, L., Zucchermaglio, C., Fatigante, M. & Alby, F. (2019) ‘Structuring times and activities in the oncology visit,’ *Social Science and Medicine*, 228: 211-222

Still waiting to be heard...Report on the inquiry into the hearing health and wellbeing of Australia, House of Representatives Standing Committee on Health, Aged Care and Sport, Parliament of the Commonwealth of Australia, viewed 26 August 2019, https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/HearingHealth/Report_1

Sisters of invention, Tutti Arts, Adelaide Cabaret Festival performance, viewed 23 June 2021.

Strathmann, C. M. & Hay, M. C. (2009) 'Working the waiting room: managing fear, hope, and rage at the clinic gate,' *Medical Anthropology*, 28(3):212-234.

Street, A. (2011) 'Artefacts of not-knowing: the medical record, the diagnosis and the production of uncertainty in Papua New Guinean biomedicine,' *Social Studies of Science Journal*, 41(6): 815-834.

Sutherland, A. T. (1981) *Disabled we stand*, Brookline Books.

Sweeny, K. & Cavanaugh, A. G. (2012) 'Waiting is the hardest part: a model of uncertainty navigation in the context of health news,' *Health Psychology Review*, 6(2): 147-164.

Tanner, L. E. (2002) 'Bodies in waiting: representations of medical waiting rooms in contemporary American fiction,' *American Literary History*, 14(1): 115-130.

Taylor, J. (2011) 'The intimate insider: negotiating the ethics of friendship when doing insider research,' *Qualitative Research*, 11(1): 3-22.

The Advertiser (1948) 'Miss Keller supported new deal for blind and deaf', *The Advertiser*, 14 July, p.2, viewed 28 June 2021, https://trove.nla.gov.au/newspaper/article/43774555?searchTerm=Helen%20Keller%2C%20South%20Australia.

Thomas, E. C., Bauerle Bass, S. & Siminoff, L. A. (2021) ‘Beyond rationality: expanding the practice of shared decision making in modern medicine,’ *Social Science and Medicine*, 277: 113900–, DOI.org/10.1016/j.socscimed.2021.113900.

Tremain, S. (2005) *Foucault and the government of disability*, University of Michigan Press: Ann Arbor, MI.

Trigg, D. (2016) *Topophobia: a phenomenology of anxiety*, Bloomsbury: London.

Tuan, Y. T. (1977) *Space and place: the perspective of experience*, University of Minnesota Press: Minneapolis.

Valente, J. M. (2011) ‘Cyborgization: deaf education for young children in the cochlear implantation era,’ *Qualitative Inquiry*, 17(17): 639-52.

Valente, J. M., Bahan, B., & Bauman, H-Dirkson (2011) ‘Sensory politics and the cochlear implant debates,’ Ch. 12, pp: 245-258 in Paludneviciene, R. & Leigh, I. W. (eds) *Cochlear implants: evolving perspectives*, Gallaudet University Press: Washington, DC.

Valente, J.M. & Boldt, G.M. (2015) ‘The rhizome of the deaf child, *Qualitative Inquiry*, 21(6): 562-574.

Van Ginkel, R. (1994) ‘Writing culture from within: reflections on endogenous ethnography,’ *Etnofoor*, 7(1): 5-23.

Waltz, M. (2016) *(Im)patient patients: an ethnography of medical waiting rooms*, PhD dissertation, Department of Sociology, Cape Western Reserve University.

Warin, M. (2010) *Abject relations*, Rutgers University Press: Piscataway, NJ.

Wikan, U. (1990) *Managing turbulent hearts: a Balinese formula for living*, University of Chicago Press: Chicago, IL.

Wilkinson, S. & Kitzinger, C. (2013) ‘Representing our own experience: ‘‘insider’’ research,’ *Psychology of Women Quarterly*, 37(2): 251-255.

Wolfinger, N. H. (2002) ‘On writing fieldnotes: collection strategies and background expectations,’ *Qualitative Research*, 2(1): 85-95.

Woodward, I. (2000) ‘Domestic objects and the taste epiphany: a resource for consumption methodology,’ *Journal of Material Culture*, 6(2): 115-136.

Woodward, I. (2007) *Understanding material culture*, Sage: London.

World Health Organisation (2009) *Newborn and infant hearing screening: current issues and guiding principles for action*, World Health Organisation Press: Switzerland.

Wright et al (2016) ‘Co-becoming Bawaka: towards a relational understanding of place/space,’ *Progress in Human Geography*, 40(4): 455-475.

Young, A. (2002a) ‘Narrative and the cultural construction of illness and healing,’ *The Journal of Nervous and Mental Disease*, 190(2): 128-129.

Young, A. (2002b) ‘Factors affecting communication choice in the first year of life – assessing and understanding an on-going experience,’ *Deafness and Education Internationals*, 4(1): 2-11, https://doi.org/10.1179/146431502790560935.

Young, A. (2010) ‘Hearing parents' adjustment to a deaf child-the impact of a cultural-linguistic model of deafness,’ *Journal of Social Work Practice*, 13(2): 157-176.

Young, A. (2018) ‘Deaf children and their families: sustainability, sign language, and equality,’ *American Annals of the Deaf*, 163(1): 61–69.

Young, A., Hunt, R., Carr, G., Hall, A., McCracken, W., Skipp, A. & Tattersall, H. (2005) ‘Informed choice, deaf children and families - underpinning ideas and project development,’ *Electronic Journal of Research in Educational Psychology*, 3(7): 253-273.

Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A. & Tattersall, H. (2006) ‘Informed choices and deaf children: underpinning concepts and enduring challenges,’ *Journal of Deaf Studies and Deaf Education*, 11(3): 322-326, https://doi.org/10.1093/deafed/enj041.

Young, A. & Tattersall, H. (2007) ‘Universal newborn hearing screening and early identification of deafness: parents' responses to knowing early and their expectations of child communication development,’ *Journal Deaf Studies and Deaf Education*, 12(2): 209-220.

Young, A., Jones, D., Starmer, C. & Sutherland, H. (2013) ‘Issues and dilemmas in the production of standard information for parents of young deaf children –parents views,’ *Deafness and Education International*, 7(2): 63-67, https://doi.org/10.1002/dei.27.

Yoshinaga-Itano, C., Sedey, A., Coutler, D. & Mehl, A. (1998) ‘Language of early and later-identified children with hearing loss,’ *Journal of Pediatrics*, 102(5): 1161-1171.

Yoshinaga-Itano, C., Sedey, A., Wiggin, M. & Chung, W. (2017) ‘Early hearing detection and vocabulary of children with hearing loss,’ *Pediatrics*, 140(2): e20162964–.

Yuill, C., McCourt, C., Cheyne, H. & Leister, N. (2020) ‘Women’s experiences of decision-making and informed choice about pregnancy and birth care: a systematic review and meta-synthesis of qualitative research,’ *BMC Pregnancy Childbirth*, 20(1): 343-343, https://doi.org/10.1186/s12884-020-03023-6.

Zivkovic, T. (2019) 'Lifelines and end-of-life decision-making: an anthropological analysis of advance care directives in cross-cultural contexts,' *Ethnos*, 86(4): 767-785, DOI: 10.1080/00141844.2019.1696857.

Appendix: Published Articles