Identity Effect of Hearing Changes:
A Qualitative Exploration of Late-deafened Adults' Experiences through Hearing Loss & Cochlear Implantation

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Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Felicity Bleckly

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This research meets the requirements set out in the National Statement on Ethical Conduct in Human Research (2007, updated July 2018) (the National Statement).

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[1] Australian spelling is used except in verbatim quotes from papers or participants' comments when they live in the USA.
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Abstract.
Identity Effect of Hearing Changes:
A Qualitative Exploration of Late-deafened Adults' Experiences through Hearing Loss & Cochlear Implantation

This thesis examines identity challenges presented by both hearing loss acquired as an adult, and regaining hearing through a cochlear implant. Hearing loss can challenge the understanding late-deafened adults have of themselves, while they reconcile with changes forced on them. Receiving a cochlear implant creates a different hearing status, another often unsettling challenge with a life-long commitment to technology.

Using an online survey administered through social media, with follow-up semi-structured interviews, participants answered questions about their hearing loss and cochlear implant experiences. Forty-four people answered the survey and 16 participated in an in-depth interview. A key finding was most late-deafened adults did not have access to support as their hearing changed, but when they did, positive role models helped them understand and cope with their hearing loss and sustain their identity. Furthermore, findings suggested more hearing healthcare providers need to introduce a support structure including referral to hearing rehabilitation, counselling and peer groups, to help late-deafened adults cope with their changing hearing status.

The cochlear implant decision was difficult for many because it meant accepting they were deaf, and knowing that through the implantation process they were likely to lose any residual hearing. Participants valued talking with people/mentors who already had an implant which often helped with the decision process. A cochlear implant changes hearing status and comments from most participants indicate once again they had to rethink their identity. Were they now hearing, deaf or something in between? After a cochlear implant, this research found some participants retained and strengthened their hearing identity, while others regained their previously held hearing identity. Nevertheless, some participants, after surgery, identified as deaf or disabled when they had not done so, prior to implantation.

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The argument for this research is that "hearing is one of our most important senses" (Shikowitz, 1991, p. 1239) and adults who become late-deafened often lose their connection to other people and the environment (Espmark & Scherman, 2003). This can have a significant impact because this invisible disability often undermines a sense of self, impacting on every part of life (Jonsson & Hedelin, 2012). Although hearing may be regained with a cochlear implant[4], it is not fully restored (National Institute on Deafness and other Communication Disorders [NIDC], 2017), and implant recipients need to navigate another shift in identity, based on a life-long commitment to technology (Lenarz, 2018).

Hearing loss is the third most frequent chronic disabling health condition for older people (World Health Organization [WHO], 2021) with late-deafened adults forming the largest proportion of deaf[5] individuals (Kashubeck-West & Meyer, 2008). According to the latest report from the Australian Hearing Care Industry Association (HCIA) (2020), one in six adults, mostly aged between 26 and 65 years, have a measurable hearing loss, with the prevalence expected to rise to one in four by 2066. Cochlear implantation, as a routine treatment for adults with profound deafness, is becoming more common (Da Cruz, 2021). According to NIDC (2021), by the end of 2019 there were around 737,000 cochlear implant recipients worldwide. Industry analysis in 2021, from the USA, reported 60.2% of all recipients were adults, and are the fastest growing cohort (Grand View Research, 2021).

In the 2019/20 financial year the cost of hearing loss to the Australian community was estimated at AUD$20billion, through lost productivity and the expense of interventions. For the same period, the social cost was estimated at more than AUD$21billion (HCIA 2020). For individuals, the adverse impact of late-deafness often has severe social and career consequences (Baldridge & Kulkarni, 2017). Given the prevalence of hearing loss in later life, it is important to know more about late-deafened adults' experiences, and the impacts on identity, to increase personal support and improve quality of life.

The premise for my research is that deafness acquired by adults post-lingually, is under-treated and under-researched. As a late-deafened adult myself, I found it challenging to maintain my hearing identity as an intelligent, successful woman. I was constantly assailed by the stress and demands of not hearing, mis-hearing, missing out or being deliberately left out, feeling stupid, embarrassed, depressed, and lonely. These are experiences I know well and through the progression of deafness my identity was eroded, leaving me with a vestige of my former self. After finding the strength to accept something I

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[4] Refer Appendix 1 from some explanations of terms including a cochlear implant
[5] deaf, written with a lower case 'd' represents those who have a hearing loss, but do not identify with Deaf culture.

could not change and reconciling with my deafness, I chose to have cochlear implants. For the first time in 30 years I could hear, and this returned me to at least a semblance of the hearing person I had been, but I was still not whole, still not completely hearing. A reversal of the negative experiences through the progression of deafness, needed to be replaced with new positive ones. It was exciting, tiring and strange, but for the first time in decades, 'deaf' was not my master identity, and this led me to question whether others had similar experiences.

My reflexivity as a researcher and, through the challenges of my personal experiences, my insider-outsider status placed me in an advantageous position to conduct this research. I already had knowledge and experience to draw on as a starting point (Charmaz & Bryant, 2010) and my reality added to the research understanding (Kirpitchenko & Voloder, 2014). Recruitment of participants was easier because of my intrinsic knowledge (Taylor, 2011) and, since qualitative research relies on gaining and maximising trust with participants, my insider status increased the possibility of establishing a stronger and quicker rapport (Wilkinson & Kitzinger, 2013).

While the literature supported some of my own experiences, I recognised gaps in the knowledge, and this allowed me to identify opportunities for research. Prior to their hearing loss most late-deafened adults do not recognise their hearing status and hearing privilege (Bauman, 2009; O'Connell, 2022). Therefore, an unexpected hearing loss often creates unrecognised and unacknowledged identity challenges. According to current scholarship "identity is increasingly recognized as an important factor in psychological well-being and other life outcomes for people who are deaf" (Chapman & Dammeyer, 2017, p. 320), but there was little in the literature which identified how challenges to identity were recognised and supported, particularly after cochlear implantation.

The existing literature foregrounds that going deaf after being hearing, involves a myriad of emotions not unlike grieving (Ritter & Barker, 2020), shedding previous beliefs about self, overcoming social barriers and embracing social and physical change (Hogan et al., 2011). Communication misunderstandings may occur and other people may not recognise the extent of late-deafened peoples' inability to hear, often ascribing stupidity (Hogan et al., 2011; Krentz, 2002), or lack of intelligence (Szarkowski & Brice, 2018) rather than considering the person may be deaf. The academic literature suggests many late-deafened adults feel displaced, neither part of Deaf culture nor fully part of the hearing world (Barlow et al., 2007). Kobosko et al. (2018) argue late-deafened adults "are forced to develop a new personal identity" (p. 3) to help them embrace the social change in their altered circumstances. Many feel diminished, shying away from the unfamiliar and frightening identity, which may result in denial, maladaptive coping strategies and can lead to mental health issues (Clark et al., 2012). The majority experience a slow hearing loss (Da Cruz, 2021), and during this progression identity

becomes fragmented. This may include re-assessing their hearing identity, losing a career identity, while accepting a deaf or disability identity (Baldridge & Kulkarni, 2017).

After having gone through the emotional identity challenges caused by hearing loss, cochlear implant recipients find that although hearing may be restored, it is imperfect (Boisvert et al., 2020). Once again these adults have to navigate a hearing change, a challenge which is both exciting, because they can now hear, but confronting, because as I will argue, for the rest of their lives they are reliant on technology for hearing.

Scrutiny of the literature revealed some research covering the personal impacts on identity of becoming deaf. However, research into the effects on identity of regained hearing and living with a cochlear implant is scarce, and I suggest this reflects the relatively recent use of cochlear implants as an accepted treatment for late-deafness (Copeland & Pillsbury, 2004; Tan et al., 2013). My research will map identity challenges of becoming late-deafened and will add to the knowledge and understanding of the emotional, psychological and psychosocial impacts of cochlear implantation. The research sought to answer the following questions:

1. What issues do late-deafened adults experience as they go deaf, and how does this challenge their identity and impact on their lives?

2. How do late-deafened adults perceive the responses of hearing healthcare providers to these issues?

3. What are the key challenges to identity for late-deafened adults when making a decision to have a cochlear implant?

4. After receiving a cochlear implant how do late-deafened adults reconceptualise their identity and what is the impact of this on their lives?

5. How do late-deafened adults perceive the responses of cochlear implant professionals to these issues?

Mapping the Research

Drawing on my own experience as an insider, the topical literature review in Chapter 2 maps existing scholarship on impacts on late-deafened adults, to identify poorly understood consequences of hearing loss/hearing gain. The literature draws attention to the profound difference in experience between the small minority of people who are culturally/signing Deaf[6], and that of late-deafened adults (Beckner & Helme, 2018; Sealy, 2015). The review includes impacts on personal identity, aspects of stigma, disability and the support structure available from healthcare providers and peer role models or mentors. Experiences are identified which force late-deafened adults across the hearing line (Krentz, 2002). This

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[6] When Deaf is written with a capital 'D' it refers to the culturally Deaf/signing culture and community

invisible boundary between those who can, and those who cannot hear, "reveals a complicated relationship between physical difference, cultural construction, and identity" (p. 3). I will argue, this review points out the limited range of research which linked hearing loss to identity impacts for late-deafened adults. Some of the facilitators and barriers which impact on identity during the decision to have a cochlear implant, are highlighted. Furthermore, missing in the literature is the challenge to identity through regained hearing with a cochlear implant.

Chapter 3 identifies the theoretical framework underpinning my research process. Grounded Theory (Charmaz & Bryant, 2010) was the starting point for planning and undertaking the research because of this theory's methodical and interpretive process. However, a mix of framework methods, all of which share underpinning assumptions informed my research. A phenomenological approach (Davidsen, 2013) provided a lens to understand meanings. Disability theories facilitated understanding of the potential positive and negative connotations of disability (Siebers, 2008), and normalcy versus abnormality (Davis, 2018). These theories suggest ways in which hearing loss might impact on the late-deafened adults' identity, while providing a perspective for exploring the social meanings of a cochlear implant prosthesis. The data was obtained using mixed methods, with a focus on qualitative interviews.

In Chapter 4, participants' experiences of late-deafness are viewed through a phenomenological lens. Participants' voices describe how they understand themselves and their experiences. The impact of deafness on their lives is investigated, with common experiences and themes identified.

Chapter 5 discusses central issues around technology to contextualise the social meanings and enabling/disabling aspects of technology when making the decision to have a cochlear implant. For most having an implant is a positive experience (Saeedi et al., 2021) but it still raises issues of identity because of another change in hearing status. This chapter discusses the role of mentors, the impacts on self in making a cochlear implant decision and whether an implant might bridge the hearing line (Krentz, 2002), perhaps returning implant recipients to a degree of 'normal'.

My research revealed far more than expected and not all findings can be discussed. The final Chapter 6 discusses unanticipated findings. The current study enhances understanding of the experience of late-deafened adults and provides a base for future studies to advance how cochlear implants impact on personal and social identities.

Chapter 2.
An Analytical Critique of Previous Research:
The Intersection of Hearing Loss, Cochlear Implantation & Identity in Late-Deafened Adults

A topical literature review established the context and background of what is known about how adult-acquired hearing loss and cochlear implantation influences identity. The review mapped similarities or differences between research studies and identified poorly understood consequences of both the late-deafness and the cochlear implant experience. The purpose was to discover opportunities for research to answer the questions as listed in Chapter 1.

The literature published on the concepts of identity reveal many theories, with a seeming contradiction of both sameness and difference between ourselves and others (Malesevic, 2006). Beckner and Helme (2018) used Communication Theory of Identity (Hecht & Lu, 2014) to understand how the late-deafened cope with their changing world. This report indicated a strong interrelationship between layers of identity – collective, relational, individual and enacted. Kuiper (2021) also argues for a fifth identity, a material identity, and for the late-deafened, hearing devices often have a negative effect on identity, particularly when devices are visible. The adverse impact of late-deafness may include re-assessing a hearing identity, losing a career identity, while accepting a deaf or disability identity (Baldridge & Kulkarni, 2017). Becoming late-deafened often alters self-perception, influences relationships, undermines socialisation through reduced communication, and impacts on every part of life (Rapport et al., 2020; Vas et al., 2017; Wallhagen, 2009).

Extensive searching revealed little attention has been paid to the psychological and psychosocial aspects of hearing loss with insufficient correlation between identity and late-deafness. Most studies of cochlear implantation focus on technological issues or audiological outcomes rather than on personal experiences and understanding of self.

Initially, studies covering those born deaf, or with a Deaf cultural identity, and young people with cochlear implants, as well as implant technological issues and outcomes, were excluded. However, since searches revealed few articles, some of these issues were later included to cover broader perspectives of hearing loss. Additional topics included deafness (in general), hearing privilege, Deaf culture, identity and disability theories, as well as concepts of stigma and normalcy.

To determine the relevancy of articles, each title, abstract and conclusion was read, to select papers pertinent to the study. Figure 1 illustrates by topic, the more than 120 papers, book chapters, websites, and grey literature analysed and coded in NVivo and Excel.

Identity Effect of Hearing Changes in Late-deafened Adults

Figure 1:

Topics of Literature Examined for this Research.

It should be noted additional topics researched, not included in figure 1, included theoretical frameworks, insider research, social media, normalcy, social meanings of technology, as well as identity.

Analysis of disciplines determined researchers worked in a wide range of fields (Figure 2) and this variety of multidisciplinary research revealed differing viewpoints for interpretations of the phenomena.

Figure 2:

Bar Chart showing the General Disciplines of Authors of Literature

The majority of research on identity came from psychology and for cochlear implants most came from otolaryngology or audiology. Deafness or hearing-loss research was generally undertaken by hearing institutes or bodies, or health and life sciences scholars. Deafness or hearing-loss research was generally undertaken by hearing institutes or bodies, or health and life sciences scholars.

Sources were evaluated to ensure credibility, and most of the literature was published in peer reviewed journals (65%). The majority of empirical research employed qualitative or mixed methods, however there was no consensus on the theoretical framework.

This literature review begins by briefly contrasting the experiences of the culturally Deaf people and that of the late-deafened adult and continues by outlining hearing privilege. The homogeneity of the literature on the late-deafness experience highlights key issues. The cochlear implant experiences are examined and finally, some of the research opportunities are identified.

Understanding d/Deaf[7], the Hearing Line & Hearing Privilege

For people who align themselves with Deaf culture using sign-language, Deaf means being part of a linguistic and cultural minority (Bedoin, 2019; Hadley & McDonald, 2019; Treloar, 2021). Studies, such as that by Fisher et al. (2018), confirm people in the Deaf community do not consider deafness "a disability, but simply an auditory status" (p. 7) with sign language the primary source of communication rather than speech. In Deaf culture, deafness is a "positive, socially-valued position" (Ferndale et al., 2016, p. 2). Those who have a Deaf identity are proud to be Deaf, do not feel impaired or identify as disabled, and do not need to be 'fixed' (Cherney, 1999; Holcomb et al., 2020; Leigh et al., 2020).

The experience of late-deafened adults is usually different from those in Deaf culture. As Beckner and Helme (2018) claimed, a divide exists in cultural values between the Deaf signing community and the late-deafened. Krentz (2002) described a hearing line, an invisible line which "separates deaf and hearing", revealing "a complicated relationship between physical difference, cultural construction, and identity" (p. 3). Late-deafened adults are forced across this invisible line which may create conflict between their accustomed hearing-self and their new or developing deaf-self. Previous research suggests late-deafened adults are shaped by the conflict between their hearing experiences (Fish, 2016) and their response to hearing loss (Barlow et al., 2007). Reduced participation in their familiar, but audio-centric world often results in trauma and anxiety (Barlow et al., 2007; Carmen & Uram, 2002; Kobosko et al., 2018).

Most people are born hearing (NIDC, 2021) and the majority take it for granted, never realising hearing is a privilege. Hearing privilege is defined by O'Connell (2022) "as the unearned advantages, benefits and entitlements reserved for hearing people that are not based on talent or effort but rather on (hearing) status" (p. 2). Some of the participants in the Holcomb et al. (2020) research reported that when they

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[7] d/Deaf includes those who have the physiology of hearing loss (indicated by the small 'd') as well as those who identify in the Deaf culture (indicated by the capital 'D'). It should be noted "…there are disputes over the appropriateness of terminology and the lines of demarcation for those populations who are 'deaf', 'Deaf', 'hard of hearing', 'late-deafened', and 'oral deaf' " The Free Library. (2014). *Meeting the needs of late-deafened adults*. The Free Library. Retrieved 1 May, 2022 from https://www.thefreelibrary.com/Meeting+the+needs+of+late-deafened+adults.-a015538206.

lost their hearing as adults, they realised their lost privilege, causing them to feel like outsiders in their own world. According to Leigh et al. (2020), late-deafened adults want their hearing restored and seek solutions with hearing aids and cochlear implants.

Experiences of Late-Deafened Adults

Approximately half of the papers (49%) covering the experience of adult hearing loss were more than ten years old. Nonetheless, similar impacts of late-deafness were still described in more recent research.

Late-Deafness Impact on Personal Identity

In *Language and Identity,* Edwards (2009), describes identity as the "heart of the person" (p. 2), that which makes humans unique. For most people identity is established at an early age through social interaction and language acquisition (Beckner & Helme, 2018; Edwards, 2009). In mainstream society hearing is usually a dominant, invisible, and unmarked identity, considered 'normal' by the culture people inhabit (Brekhus, 1998). Bauman (2009) explained he had not realised his 'hearingness' because it "was an invisible identity" (p. 243). He only recognised it as part of himself when working with Deaf students, and then he consciously "became hearing" (p. 240). Hearing identity may be invisible, but it becomes vulnerable and subject to injury with the onset of deafness (Bauman, 2009).

The only research found which specifically linked late-deafness to layers of identity was conducted by Beckner and Helme (2018). This research pointed out the contradictory factors shaping overlapping identities, and theorised that it is through communication and relationships that people maintain their identity. This becomes problematic for the late-deafened because of reduced communication. For many late-deafened adults their sense of self is threatened as they strive "to maintain a normal identity" (Jonsson & Hedelin, 2012, p. 314).

Late-deafened adults frequently experience identity interference. They reported a perceived incompatibility with both their earlier-selves and with other people. A number of researchers have found late-deafened people described not knowing who they had become (Adler, 2018; Baldridge & Kulkarni, 2017; Jonsson & Hedelin, 2012), with no continuity of self-identity. Paradoxically, they needed to consciously affirm their previous hearing identity, while at the same time constructing a seemingly conflicting parallel identity within a somewhat hostile audist paradigm; one based on hearing, another on hearing loss (Baldridge & Kulkarni, 2017). This often resulted in stress, anxiety and psychological trauma (Carmen & Uram, 2002). Thus, deafness has been described in the literature as a threat to the fundamental understandings of self (Adler, 2018; Barlow et al., 2007; Chapman & Dammeyer, 2017).

Audism – The Impact on Social Identity

In an audio-centric world 'audism' as a concept, points towards hearing dominance, which creates barriers to social equality for late-deafened adults. Audism includes a negative attitude to deafened people by those who have hearing (Berke, 2020; Eckert & Rowley, 2013). Sometimes audism is experienced through overt and intentional discrimination, but it may also be unintentional, such as raising your voice to a Deaf person or complimenting them on their speech (Wilson & Atcherson, 2017).

The literature recognised how deafened adults are judged based on how hearing-like they appear. Several studies highlighted ableist expectations that deafened adults have to prove normality and pass as hearing (Ellcessor, 2018; Ferndale et al., 2016; Leigh et al., 2009; McDonald, 2014b). A number of studies found that many late-deafened adults were frequently seen as confused or lacking intelligence (Cowie et al., 1982; Fish, 2016), because of inappropriate responses or speech changes (David et al., 2018). The literature demonstrates that 35 years after the Cowie et al. (1982) investigation, similar societal attitudes are still reported (Baldridge & Kulkarni, 2017; Heffernan et al., 2016). These attitudes can be pervasive, influencing the late-deafened adults' perception of self while creating a feeling of "disempowerment" (Wilson & Atcherson, 2017, p. 23), often adding to dysfunctional coping strategies.

Key Issues of the Late-Deafness Experience

Many late-deafened adults have liminal identities of privilege and oppression, existing on the margins between Deaf and hearing worlds (Barlow et al., 2007; Chapman & Dammeyer, 2017; Cherney, 1999). They believed they had an ascribed identity forced on them by hearing counterparts (Kobosko et al., 2018), often as disabled (Adler, 2018; Wallhagen, 2009). They experience feelings of displacement, discrimination, marginalisation (Lesch et al., 2019), and invisibility (Beckner & Helme, 2018; Bedoin, 2019; Ferndale et al., 2016).

The existing literature sets out diverse ways in which late-deafened adults frequently use adaptive or maladaptive coping strategies to control their own, and other people's, reactions to deafness. Adaptive coping strategies include positive management of their situation such as positioning themselves in the best place to hear and see, using lip reading or asking for repetition or rephrasing (Fish, 2016; Hallberg et al., 2000; Rapport et al., 2020). However, because of the heightened need for concentration, the literature also finds many of these people suffer extreme fatigue (Adler, 2018; Rapport et al., 2020; Rothschild & Kampfe, 1997). To alleviate fatigue, many withdraw from social interaction, often seen as a maladaptive response, resulting in isolation, exacerbating loneliness which may lead to depression (Dillon & Pryce, 2020; Domagała-Zyśk, 2019; García et al., 2020; Lawrence et al., 2020). These psychological pressures create a sense of unravelling-self (Clark et al., 2012), and emotions can become

so strong that some participants reported suffering feelings of oppression, even contemplating suicide (Barlow et al., 2007; Luey et al., 1995).

Stigma – Impact on Personal & Relational Identity

There are two aspects of hearing loss which may cause stigma for the late-deafened adult; the hearing loss itself and wearing a hearing aid. Goffman (1963) asserted stigma is a "deeply discrediting" (pp. 11,12) attribute which marginalises someone based on personal differences making them seem weak or less than normal, which can result in labelling with negative stereotypes associated with discrimination or prejudice. Heffernan et al. (2016) and Beckner and Helme (2018) found that hearing loss for late-deafened adults negatively impacted on personal and relational identity, marking (or stigmatising) the person as aged (Wallhagen, 2009), stupid (Schlau, 2004), difficult or unfriendly (Heffernan et al., 2016). Subtle value judgements of others about a hearing aid or hearing loss, impacted on late-deafened people's sense of identity, resulting in feelings of reduced self-worth (David et al., 2018). Late-deafened adults who internalise these stereotypes find stigma is a major challenge in managing their identity and "struggle to maintain a positive self-concept" (Corrigan et al., 2009).

Given the heterogeneous nature of those with hearing loss, there were inconsistent findings around the wearing of a hearing aid. Jonsson and Hedelin (2012) reported on studies which did not find shame and stigma associated with a hearing aid. However, according to some participants in the Wallhagen (2009) research a hearing aid is a visible manifestation of a disability creating "alterations in self-perception" (p. 68). This can lead to denial of hearing loss and refusal to wear the aid, both of which can result in individuals being "perceived as not involved or confused" (p. 70), and may contribute to unfair treatment or discrimination, leading to withdrawal and isolation.

The greatest incongruity was around the benefits of hearing aids. A number of studies indicated the use of a hearing aid improves quality of life and increases social participation because auditory improvement helps communication (Clark et al., 2013; Heffernan et al., 2016; Ismail et al., 2021). Nevertheless, the majority of research indicated people consider hearing aids only provide limited help. Reported in the literature around 25% of people who need a hearing aid do not have one (David et al., 2018), and between 25% and 50% of people who do have one, do not wear it (Domagała-Zyśk, 2019; Espmark & Scherman, 2003). This suggests a hearing aid can be a visible symbol, adding to the shame, stigma and negativity of hearing loss, inferring a "less intelligent, less confident, weak and disabled" (David et al., 2018, p. 126) identity.

A considerable amount of literature identifies stigma as a major barrier to late-deafened adults seeking help for their hearing loss (Bierbaum et al., 2019; Domagała-Zyśk, 2019; Heffernan et al., 2016). Media portrayal of hearing aids, as well as the views and comments of some professionals, may inadvertently

reinforce the shame and stigma of hearing loss (David et al., 2018; Wallhagen, 2009). However, Wallhagen (2009) emphasised there was limited data available on why hearing loss and hearing aids cause stigma and it needed to be better understood. Beckner and Helme (2018) reiterated this, saying research into disability needs to examine the influence of stigma on identity.

Disabled Identity & Being Normal

Scholarly understandings provide models which interpret disability in a number of ways; a medical issue, a human rights issue from a political or activist standpoint, or societal perception (Berghs et al., 2016). A full discussion around disability models is beyond the scope of this thesis but suffice it to say, the most pertinent understandings of disability, from the perspective of hearing loss in late-deafened adults, are the medical model, and the social model of disability.

In a medical model, a disability is interpreted as a defect, an impairment imagined as within the individual (Skelton & Valentine, 2003). It is seen as reduced functionality, and situated "exclusively in individual bodies and strives to cure them" (Siebers, 2008, p. 54). Promoting a 'medicalised intervention' maintains the "ableist prerogative" (Goodley, 2014 p.22). Campbell (2009)[8] argues this means "the disabled individual is required to embrace, indeed to assume, an 'identity' other than one's own" (Goodley, 2014 p.22). As Bedoin (2019) found, when examining links between ethnicity and deafness, "deafness often prevails" (p. 88) over other identities. This was supported by Barnartt (2001)[9] stating disability is often "ascribed 'master status'" (Adler, 2018, p. 805).

Within the social model of disability, there is an important distinction made between impairment (the functional limitation), and disability (societal restriction) caused by lack of accessibility and oppression (Goodley, 2014 p.22). Therefore, a social model would suggest that hearing loss, or the inability to hear, does not determine identity. Moser (2006) argues "that disabled is not something one is, but something one becomes" (p. 373). Using this social model, the disability is not so much experienced in the physical impairment, as in the barriers which limit the late-deafened person – firstly through misunderstandings due to communication difficulties, and then through lack of access, marginalisation and discrimination.

Disability studies around late-deafness highlight the emphasis on 'normal' (Baldridge & Kulkarni, 2017; Beckner & Helme, 2018; Dillon & Pryce, 2020; Jonsson & Hedelin, 2012), with medicalised solutions or technology, to eliminate the perceived problem (Boisvert et al., 2020; Mäki-Torkko et al., 2015). As Davis (2018) says, to understand disability we first need to understand 'normal'. According to Davis (2018) "the problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the problem of the disabled person" (p. 24). Since deafness is outside the experience of most

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[8] as cited in Goodley (2014) – the Campbell report was unavailable
[9] as cited in Adler (2018) – the Barnartt report was unavailable

late-deafened adults, they accept rather than challenge the definition of hearing as 'normal' (Baldridge & Kulkarni, 2017; Skelton & Valentine, 2003). For them, deafness is abnormal (Ferndale et al., 2016) and it is for this reason they seek solutions to regain hearing.

Influence of Role Models & Mentors on Identity

The literature is mostly silent on role models or mentors for late-deafened adults. McDonald (2014b) said she had no adult mentors and wrote 'The art of being deaf: a memoir' (McDonald, 2014a) in the hope it would provide a mentoring role for other deafened adults.

Deaf culture recognises the contribution of Deaf role models or mentors for identity development and maintaining self-esteem. A mentor shares their experience guiding people to make their own decisions. A role model is someone who provides an example, whose actions may, consciously or unconsciously, be emulated (Healy et al., 2012). Deaf mentors are most often present within Deaf schools or clubs and provide examples of appropriate behaviour in navigating the "societal, psychological and physical barriers" (Cawthon et al., 2016, p. 115) of stigma and discrimination which Deaf people face in an audio-centric world. The Deaf Mentor program (Hamilton & Clark, 2020) provides support and assistance to hearing parents who are raising Deaf children helping them recognise their child is "different but not broken" (p. 713). The systematic literature review conducted by Cawthon et al. (2016), focussed on how role models and mentors address critical needs for the parents of Deaf children. This review did not focus on the late-deafened, however their research highlights the importance and value, of role models and mentors.

Hearing Healthcare Providers for Navigating a New Deafness Identity

Existing literature suggests there is a lack of trust in hearing professionals. An interesting observation in the recent Dillon and Pryce (2020) research found some participants wanted co-ordinated care from hearing healthcare providers who had a hearing loss, because these providers would understand their experiences. There is a perceived lack of continuity and co-ordination between the many professionals consulted (General Practitioners (GPs), Ear, Nose and Throat specialists, Audiologists, or others), which resulted in repeatedly retelling their hearing history (Bierbaum et al., 2019; Rapport et al., 2020). Unco-ordinated services resulted in intermittent and interrupted help to overcome obstacles associated with hearing loss (Barlow et al., 2007; Bierbaum et al., 2019; Lesch et al., 2019; Weir, 2015).

Another aspect mentioned in the literature was that hearing healthcare providers, perhaps inadvertently, added to stress through poor communication (Rothschild & Kampfe, 1997). Much of the more recent research stated some healthcare providers were insensitive and lacked knowledge of the issues late-deafened adults face (Adler, 2018; Aguayo & Coady, 2001; Barlow et al., 2007; Dunn & Burcaw, 2013; Espmark & Scherman, 2003; Rapport et al., 2020; Weir, 2015). Participants felt these

professionals did not provide support for their psychological and psychosocial needs (Dillon & Pryce, 2020; Jonsson & Hedelin, 2012), instead, often offering more powerful hearing aids, perhaps influenced by the need to meet sales targets (Bierbaum et al., 2019). This resulted in poorer hearing aid up-take, outcomes, and satisfaction.

Rothschild and Kampfe (1997), 25 years ago, identified the need for counselling, rehabilitation and referrals to peer groups. Late-deafened adults in more recent research, reported they did not receive referrals to counsellors (Lawrence et al., 2020; Lesch et al., 2019; Rapport et al., 2020). According to Lawrence et al. (2020) support and psychosocial counselling may be beneficial to increased quality of life. However, hearing healthcare providers acknowledged they did not have the skills to deal with the psychological, and especially, the psychosocial issues their patients experience in the real world (Dunn & Burcaw, 2013; Weir, 2015). Nevertheless, recent research indicated audiologists have become more aware of the psychological needs and Bennett et al. (2020) found that over half the audiologists in her research attempted to address issues of psychological well-being. Bennett et al. (2022) stated "clinicians called for increased diversity in program offerings, specifically relating to the emotional, relational and social impacts of hearing loss" (p. 130). However, this study also found there were barriers to providing support, such a lack of resources or funding.

Hearing rehabilitation is needed because hearing is important "not only…for communication and spatial orientation, but also…as affirmation of our existence as human beings" (Espmark & Scherman, 2003, p. 106). However, Barlow et al. (2007) argued there was little research which showed rehabilitation improved coping, and continued by stating there was little published data about the experiences of rehabilitation for late-deafened adults. Nevertheless, researchers from Sweden (Espmark & Scherman, 2003), UK (Barlow et al., 2007), USA (Fish, 2016), and Poland (Domagała-Zyśk, 2019) all reported there should be more professional counselling and rehabilitation. This indicates there has been little or no improvement in providing these services over the past two decades at least in the countries of these researchers. In Australia, Bennett et al. (2020) suggests audiologists should make referrals to GPs or psychologists for support and counselling. However, most allied health services are privatised which can make access harder and be cost prohibitive.

Key Issues Emerging from the Cochlear Implant Experience

There is a noticeable difference between the research into late-deafness and that into cochlear implantation. The deafness literature, while referring to the medical aspects of deafness, focused on the behavioural consequences and impacts of hearing loss. However, the majority of research covering cochlear implants, such as that by Tan et al. (2013), focused on the medical, audiological, technological, and engineering aspects of implants. Compared to late-deafness research, Ramos-Macías et al. (2016) stated there are substantially fewer studies on the impact on quality of life after cochlear implantation.

This is perhaps because cochlear implantation is a relatively recent, but evolving treatment for late-deafness (Copeland & Pillsbury, 2004; Lenarz, 2018).

Little attention has been paid to how those who are implanted (and their families) learn to live daily with a cochlear implant (Mauldin, 2014). Few studies have investigated a link between being a cochlear implant recipient and identity (Kobosko et al., 2018). Therefore, as Sealy (2015) said, quoting Lane (2005) it is not yet known how "social identity or psychological adjustment" (p. 22) is impacted over time for cochlear implant recipients. However, where found, literature was examined to understand the key issues and concerns around cochlear implantation, to determine how these might relate to issues of identity. There is representation in the media that cochlear implants are primarily for children (Mauldin, 2020). Bierbaum et al. (2019) suggested this widely held belief is one of the barriers to adults enquiring about having an implant. This may be one reason there is little research into the impact on identity of late-deafened adult cochlear implant recipients, a gap which provides an opportunity and emphasises the importance of my research.

Reported facilitators or barriers in the decision process of cochlear implantation may offer insights into the relationship between deafness, having an implant, and identity. As discussed earlier, a medical understanding of disability seeks to eliminate the problem and highlights the fixation on 'normal'. Technology "influences the definition of disability" because it has the capacity "to change health outcomes" (Wise, 2012, p. 169). This is discussed, in the cochlear implant context, in Chapter 5.

Late-deafened adults were frustrated with ineffective verbal and aural communication (Bierbaum et al., 2019). They experienced unequal treatment at work (Fish, 2016; Heffernan et al., 2016), and believed returned hearing would improve career prospects (Clinkard et al., 2015; Dillon & Pryce, 2020; Jeffs et al., 2015). They desired increased social interaction to mitigate isolation and improve relationships (Bierbaum et al., 2019). Although uptake is low, most often the decision to have a cochlear implant is made by adults who want to resolve their hearing issues (Bierbaum et al., 2019; Dillon & Pryce, 2020). Some researchers found those who received support and encouragement, from family, friends or peers about the process of having and living with an implant, influenced their decision.

Bierbaum et al. (2019) notes that potential recipients fear the cochlear implant surgery with unknown outcomes. This report continued saying that negativity and stigma towards hearing aids, overlaps into decision making around a cochlear implant. Thus, when people see the large and visible cochlear implant speech processor (Dillon & Pryce, 2020; Fish, 2016), they fear this visibility will be another marker of stigmatisation. None of the reports confirmed or denied whether the fears of stigma prior to implantation were actually experienced. One major concern was losing residual hearing through the

surgery (Bierbaum et al., 2019; Ebrahimi-Madiseh et al., 2020) which would result in complete deafness unless wearing the processor.

Participants in the studies from Dillon and Pryce (2020) and Rapport et al. (2020) felt supportive services were lacking from hearing healthcare providers of all kinds, to help with the implant decision. Da Cruz (2021) pointed out that doctors have an important role in recognising those who could benefit from an implant, suggesting the inability to hear on a phone was perhaps a trigger a cochlear implant referral should be provided.

The research did not examine why a cochlear implant decision is difficult from the psychological perspective, although Adler (2018), and corroborated by Bierbaum et al. (2019), and Jeffs et al. (2015), highlighted the importance of mental readiness. They suggested hearing healthcare professionals lacked both the knowledge of cochlear implants and were also unable to provide help for the psychological impacts of implantation.

Cochlear Implantation Impact on Identity

A cochlear implant returns the majority of recipients to a semblance of hearing, and for most, this is a positive experience (Boisvert et al., 2020; Da Cruz, 2021). However, research undertaken by Kobosko et al. (2018); (2015) stated few studies had looked at the psychological aspects of cochlear implantation but claimed the psychological well-being for those who have implants is on a par with the normal hearing population.

There are a number of published studies which describe how a successful cochlear implant changes life. However, this was not linked to a change in identity. Recipients reported using coping strategies less (Kobosko et al., 2015), had reduced "listening-related fatigue" (Rapport et al., 2020, p. 6) and felt less anxious or fearful (Jeffs et al., 2015). These studies indicate recipients feel less of a burden (Jeffs et al., 2015; Kobosko et al., 2015). They became more independent with the ability to again choose what they do, without needing help (Ramos-Macías et al., 2016). This led to greater dignity (Adler, 2018) suggesting at least some sense of re-empowerment and autonomy through regaining more control over their lives (Mäki-Torkko et al., 2015). Many studies reported self-esteem increased after an implant, which led to increased confidence (Chapman & Dammeyer, 2017; Clark et al., 2012; Jeffs et al., 2015; Kobosko et al., 2018; Kobosko et al., 2015; Ramos-Macías et al., 2016; Rapport et al., 2020; Saeedi et al., 2021). Other research indicated self-talk became more positive, communication easier and relationships improved. Overall, recipients reported less depression, quality of life was enhanced, and an implant had a positive impact on well-being (Dillon & Pryce, 2020; Rapport et al., 2020; Saeedi et al., 2021). These comments imply implant recipients have an improved quality of life when compared to their late-deafened experiences.

From this body of research there is little doubt the majority of recipients are satisfied with the outcomes of their cochlear implants, giving them the ability to return to a more 'normal' hearing life. There are suggestions in the literature that having a cochlear implant introduces another hearing crisis. Kobosko et al. (2015) correlated the importance of self-esteem for satisfaction with cochlear implantation but only marginally commented on the issue of identity, claiming confusion among recipients who did not know how they identified: "deaf, hearing or half-deaf" (p. 606).

The Research Opportunities

This literature review highlights that the majority of the research on late-deafness included the observable impacts, and some behavioural outcomes of late-deafness, with little correlation to the impact on identity. Many of the reports emphasised that hearing healthcare providers focused on the pathology of hearing loss, and not on the consequences of this loss. The literature does, to a degree, cover some of the sociocultural and psychological impacts of hearing loss but clearly says there is more support needed from hearing healthcare providers to address these issues. Despite reports showing peer group support helps with managing the stigma of hearing loss (David et al., 2018), discussions around role models or mentors for late-deafened adults was scarce.

There is no body of work which investigates the impacts of cochlear implantation on identity. Counselling from hearing healthcare providers for adjusting to hearing through a cochlear implant seemed to be lacking. Despite an increasing recognition of the need for support, most healthcare practitioners did not provide referrals. Some of the issues mentioned by Clark et al. (2012) will be identified in my research.

> Future studies will likely demonstrate that 1) strong social support networks help to reduce maladaptive emotional responses; 2) encourage and facilitate practice of speech perception with the CI[10] and its use in spoken communication and 3) provide logistical support for improved access to care (Clark et al., 2012, p. 7).

Summary

Collectively, this literature review suggests that identity challenges in the late-deafness and cochlear implant experience have been under-researched. My study aims to address some of these issues including support structures for late-deafened adults and cochlear implant recipients, how they describe their identity during the deafness experience and whether this changes after cochlear implantation. This will add to and extend understanding and knowledge of late-deafened adults' experiences. In the next chapter, I investigate the theoretical framework and explain the methodology of my research.

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[10] CI is an acronym for cochlear implant and is used in some quotes in this thesis

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Chapter 3.
Research Strategy:
Identifying the Theoretical Framework & Research Methodology

In this chapter the theories behind the design, method and analysis of my research are identified. The chapter starts with a discussion of the frameworks upon which the research is based. It continues with a description of how the data was obtained and finishes with analysis methods.

The Grounded Theory Approach

Heale and Noble (2019) argued a theoretical framework provides the foundation for all aspects of a study: from the literature review, to identifying the research questions, the research design, the methodology, and defining how the study extends existing knowledge. There was no consensus in current literature regarding the best theoretical framework to investigate this topic. However, research into late-deafness and cochlear implantation often used qualitative and mixed methods. A phenomenological approach was employed in two late-deafness research papers, with grounded theory mentioned in three studies covering the experience of deafness, as well as in five of the 24 cochlear implant papers. After examining the five major qualitative research approaches – ethnography, narrative, phenomenology, grounded theory, and case study, my research was designed on the precepts of constructivist grounded theory (Charmaz & Bryant, 2010), an extension of the grounded theory proposed by Glaser and Strauss in the middle of the twentieth century. Grounded theory is used when "little is known about the phenomenon" (Chun Tie et al., 2019, p. 1). In the constructivist approach, data generation and analysis are conducted simultaneously by the researcher, who seeks to understand how participants find meaning in their experiences.

While traditional phenomenology and grounded theory are based on different theoretical philosophies and have different approaches to the questions, the common ground underpinning idea of both is lived experience. The shared view of these frameworks is what is needed to make sense of the data. It is also important to note that elimination of interpreter knowledge in the process analysis is not possible. The research used a mingling of theories, underpinned by the assumption that an interpretative understanding of phenomena in lived experiences can be obtained through clarifying meaning and identifying emerging themes... This approach required linguistic rather than numerical data. Therefore, interviews which were flexible, adaptable, open-ended and exploratory (Elliott & Timulak, 2005) provided data to answer the research questions.

The advantage of basing the research on grounded theory was the focus on open-minded, disciplined, systematic and rigorous enquiry which collected in-depth data to develop an understanding of the fundamental meaning drawn from particular situations and contexts. However, grounded theory has

disadvantages because it is time consuming, the research can be difficult to replicate and it can be challenging to reduce researcher bias (El Hussein et al., 2014). To minimise some of the disadvantages, automatic audio transcriptions decreased the time for transcription, while being reflexive identified potential points of researcher bias (Charmaz & Bryant, 2010). Coding was undertaken throughout the research process to identify emerging "social and psychological…actions" (Chun Tie et al., 2019, p. 5) which could direct future interview questions. The analysis identified terms used by participants to generate themes which explained the meaning of the data. Constant comparison between interviews allowed code development, a key element of grounded theory (Charmaz & Bryant, 2010; Chun Tie et al., 2019), resulting in systematic identification of issues (or theories) to answer the research questions. This interpretive process aligned with the way several studies in the literature review were conducted, which allowed a comparison of outcomes between my research and previous scholarship.

There is an argument from sociologists that only those who have the lived experience can understand that experience (Khatwani, 2020), i.e. only a late-deafened adult, cochlear implant recipient can truly understand these life changing experiences. Khatwani (2020) also identified problems which might influence objectivity in social science research. These include the researcher's interest and experience in the topic, plus community and cultural values and compassion for the group being researched. Nevertheless, the method of enquiry "keeps researchers away from their personal values, feelings and also keeps research less biased" (Khatwani, 2020, p. 132). The use of a survey plus interviews provided some triangulation, indicating opinions from interviewed participants might be more commonly accepted.

This research seeks to understand the perspective of my participants, and since I am an insider researcher and share similar experiences, this made it easier to interpret meaning from participants' comments. Every part of the research was informed by my insider perspective: the approach, design, questions, analysis, and conclusion (Kirpitchenko & Voloder, 2014). This constructivist subjectivism, as opposed to a positivist objectivism, assumes because I shared some of the experiences of participants, I was part of the process, bringing an insider's view to the problem. I had a starting point and I was, therefore, more able to observe and interpret terms and feelings. Comparing my perspective and careful analysis uncovered the meanings in participants' stories but the process required "analytical thinking, reflection and interpretation" (Davidsen, 2013, p. 323). I was particularly conscious of a range of experiences where they differed from my own, and stated where I incorporated my own experience into the research findings (Wilkinson & Kitzinger, 2013).

My insider status meant recruitment of participants was easier (Taylor, 2011) with the possibility of establishing a stronger connection (Wilkinson & Kitzinger, 2013). Participants could be more confident I

represented their story truthfully and were more willing to share their feelings. They realised I understood the terminologies participants used and, on a deeper level, I understood the emotional, confronting, and technological issues they faced.
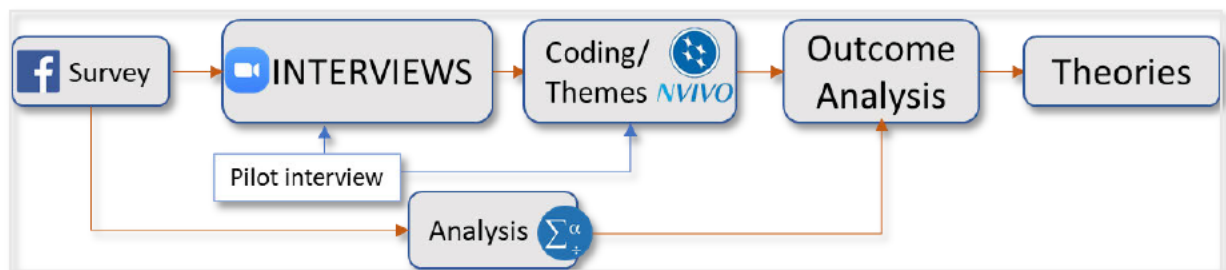
Empirical Research Design

The purpose of this study was to garner information to answer the research questions, through listening to the stories of late-deafened adults who had also received at least one cochlear implant. I employed three methods to gather data: (1) an on-line survey, (2) digital interviews over Zoom, with options for text chat or email, and (3) additional comments from participants when they reviewed interview transcriptions. The research used mixed methods with the emphasis on qualitative rather than quantitative data. Figure 3 illustrates the research design.

Figure 3:

Flow Chart of the Research Design

The research commenced with a survey on Facebook hearing loss groups, inviting participants to participate in interview. The first interview was transcribed and coded which identified additional questions for future interviews. All interviews were coded and combined for the final report.

Survey Design

The primary purpose of the survey was to allow participants to self-select to be interviewed, as required by the ethics committee. Existing surveys were examined for relevance, including the WHOQOL-BREF (World Health Organization Seattle Quality of Life Group, 2020) and a number of Cochlear Implant Quality of Life questionnaires (McRackan et al., 2019) but these did not include questions which would provide answers for my research. While the survey would provide additional information, it was not designed to gather numerical data which would be generalisable across the late-deafened population. To ensure integrity participants were anonymised automatically within LimeSurvey (2021). It was designed so no one person could answer twice and included a simple question which had to be answered to guarantee a human was participating. It explored factors which impacted on and influenced respondents' perception of identity during the various stages of hearing loss and the implantation experience. Questions in the survey (refer Appendix 3 and Appendix 4) were grouped under three headings: demographics, deafness history and experiences, cochlear implant history and

experiences. By leaving their email address, participants indicated their willingness to take part in an interview via Zoom, email or text chat. I created this on-line survey, discussed it with supervisors, and had it approved by the ethics committee (Refer Appendix 9).

Interview Design

The interview was designed to listen to participants' stories, to investigate their personal life experiences. It attempted to unravel whether participants' identity was challenged through hearing loss, and how identity changed once they became a cochlear implant recipient. The interview was semi-structured with prompting questions (refer Appendix 6) to ensure participants covered the research issues.

Criteria for Selecting Participants & Sampling Method

Late-deafened adults who have cochlear implants are a very small proportion of the overall population. It is a niche group, not easily contactable in person, and social media groups were considered the best place to invite participants. The COVID-19 crisis also provided limited opportunities for face-to-face research. Nevertheless, there is a compelling case to access participants via social media because studies conducted over the past five years, found social media is ideal for late-deafened adults because it removes the communication barrier which may occur face-to-face (Argenyi & Kushalnagar, 2019; Kožuh & Debevc, 2018; Manchaiah et al., 2020). There is also consensus among other studies, reporting social media use for accessing health information (Šmahel et al., 2018), especially among disability communities is rapidly growing (Kožuh & Debevc, 2020; Sweet et al., 2020). Of the many social media platforms available in English, Manchaiah et al. (2020) stated Facebook is one of the communication channels most likely to reach older adults with hearing loss.

The characteristics of participants were defined to ensure the research was robust (Tongco, 2007) and the required attributes for participants and the populations sampled are outlined in Table 1.

Table 1:

Defining Participant Demographics & Populations Sampled

Participant Demographics	Populations Sampled
1. Adults over 18	- Cochlear implant Experiences Facebook group
2. Had once had hearing	https://www.facebook.com/groups/ciexperiences
3. Had been late-deafened	- Bi-lateral CI Warriors Facebook group
3. English speaking from any country	https://wwwfacebook.com/groups/325256355436065
4. Male or female	- CICADA Queensland
5. Single sided or bi-lateral of any brand implant	https://www.facebook.com/CICADAQueensland
7. Has access to Zoom or email	
8. Willing to participate in an interview	

Although participants were not purposively selected (Chun Tie et al., 2019), the method was convenience, non-probability sampling (Simkus, 2022), because as a general principle, only people who are late-deafened participate in the social groups where the invitation was posted. In addition, the survey required people to confirm they had the characteristics required before commencing to answer questions and self-select for interview participation. There was a small element of snowballing when a participant requested permission to post the survey on CICADA[11] Queensland social media.

After receiving responses it became apparent that most participants were living in the USA and that more females than males had responded. To stimulate male and Australian responses, a request was made in the comments under the invitation posted to Facebook. When choosing those to interview, answers to the survey were viewed and it was deemed all were potential interview participants, and those who agreed to an interview were contacted.

For this thesis it was anticipated between 12 and 15 interviews would provide sufficient data to answer the research questions. This number was based on judgments by Guest et al. (2006) who said data saturation occurred most often after the analysis of 12 interviews. Baker and Edwards (circa 2013) surveyed 19 researchers (including Charmaz), and most suggested 14 interviews would provide data saturation.

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[11] Cochlear Implant Club & Advisory Association (CICADA) Inc, Australia. https://cicada.org.au

Methodology

The survey invitation (refer Appendix 2) was posted to two Facebook groups with a second invitation posted to one group approximately two weeks later. There was a limitation in posting to Facebook because within approximately 24 hours the invitation was no longer visible. However, by making comments in the post, survey visibility increased for another few hours, thus increasing response. Forty-four people answered the survey of which 17 were men and 27 women. Twenty-seven participants agreed to an interview, and another eight said maybe. All were contacted via email.

Table 2:

Number of Participants agreeing to an Interview who Signed a Consent Form.

All indicated their preference for interview method with most who signed the consent form preferring Zoom. Eighteen responded with 16 completing the signed interview consent form (Appendix 5).

Interview Preference	Contacted (not all Interviewed)	Consent Form Received
eMail	18	5
Zoom	12	10
Text chat or eMail	2	1
Text chat or Zoom	2	0
No interview	10	0
TOTAL	44	16

All participants were over the age of 18, had been hearing, and became deafened in adulthood. All had received at least one cochlear implant of any brand, and most had been bi-laterally implanted. Ten resided in Australia and 27 in the USA, with the balance of participants from seven other countries, only one of whom responded to an interview request. Participants ranged from 20 to over 80 years of age (Figure 4) and might be considered educationally elite because 16 had completed undergraduate, and 18 post-graduate studies. Thirty-two went slowly deaf, and of these, 21 were deaf for more than 10 years before receiving an implant. Of those answering the survey 20 had their first implant more than five years ago and 28 had bi-lateral implants.

Figure 4:

Participants Interviewed by Age Group

The majority of interview participants were aged between 50 and 79 years of age representative of the late-deafened cohort.

Most interview participants were bi-lateral. Of those interviewed, four had only a single implant, however two were waiting to have their second implant activated, and one was about to undergo bi-lateral surgery. Figure 5 shows the length of time interview participants had been implanted with their 1st and 2nd (bi-lateral) implants.

Figure 5:

Interview Participants showing the number & Length of Time Implanted with 1st & 2nd Implant

The majority of interview participants had bi-lateral implants with only two a single implant.

Conducting Interviews

Interviews were organised over email and set up at a time convenient to each participant. At the commencement of each interview participants were asked to agree to and turn on Zoom recording. An additional audio recording was made using Otter on a separate device, as a back-up because internet connection was not always stable. I disclosed my status as a late-deafened adult and bi-lateral cochlear implant recipient through the recruitment process and reiterated it during the interview.

Each interview was transcribed and examined before additional interviews were undertaken to identify themes which might be included in future interviews. As an example: After one interview I pondered why this participant had maintained his identity and self-esteem, and I realised it was because he had family members' experiences to draw on. This allowed him to better understand the issues he was facing, and subsequent interviews probed deeper into the support structures participants had to understand how this may have impacted on them.

Thirteen interviews were completed over three weeks during November 2021 and an additional four were undertaken in early December. Eleven women and six men were interviewed although one female was eliminated because it was found she did not fulfil the participant criteria (refer Table 3 for demographics of participants) with one interview via text chat, five via email and 11 over Zoom. Each interview was automatically transcribed from the Otter recording, then listened to and edited. Within two days of each interview, the edited transcript was emailed to participants for confirmation. Most responded and some took the opportunity to add more detail.

Table 3:

Demographics of Interview Participants

Includes Gender, Age, Relationship status, Cochlear Implant Experience, Country of Residence, Interview Type, Length & Number of Words in each Transcript. Interviewer words were not removed. P8's responses were eliminated during analysis because it was a relative who had a cochlear implant.

Interview Participant	Gender	Age Range	Relationship status	Length of time since 1st implant	Length of time since bi-lateral implant	Country	Interview type	Interview length	# Words
P1	Male	60-69	Married	1-5 years	<1 year	USA	Zoom	51 minutes	7,310
P2	Female	30-39	Married	<1 year	Simultaneous	USA	Zoom	55 minutes	9,410
P3	Female	70-79	Married	>10 years	>10 years	Australia	Email	3 emails	4,678
P4	Female	30-39	Single	<1 year	Only 1 implant	Singapore	Chat	85 minutes + 1 email	5,983
P5	Female	50-59	Married	<1 year	<1 year	USA	Zoom	103 minutes	11,708
P6	Female	50-59	Separated	6-10 years	1-5 years	USA	Zoom	52 minutes	8,308
P7	Female	70-79	Married	>10 years	>10 years	USA	Email	2 emails	5,344
P9	Female	60-69	Married	>10 years	>10 years	USA	Email	8 emails	13,581
P10	Male	70-79	Married	6-10 years	1-5 years	USA	Zoom	61 minutes	9,069
P11	Male	70-79	Widowed	1-5 years	Only 1 implant	Australia	Email	2 emails	3,669
P12	Female	60-69	Married	6-10 years	1-5 years	Australia	Zoom	64 minutes	11,603
P13	Male	60-69	Married	6-10 years	6-10 years	USA	Email	61 minutes	8,822
P14	Male	60-69	Married	>10 years	<1 year	USA	Zoom	49 minutes	7,493
P15	Male	50-59	Married	<1 year	<1 year	USA	Zoom	80 minutes	15,743
P16	Female	50-59	Married	<1 year	<1 year	USA	Zoom	63 minutes	13,049
P17	Female	Over 80	Widowed	6-10 years	6-10 years	USA	Email	3 emails	3,717

Analysis of Interviews & Survey

Interview Coding

Each interview transcript was anonymised and imported to NVIVO (2020). Analysis was data driven from the transcriptions and during the coding process the coding tree developed with themes emerging (refer Appendix 8 for tables of coding tree).

The first transcription was coded, and additional questions were included in future interviews to reflect emerging themes. Coding samples were discussed with the supervisor and examples of coding are included in Appendix 7. Notes were made after each interview, adding impressions and perceptions at the time it was coded. Few new codes were identified after 12 interviews (Figure 6). Data saturation was considered to have been reached after 16 interviews.

Figure 6:

New Codes by Interview

Showing most Codes were Identified from the First Interview with no New Codes after 12 Interviews

Codes were initially developed semantically from the words and terms participants used. It should be noted that open-ended questions from the survey were collated and included in the analysis, coding the responses to align with the codes from interviews. Once all interviews and open-ended questions had been coded, codes were grouped into major themes as shown in Table 4. Analysis was then undertaken to determine the relationship between themes and identity illustrated in flow chart Figure 7.

Table 4:

Major Themes, with # of Child Codes, Showing the # of References Under Each Theme.

Figure 7 shows the Relationships between Major Themes. Tables at the start of Chapters 4 and 5 link Subheadings to each of the Major Themes. A full list of all child codes is included in Appendix 8.

Major Themes	# of child codes	# of references
Identity	23	419
Hearing History	3	111
Consequences & impact of Late Deafness	75	1,005
Hearing Aids	9	227
Cochlear Implants	97	1,332
Implant Processor	11	78
The Hearing Divide	26	495
Peer/Family Support	5	114
Healthcare professionals	12	186

Figure 7:

Diagram Showing Relationships Between Major Themes & the Link to Identity.

The link between themes and identity is discussed in Chapters 4 & 5 and shown in Appendix 7.

Survey Analysis

The 44 survey responses were exported anonymously from LimeSurvey (2021) to Excel and SPSS (IBM, 2015) with the number of responses, calculated for every question (refer Appendix 4 for frequencies). It should be noted that four respondents stopped answering the survey at the end of all deafness questions, and two others did not continue to answer questions related to life changes due to their implant. Their answers about deafness were relevant and were included in the deafness experience analysis. However, this meant there were 40 responses for basic cochlear implant questions (e.g., how long they had their implant(s) etc), and 38 survey responses for implant experience questions (rather than 40). Cross tabulations were run for a comparison between demographics, however because the number of participants was small, significant differences could not be calculated. As examples, Figure 8 and Figure 9 show two cross tabulations. Survey answers mapped a range of responses which were correlated with interview questions, suggesting positions mentioned in interviews might be more widely held. Once the survey had been analysed and open-ended questions coded, transcriptions of interviews were re-read and assessed to ensure the analysis was sufficient to discover meanings. This included searching for repetitive or commonly used words or ideas, or stories participants told. Participants shared many experiences which were interesting, and important, some of which are mentioned in the following chapters, but since many experiences were not the primary focus of this thesis, some of these may be developed for other papers or future research.

Figure 8:

Example of Cross Tabulation between USA & Australian Survey Participants Showing Education Level of Participants from Each Country.

Figure 9:

Example of Cross Tabulation of those Interviewed & those Not Interviewed

Showing Age Range

Anonymity & Security

Survey answers had been anonymised automatically within LimeSurvey (2021). Where participants left their email address, this was not included when responses were downloaded for analysis. Email addresses, required to contact participants, were stored in a separate file to any of either the survey or interview responses. Any names within transcripts have been removed and coded as P1 to P17 or S1 to S44.

- P indicates a participant who answered the survey and was interviewed.
- S indicates someone who answered the survey and was not interviewed.

When survey statistics are used, except if explicitly stated, the statistic includes all responses regardless of whether participants were interviewed or not. Upon completion of the research local backups and computer files will be moved to a secure file depository.

Next Chapters

The data revealed far more than can be reported in this thesis. Many of the findings aligned with existing scholarship. For example: coping strategies or feelings of isolation, reported by a number of researchers including Moser et al. (2017), Kobosko et al. (2015) and Mäki-Torkko et al. (2015) etc. Therefore, in the following chapters the focus is on the impacts of hearing loss and cochlear implants which were covered inadequately in the literature, and these could be considered significant or unexpected findings.

Chapter 4.
Understanding Participants' Hearing Loss Experiences

For most participants in my research hearing loss was unexpected and unwelcome. They were raised within the hearing community and with the cultural expectations associated with that community, but their 'hearing' status was unmarked, commonplace, normal, and only recognised when they became deaf. Bauman (2009) described only consciously recognising his own hearingness when he experienced the contrast of deafness. This is supported by a comment from P2 who said, *"I didn't realise (hearing) was part of who I was, until I was no longer…hearing…it was just part of my identity…and then I was physically deaf…culturally hearing…it was (this) kind of…limbo place"*. This chapter seeks to understand and explore late-deafened adult participants' attitudes and hearing loss experiences and how it relates to identity (Table 5 & Figure 7) to address the following research questions:

1. What issues do late-deafened adults experience as they go deaf, and how does this challenge their identity and impact on their lives?

2. How do late-deafened adults perceive the responses of hearing healthcare providers to these issues?

Table 5:

Table Showing how Headings & Discussion in this Chapter relate to Major Themes.

This table is based on Chapter 3, Figure 7: Diagram Showing Relationships Between Major Themes & the Link to Identity. While all subheadings link to identity they are a separate concept generated from the analysis.

Major Themes	Heading/Subheadings in thesis

Consequences & impacts of late-deafness	Ch 4: <u>Understanding Participant's Hearing Loss Experiences</u>
	• Participants define Deafness
	• Self-identity related to Definitions of Deafness
	   • The slow creep of hearing loss
	   • Emotional impact of Deafness on Identity
	• Social Experiences Impact on Identity
	• Deafness Impact on Career Identity

Hearing aids	Ch 4: <u>Hearing Aid</u> The Stigmata of Deafness
Support Peer/Family/Professional	Ch 4: <u>The Importance of Role Models or Mentors Counselling & Peer Group Connection</u> • Positive Role Models Help Sustain Identity • Negative Role Models Undermine Identity
The Hearing Divide • Phone Use • Sign language • Music	Ch 4: <u>The Hearing Divide</u> • Exclusion from the Language of the Hearing Majority • Inability to Use the Phone • Loss of Music – Crossing the Hearing Divide
Identity	Ch 4: <u>Disabled Identity</u> • Understanding Normal

Participants Define Deafness

Knowing how late-deafened adults define deafness is significant because their viewpoints may influence their understanding of their changing identity. An open-ended question in the survey explicitly asked, 'What is your definition of deafness?' The majority of participants characterised deafness in two ways. When answering the survey, 19 of the 44 participants defined deafness as a complete absence of sound, explaining it was *"like living in a silent movie"* [S23], or *"a silent world"* [S34]. In contrast, 21 defined deafness as the absence of clarity or distinguishable sound. A common theme from interview participants, when identifying deafness, was *"not hearing sufficient sound to understand speech or recognise threats"* [P11]. P4 mentioned the consequences saying deafness hinders *"communication with other people"*.

For others, deafness was defined differently. One survey participant said deafness was *"a missing link in life''* causing people to treat her as *"stupid rather than deaf"* [S43], a stigmatised position reported by Heffernan et al. (2016) and Beckner and Helme (2018). P6 found her personal experience of deafness was a *"form of death. I lost who I was",* not fitting into the Deaf or hearing worlds.

Despite nine of the 44 surveyed saying they interacted with the Deaf community, only two defined deafness as part of Deaf culture, with one declaring *"I am Deaf and proud"* [S11] reflecting the Deaf pride perspective, or perhaps the social model of disability. One other person defined deafness in a positive way saying it provided quietness, equating to *"peaceful solitude"* [S10]. Another, while saying deafness meant *"no sound",* added an interesting definition by considering people as deaf if they *"can hear but do not listen"* [S6].

All 44 participants' definitions largely fell into a medical model of hearing loss, a model widely adopted in the hearing world. In such framings, deafness is something to be cured (Power, 2005) rather than part of the distinctive, visually oriented Deaf culture. Understanding these multi-faceted definitions of deafness may provide insights into the way participants seek to position their own identity.

Self-Identity Related to Definitions of Deafness

Some participants linked their definition of deafness to their understanding of self. P5 identified as a hearing person, defined deafness as *"100% can't hear",* but said, *"that's not me though"* although she was *"close to totally deaf".* In the interview she explained deafness *"did not embrace me"* because *"I fought hard to make sure I could keep living my life the way I needed to".* P17 had a hearing identity and defined deafness along the lines of his own experience, as *"the inability to hear sounds without aids/implants"*, and as his loss progressed, *"I began to identify as hard-of-hearing or deaf…but never felt either truly described me adequately".* P1 had a strong hearing identity claiming, *"I completely identified*

as a hearing person" but also said he was "very hard-of-hearing". His definition of deafness was "if your hearing loss severely interferes with…living your life as you know it then you consider yourself deaf".

There were inconsistencies between the way individuals explained how they understood themselves. Half of the 44 survey participants said deafness changed them, with 18 feeling they had lost something, and 10 said 'Yes' to the statement 'I no longer knew who I was'. Of the 16 interview participants, when answering survey questions, nine of them claimed deafness changed them. But in seeming contradiction, these same nine people stated during interviews they had a hearing identity which did not change because of hearing loss. A comment from P2 may explain this paradox. She said "you've been hearing for most of your life, then all of a sudden you're not hearing. You're stuck in this hearing world as deaf, but culturally hearing".

From some participants' comments it was difficult to ascertain whether they defined 'deaf' as 'cannot hear at all' or whether they meant culturally Deaf. P9, who did join Deaf culture, made seemingly conflicting statements, saying "I definitely identified as Deaf" but "I saw myself as more hearing challenged". P12, who did not identify as culturally Deaf, framed herself in several different ways, not really knowing how she identified by saying "I'm willing to settle as a deaf person...(yet) I'm hearing impaired or compromised, or something". In an interesting observation, P15 said "I don't think my identity has changed…either my own perception…or anybody else's perception". These inconsistencies seem to highlight a conflict between identity and hearing status which may be better understood by the manner in which hearing loss occurred and the impacts of social interactions.

The Slow Creep of Hearing Loss

Late-deafened adults most commonly experience a slow hearing loss (Da Cruz, 2021). Only 6 of 44 participants experienced a sudden loss, with 38 reporting they lost their hearing over a number of years, drifting towards the invisible divide between those who can, and those who cannot hear. As hearing loss progressed they compromised, making subtle changes such as finding the best listening environment like sitting "in the front row" [P7], or becoming "a really good lip-reader" [P6]. The compromises continued until hearing loss was severe/profound, or as P1 said, when "I finally realised…my ears were shot". From my own experience, with slow hearing loss I always maintained my hearing identity because there was no single point where I crossed into being deaf. Could this be why many of these late-deafened adults still maintained a hearing identity even though physically unable to hear?

Emotional Impact of Deafness on Identity

When an adult becomes deafened they must overcome formative experiences. This is especially difficult without clear boundaries between the old and new identity (Malesevic, 2006). The incongruence

between past, expected and new experiences create painful, and emotional stress because as Kobosko et al. (2018) states, they are "forced to develop a new personal identity" (p. 3) that includes deafness.

Interview participants reported how the emotional impacts of deafness influenced the way they felt about themselves. P14 said *"I didn't feel good about myself"* and P17 said he felt *"extremely vulnerable"* because "*the stress and strain of trying to hear was…overwhelming…I felt constant emotional turmoil".* P6 stated she *"had a lot of anger…feeling like I was nothing"* and continued *"I became… withdrawn, highly dependent (and) I lost my identity".* P16 went even further saying *"I did not go deaf, you might say, with dignity. I went deaf kicking and screaming all the way.…I threw a fit because I lost my hearing, and…became severely depressed".*

However, for some, hearing loss impacted on them in ways which did not undermine their identity. P1 explained, *"my basic identity hasn't changed…I was always part of the hearing world but just wasn't doing as well as the rest of the hearing people".* P13 stated he needed to focus on understanding people, but it did not *"affect how I feel about myself".*

P2, an African-American woman with two PhDs, had been rudely confronted by other professionals challenging her deafness and authenticity. She explained,

> *I was talking to somebody today at the conference and I feel like sometimes you get questioned about your…credentials more when you have a disability than you do when you don't. So here I am, I'm a woman, I'm brown, and somebody was challenging my lived experience, because they read a book…it's like trying to gaslight me. I don't experience what they've experienced in life and so, gosh, it was a little bit frustrating* [P2]*.*

Continuing, P2 stated others had expectations of her, and this created stress because she did not know what to do in so many situations. She claimed *"I went through a lot of stages. Yeah…I went from feeling completely helpless, to being like, okay I'm hard of hearing. I'm not really wanting to be deaf".*

Participants' definitions of deafness and how they describe themselves, amplify the invisible boundary of the hearing divide. Their comments emphasise the emotional pressure these late-deafened participants felt which continued in social situations.

Social Experiences Impact on Identity

For some, hearing loss made the social world inaccessible, and all interview participants elaborated on the social alienation they experienced. At least three defined deafness as isolation, commensurate with the way many described their experiences of being left out of the social world. P16 emphasised *"isolation, isolation, isolation is the best way to describe late-deafness".* She felt rejected by *"both*

communities", Deaf and hearing people, because she could communicate with neither. Nine of the interview participants, while not defining deafness as isolation, said they felt isolated and deliberately withdrew to avoid the difficulties of communication. As some said they *"felt left out...not totally accepted"* [P5] and were *"not part of the group"* [P2].

Other interview participants explained how they could not keep up with conversations and the fear of mishearing undermined confidence. Dunn and Burcaw (2013) argued that "finding meaning in a disability can be daunting" (p. 153) and personal identity can be destabilised when the late-deafened try to be "a hearing person" (p. 153). When participation becomes awkward, according to Kobosko et al. (2018), this may result in experiencing stigma, and loss of self-esteem. P17 recounted *"saying something inappropriate or untimely"* meant she was labelled and thought stupid, in line with findings in other reports (Heffernan et al., 2016). Barriers in social interaction often led to withdrawal and some participants used avoidance to mitigate the shame of awkward responses, drifting away from social networks.

These comments correspond with survey answers where 41 participants thought it was harder to socialise, 40 said it was because they misheard and made mistakes, 26 feared they might embarrass themselves or need someone to help, and 19 reported their speech changed. Of the 44 participants answering the survey, 34 said they withdrew from social groups because they experienced communication problems and 33 of these emphasised they felt isolated from other people.

Interview participants also explained less-tangible experiences and attitudes which added to difficulty in social interactions. Consistent with findings in many studies such as that by Rapport et al. (2020) or Ambert-Dahan et al. (2017), five participants mentioned extreme fatigue and exhaustion because of the concentration needed to socialise, and six said the effort needed to hear was frustrating. Three participants described being fretful, anxious, or stressed and two others were confused. Of all surveyed, 26 participants said they lost their independence, 12 said friends avoided them, and seven suffered discrimination. Two interview participants mentioned being frustrated by unintentional audist comments such as 'never mind', 'it doesn't matter' or 'I'll tell you later', because, as I personally felt, the message conveyed was 'you don't matter'. In fact, hearing loss impacted on *"so many different things"* [P14], and some became seemingly resigned that they had to *"accept it"* [P4], although P17 said she *"was not comfortable with, or accepting of my hearing loss"*.

The majority of interview participants had a hearing identity and defined deafness as a medical issue reducing life enjoyment and social opportunities. This caused a tension between the way they understood themselves and the way they identified themselves; they could not hear but most did not describe themselves as deaf.

Deafness Impact on Career Identity

There is a common audist expectation all should have hearing in the workplace. Deaf people (and by their lack of hearing, the late-deafened) Krentz (2002) and Winn (2007) argue, are among the most underemployed groups. "A career identity is part of…self" (Meijers, 1998, p. 1) and a number of those interviewed identified themselves based on their job saying such things as *"I am an engineer"* [P1], *"I'm a trained professional…I'm a property manager"* [P13], or *"I am a computer person"* [P15]. Some referred to their career identity in the past tense indicating a lack of career continuity by saying *"I was a consulting design engineer"* [P10] or *"I was a high school music teacher"* [P12]. The impact on their career due to hearing loss, was mentioned by 34 of the 44 participants. This issue was highlighted in a number of studies such as that by Bat-Chava et al. (2002), which reported late-deafened adults found that a lack assistive technologies in the workplace "may have a negative effect on career opportunities" (p. 33).

Job loss, or fear of job loss, was "perceived as a threat to…social identity and self-worth" (Barlow et al., 2007, p. 446). Hearing loss impacted on the careers of almost all 44 participants; 13 had to change careers, 12 indicated they were passed over, and nine lost their jobs. At least two participants felt forced out and *"retired early"* [P17]. *"I'd lost a very high end job…basically they retired me"* [P16]. Still others had to make major adjustments, use assistive devices or were *"compelled to rely on (staff)"* [P17].

Many participants indicated that episodes of disruption in their career created emotional issues. S7 said *"I had become withdrawn and depressed after having to give up my career".* Job loss caused anxiety because applying for new positions presented substantial challenges. S33 said *"I couldn't work because of my deafness. I tried, but companies wouldn't hire me"*. P7 said that without hearing she had trouble finding jobs and explained:

> *I wasn't a very impressive interviewee because I didn't always hear their questions well. I felt disempowered when potential employers only saw my hearing loss and not my other skills and attributes. My physical inability to use the telephone eliminated me from many positions. I was considered overqualified for jobs that didn't include phone duties. I managed to get a job that didn't require me to hear…(and) after six months I found a more suitable job that I could somewhat fake the parts that required me to hear* [P7].

P7's comments were not alone, and eight interview participants mentioned the problems they experienced because of the, often fundamental, requirement to use a phone at work.

Dealing with hearing loss and negotiating the hearing divide was outside participants' experiences so finding others who had navigated this challenge, helped some accept their new reality.

The Importance of Role Models or Mentors

Previous studies were mostly silent around role models or mentors for the late-deafened. Going deaf was never easy for any of the 44 participants and most relied on themselves to understand and navigate their experiences. P4 said *"it's a battle I fought alone"* and P3 said *"I had to rely on myself",* a point also made by McDonald (2014b) who stated in her essay, "I had to work things out for myself" (p. 80). Some received sympathy, but most hearing acquaintances could not understand their experience. S33 stated *"It's hard for hearing people to understand that in a room full of…people, you still feel completely alone".* This echoed occasions when I felt I was invisible in full sight.

P5 did not have role models and posed the question, *"how do you…know someone has a hearing loss? How do we get people that kind of support?"* The invisibility of hearing loss makes it difficult to recognise and connect with others who have similar experiences. The Rapport et al. (2020) study found that hearing aid users found it hard to access hearing health information, yet these people needed to feel supported in understanding the "changes in their hearing loss and needs" (p. 5). The professionals who treat late-deafened adults are recognising the importance of connecting them with role models or mentors (Bennett et al., 2022) which may help with navigating a changing identity.

Counselling & Peer Group Connection

Most interview participants did not have access to professional counselling or make peer group connections during their hearing loss. Rothschild and Kampfe (1997) recognised the need for connection to help the late-deafened understand their experiences, yet two decades later, most did not receive referrals from hearing healthcare providers. P17 said *"I have not received…any…hearing support counselling from these professionals"* and P1 said *"before I got my implants there was no mention of…any counselling. No"*. The one exception was P9 who, with her husband was referred to hearing rehabilitation classes at the audiology department of a local university. P9 said that *"meeting deaf people showed me it was possible to have a great quality of life as a deaf person".* P3 said she wished professionals would refer late-deafened adults to support groups because they *"need to talk to those just like them"*.

Since participants perceived a lack of face-to-face counselling and peer group support, some accessed social media, particularly for cochlear implant information and found it a useful source of information. P2 stated *"I did reach out to people on (Facebook)".* However, there was no referral process and, as P6 commented, *"I didn't find the group until after my implant"*.

Nevertheless, recent research focusses on addressing some of the shortfall in audiology settings for counselling and rehabilitation. Bennett et al. (2022) found "clinicians called for increased diversity in

program offerings, specifically relating to the emotional, relational and social impacts of hearing loss" (p. 130). However, this study also found there were barriers to providing support, such a lack of resources or funding.

Positive Role Models Help Sustain Identity

A discovery in my research was that those who had family members, or role models with hearing loss, drew on these peoples' experiences to help them understand their changed circumstances which seemed to sustain their self-esteem and identity. After interviewing P1, I pondered why his hearing identity had remained unchanged through the years of hearing loss. He came from a large family, mentioning his grandparents, parents, as well as brothers and sisters all wore hearing aids. He elaborated.

> *Since I could hear good growing up through my formative years, I completely identified as a hearing person, because I was. My parents and grandparents wore hearing aids when I was young, but all us kids grew up together hearing good…like, we talked about (it), but I don't feel it changed that core identity. And now I am totally deaf, no residual hearing at all, and with these CIs I still identify as a hearing person* [P1].

From family experiences P1 knew about hearing loss saying, *"to communicate in our family you had to talk loud and straight to them…and in a quiet place. I got used to talking to…hard-of-hearing people. We all recognised that we had the same problem"*. I suggest these positive experiences, with family members as role models, is why P1 maintained his hearing identity.

Some participants explained how role models helped them. P9 experienced hearing loss after a childhood accident, although she became deafened as an adult, and had a very positive role model. Although her mother was not deaf, P9 said *"Mom[12]…taught me to self-advocate"* which helped P9 cope with discrimination. P9 maintained her identity was *"not hearing but not really deaf either"*. P10, who identified as hearing but with a hearing disability, and only used the word deaf *"as a description"*, had a family history of hearing loss. He said having his father as a role model allowed him to save *"false steps and (gave him) the ability to tackle the problem head on".* He always felt comfortable with a hearing aid and quipped *"my daughter thought…every man, in my family wore a hearing aid. She thought that was normal".*

Other participants discussed how knowing someone who had a hearing loss *"would have made it easier"* [P6], because *"there's a lot of trial and error figuring things out"* [P2]. P11 claimed it would "*have helped me deal with (my hearing loss) faster and better".*

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[12] USA spelling used whenever a participant lives in the USA

Negative Role Models Undermine Identity

Some participants had role models who undermined their confidence and identity. Two participants were influenced by their mothers' less than positive attitudes towards deafness. P12 said *"I was very aware of how much (my mum) hated hearing aids. It was a source of…embarrassment and frustration (and) daily stress…in the family"*. P12 resisted *"getting hearing aids"* because of her mother's influence. P5 admitted being influenced by her mother's attitude. *"I knew my mom was hard-of-hearing. She didn't have a positive attitude. I did not want to be like my mom"*. P5 continued, saying deafness changed her, but claimed she maintained her identity although losing confidence. P7 had a family member who was even less supportive. When she suddenly lost her residual hearing her (now ex) husband did not believe her and *"accused me of trying to get out of getting a job"*.

Most participants were not referred for counselling, but since some had a family history of late-deafness, they had role models who influenced their understanding of their changing identity. These findings suggest further research should be conducted in how and when to connect late-deafened adults with appropriate role models.

Disabled Identity

Hearing loss was considered a severe handicap (de Graaf & Bijl, 2002) by most participants which resulted in a diminished sense of self. As described earlier, the majority were educated, career oriented and earning good incomes, which is at variance with common social assumptions of the kinds of people who may be labelled 'disabled', or understood as 'abnormal' or 'inferior' (Goodley, 2014). It is, therefore, not surprising that 25 of those surveyed, while functionally unable to hear, did not consider themselves disabled. Some, who were later interviewed, while not calling themselves disabled, did claim they had a *"hearing disability"* [P3, P10, P12], or said *"I just felt I had a disability"* [P5]. Although physically deaf for many years, P9 paradoxically claimed *"I see myself as hearing challenged, not hearing disabled or having a hearing loss".* In contrast, 19 of the 44 surveyed did say they considered themselves disabled.

Understanding Normal

A key aspiration for many of the participants was being 'normal', similar to those in the Dillon and Pryce (2020) research. Normal hearing people fit within hegemonic understandings of normalcy. They have the freedom to access any space or activity, without considering whether they might mis-hear, misunderstand, be embarrassed, be left out or stigmatised. The same cannot be said for interview participants. P15 wanted to be a *"normal hearing person"*, saying he had to *"pay attention to a lot of things that normal hearing people don't normally pay attention to".* He wanted *"the ability to basically*

just operate in a normal fashion…being able to hold jobs, communicate with people and so forth". P12 *"found it very hard to be normal"*, and P14 wanted a return to *"normalcy"*. P7 did not like his hearing aids *"because everyone wants to be normal"*. At least six survey participants who were not interviewed, wanted *"a normal life"* [S42].

If normal people can hear, then deafness marks late-deafened adults at least as different. Many participants were embarrassed because of their difference and were *"self-conscious about their inability…to hear normal conversation and communicate via speech"* [P14]. A number of participants described their fear of being different in various ways such as being *"panicky"* [P14], *"traumatised"* [P15], *"desperate"* [P12], *"devastated"* [P2], or feeling like they were "*scared…uncertain…nothing… broken"* [P6].

Participants' limitations were not always acknowledged, and hearing people expected them to be normal. P3 said *"many people just could not understand why I was speaking so well yet couldn't hear or understand them"*. A *"pet peeve"* for P13 was *"Oh. You don't speak deaf"* and, others made similar comments, underlining the issue of unintentional audism, saying they were often complimented on how well they spoke because they did not look deaf, a point made by Wilson and Atcherson (2017). P7 had fluctuating hearing and said, *"on 'deaf' days I felt like I was in a glass jar, (however) I always had normal sounding speech…I looked normal…I spoke normally"* and therefore her deafness made her invisible. She said people never even considered she might have a hearing loss, they thought *"maybe this person is a little slow…or I was rude",* a point P9 and P5 both made because they had been considered *"stuck up"*. It is the invisibility of deafness which creates the perception that the person is not normal. These comments emphasise a hearing divide.

The Hearing Divide

As mentioned in Chapter 2, Krentz (2002) described a hearing line as an invisible "imaginary boundary that separates deaf and hearing" (p. 1), revealing "a complicated relationship between physical difference, cultural construction, and identity" (p. 3).

In my study, four issues mentioned by participants flagged a hearing divide. These were (1) the inability to enjoy music through hearing, (2) the inability to participate in language through normal hearing and speech, (3) not hearing on a phone and the impact of this on careers, and (4) the need to wear a hearing aid. Then there is a cochlear implant which may or may not straddle the hearing divide. Discussion around this, is undertaken in Chapter 5.

Loss of Music – Crossing the Hearing Divide

Music enjoyment was eroded through hearing loss. Despite my own musical background, my research did not include questions about music. However, all but one of 16 people interviewed mentioned either loss of music and/or renewed musical experience with a cochlear implant. Two participants told their stories around music performance. P1 said *"I couldn't play in a band anymore"* and P12 told me *"everything about my life was to do with music"*. Personally, when I could no longer hear well enough to perform, I sold my piano, an admission that deafness had defeated me. Notwithstanding the importance of music, a full discussion lies beyond the scope of this study.

Exclusion from the Language of the Hearing Majority

A significant marker of the hearing divide is whether someone struggles "to convey their identities in the language of the hearing majority" (Krentz, 2002, p. 54). Deaf people consider themselves a linguistic minority, using visually oriented sign language, situating them on the Deaf side of the hearing divide. With the ability to speak, late-deafened adults often considered themselves on the hearing side, even though they could not hear, because as argued by Krentz (2002), "a voice indicates which side of the hearing line a person belongs to" (p. 184). If participants considered learning sign language almost all had no-one in their lives who signed, so they felt it served no purpose. P7 explained she did not know anyone who used ASL[13] and *"sign language seemed to be of little value because I can speak for myself"*. However, for a few, long-time deafened, sign language added to empowerment. P2 said *"I think the more I've learned ASL, the more people I've met, the more empowered I've become"*.

Even when participants investigated the Deaf community, they did not feel they fit. *"I'm not totally a 'hearie', but I don't know deaf culture that well"* [P4]. P2 stated *"When…you've been…hearing for all of your life and all of a sudden you're not hearing, you don't just fit into Deaf culture"*. One Australian participant said *"I found the Deaf club strange as I could not communicate, and it seemed split with Deaf and deaf, (those) who were not Deaf enough"* [P11]. Five interview participants were part of the Deaf community, but others did not even know the community existed, as P11 stated, *"I had no knowledge of…Deaf community"*.

There is much to explore about the Deaf community and culture, and sign language (Szarkowski & Brice, 2018), as well as how they deal with audism (Eckert & Rowley, 2013). However, my research investigates the experiences of late-deafened adults who, with a few exceptions, rarely ventured into the Deaf community. This paper cannot provide a comprehensive review of how participants did or did not engage with the Deaf community.

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[13] ASL is an acronym for American Sign Language

Inability to Use the Phone – Unintentional Audism

Most hearing people do not think twice about using a phone and while they may experience some difficulties if making calls in (say) background noise, the issues are not as frequent or intense as they are for those with a hearing loss. However as discussed in the research from Wilson and Atcherson (2017), exclusion from phone use meant participants experienced unintentional audism. More than half interview participants mentioned that while they were deaf, they were not able to use the phone[14]. One survey participant defined deafness around phone use and in so doing highlighted crossing the hearing divide by saying *"when I was hard-of-hearing I could still hear on the phone…deaf is when I could no longer hear on the phone"* [S20].

As reported in other studies (Cherney, 1999; Fish, 2016), many participants tried assistive devices to improve phone use. S6, who was not interviewed, said using a captioned phone[15] tripled her phone bill, and she could not afford to continue the service. P10 modified mobile phones to include a stronger t-coil[16], which he said voided the warranty. Some participants also experienced call anxiety because they might have to ask for repeats, mis-hear or, as S44 feared, give *"mistaken advice"*.

Due to the problems with phone use, at least half of all interview participants, while they were deaf, needed someone to help them make phone calls. P17 stated he had to rely on his secretary and found this embarrassing. It was one reason he took early retirement. P9 paid her young daughter a quarter[17] to make phone appointments for her. P10 and P15 needed their wives to listen to calls, repeating what the caller said, and then they could respond.

Hearing Aid – The Stigmata of Deafness

Wearing a hearing aid signalled difference and marked the late-deafened as crossing that hearing divide. Davis (2018) argued "physical difference becomes synonymous with the identity of the person" (p. 32) and a hearing aid signals a difference, a stigmatic mark. P2 said a hearing aid *"announced my disability"* and seven other survey participants said the aid symbolised their hearing loss, creating stigma. Of the 34 participants who wore hearing aids most of the time, 26 often felt embarrassed by them. About half, or 21 participants, said they experienced stigma because of their deafness, although they did not elaborate, seven said it was, in part because of their hearing aid. Of the 16 interviewed when answering the survey questions, none felt their hearing aid caused them stigma, although nine felt their hearing loss did.

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[14] Phone use is hearing on any phone, without text or visual displays, particularly those most often used in the workplace.
[15] A captioned phone displays voice content as text on an inbuilt screen, sometimes may use a third party captioning service.
[16] T-coil (telecoil) is an adapter built into a phone handset and the sound from the caller is inductively coupled with the coil in the hearing device which can make understanding speech clearer.
[17] Quarter = USD$0.25

Six participants in the survey said they tried to hide their hearing aid, with three regarding the device as ugly or cumbersome, a view reported by participants in other research (David et al., 2018; Wallhagen, 2009). Commensurate with a number of studies, such as that by Heffernan et al. (2016), others reported a social norm that hearing aids were often associated with the stigma of age saying *"I was too young for a hearing aid"* [P2] or it *"made me look old"* [S3]. As hearing loss progressed, interview participants reported they stopped wearing their hearing aids because *"they weren't helping"* [P2]. Increased amplification did not lead to increased understanding, as P1 said, *"they made everything loud, but I still couldn't understand speech"*.

Chapter 5.
Understanding Participants' Cochlear Implant Experiences:
Biologically Deaf, Technologically Hearing[18] – An Unknown Challenge to Identity

For most late-deafened adults hearing loss is considered a negative attribute, one which reduces quality of life, removing them from experiences previously accepted as normal. Among respondents in this study, decreased life satisfaction was a major motivator driving the implant decision. However, little is known about how a cochlear implant impacts upon identity (Sealy, 2015), and how late-deafened adults reimagine themselves because of their altered, technological state. Comments from participants indicate their identity did change with P4 stating her *"cochlear implant really gave me my life back. I felt alive again"* and P5 claiming "*I feel much more like myself…it's not work to be me anymore".*

In this chapter, I first explore central issues surrounding the enabling/disabling aspects of technology to contextualise the decision for, and outcomes of, a cochlear implant. I continue, identifying key concerns and expectations around making the decision, the role of mentors, what issues impacted their lives and how they identify after the implant. This chapter addresses the research questions:

3. What are the key challenges to identity for late-deafened adults when making a decision to have a cochlear implant?

4. After receiving a cochlear implant how do late-deafened adults reconceptualise their identity and what is the impact of this on their lives?

5. How do late-deafened adults perceive the responses of cochlear implant professionals to these issues?

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[18] I use biologically deaf, technologically hearing because this is what my husband calls me

Table 6:

Diagram showing how the Discussion under each Heading in this Chapter 5 Links to the Major Themes. This table is based on Chapter 3, Figure 7: Diagram Showing Relationships Between Major Themes & the Link to Identity. While all subheadings link to identity they are a separate concept generated from the analysis.

Major Themes	Heading/Subheading in thesis
Cochlear implants	Ch 5: <u>Understanding Participants' Cochlear implant experiences</u> • Technology a Signifier of Disability • The Implant Decision: The Transition Phase • Career Identity through a Cochlear Implant
Implant Processor	Ch 5: <u>Biologically Deaf, Technologically Hearing</u> • Processor as a Marker of Stigma
Support Peer/family/ Professional	Ch 5: <u>Cochlear Implant Role Models & Mentors</u> • Future Role Models & Mentors
The Hearing Divide • Recovering autonomy • CI Phone Use	Ch 5: <u>Crossing the Hearing Divide</u> • Recovery: Regaining Hearing, Unlearning Negative Experiences & Autonomy & Identity • Re-enabling – Life Changing Technology - Regaining Access to Phone use
Identity	Ch 5: <u>Technologically Changed: A New Identity</u> • Identifying as deaf after Implant • Identifying as Disabled after Implant

Technology – a Signifier of Disability

As discussed in the literature review, disability has been defined in a range of ways: as physical limitation; as a product of social and economic barriers; producer of social stigma or a combination of all. Many participants in this research noted the social and economic barriers posed by losing hearing later in life although the language of audism was not used, however, these insights have some connection to equality rather than physical differences. Participants sought to remedy the social isolation associated with hearing loss in an audist world by seeking peer support online. Rather than seeking political changes to understandings of 'normal' as the social model would propose or shifts in mainstream practices and prejudices to make participation in the hearing world easier for late-deafened people, most participants viewed the experience of falling outside the social norm of the hearing world as best remedied through individual medical interventions. Participants noticed the way amplification technologies like hearing aids served to mark them out as different. As Goodley (2014) points out, enabling or prosthetic technologies are most commonly understood as a marker associated with impairment, embodied difference and "often a negative, marked and stigmatised social position" (p. xi). Participants did not always accept this negative connotation, particularly of cochlear implants. A number advocated for change by spreading awareness of hearing loss and cochlear implant issues through *"presentations (in the) community"* [P6, P9] and *"local schools"* [P9]. Some lobbied for changing norms

such as *"captions in movies, signage at airports, train and bus stations and on buses (and) for hospitals to become hearing loss friendly (by providing) captioned telephones"* [P3]. Fitting within the 'minority model' of disability, a social philosophical approach to disability connecting it with well-being (Gosse, 2017), some participants advocated for educational and political change by *"talking to audiologists"* [P1] about cochlear implant referrals and benefits. Another *"spoke to insurance companies for approval to upgrade (implant processors)"* [P7]. While the social model of disability emerges from activism, nonetheless, amplification technologies continued to play a role in marking out participants' identities.

Wise (2012), would agree with Goodley (2014) saying "technology influences the definition of disability". However, while not everyone would agree, he points towards the way that technologies have been seen as individually curative and might be associated with an understanding of deafness as deficit, since they are "attempt(ing) to address some deficiency in…the human condition" (p. 169). From the perspective of a cochlear implant recipient, technology promises a degree of normal (Moser, 2006), enabling those with hearing loss to be more hearing-like, returning the ability to participate with the hearing majority.

A cochlear implant is a surgical prosthesis (Tan et al., 2013) to aid hearing. As P2, P4 and P9 claimed, *"a tool"*, which allows them to function independently in ways they could not with a hearing loss. There is little research into how disability and identity is signified and redefined when a person has a cochlear implant. Therefore, the acceptance and social meanings around prosthetics, after (say) limb amputation, may shed some light. In research by Murray (2005), it was found that having a prosthetic limb played "a social role in the lives of persons with a limb loss" (p. 425). Concealing the prosthesis allowed "participants to ward off social stigmatisation that in turn enabled their social integration and the reduction of emotional problems surrounding such disability" (p. 425). Hiding the prosthesis allowed the amputee to be seen as more 'normal', and this "helped to maintain identity as a competent adult" (p. 431). From the perspective of the participants in my research, a cochlear implant is enabling, allowing better assimilation into the hearing world, however unlike those in the Murray (2005) research, and discussed later, many implant recipients are proud of their prosthesis and seek to display it.

Cochlear implant technology has the ability to transform lives. However, this technology, when viewed as a medical model of disability, while resolving functionality and returning the recipient to a degree of hearing 'normal', can also signal disability. The large and visible implant processor can be associated with the stigma of a hearing aid (Wallhagen, 2009, p. 67). Furthermore, technological hearing is not perfect, and a remnant of impairment is present through some functional limitation. This may result in discrimination and stigmatisation through lack of access in public or social situations and, in particular, work opportunities, moving the understanding of disability from the individual to the social model of disability.

The Implant Decision: The Transition Phase

The decision to receive an implant and the process of undergoing implantation was a transition phase for most participants in this research, a time of personal instability, while venturing into something unknown with uncertain outcomes. P14 explained *"I didn't know enough about the cochlear implant to know what it was even going to be like",* and P15 *"went into it with low expectations".*

A number of participants felt hearing loss professionals were reluctant to refer them for a cochlear implant. P17's physician did not think he needed implants and *"without his referral, I felt no need to further consider them".* Participants received confusing messages such as *"I can't promise that you're going to hear again...there's a possibility"* [P6], or *"a lot of people can hear with it, but there's no guarantee"* [P14]. P3 was devastated when told she would never hear again, and was ineligible *"because I lipread too well, spoke too well and was well adjusted to being deaf".*

While participants did not explicitly describe the decision to have an implant in terms related to identity, in a recent case study by Adler (2018) the implication of identity in making the decision was apparent. In this study Adler (2018) explained Sam became comfortable in herself and this "identity transformation was what ultimately led her to pursue the physical change of receiving a cochlear implant" (p. 805). This case study reflects comments made by participants which imply their decision was also centred around identity.

Comments from a survey participant, who was deaf for longer than 10 years, point towards the decision to have an implant as delineating between hearing and deaf identities. Accepting his deaf identity freed him to choose to have an implant.

> *In my view...prior to cochlear implantation I did not really consider myself 'deaf' by definition (i.e. not able to hear any sounds through my ears), but in reality I was deaf, and needed to accept this. It was accepting this that helped me decide to become implanted* [S44]*.*

P12 had confidence that with an implant she would understand speech but if it compromised music she claimed, *"I just wouldn't know who I was anymore".* While waiting for surgery, she *"basically grieved the whole next six months"* at the thought of losing music. P12's comment is in line with previous studies which reported "not being mentally ready for a cochlear implant was (a) barrier" (Bierbaum et al., 2019, p. 5) in deciding to have an implant.

There is no doubt all 38 participants wanted to hear, however for some, having an implant seemed like a last resort. *"I really didn't have a choice"* said P15 who expressed some doubts because of a misunderstanding of the technology. He had seen children with implants *"wired up...they had that thing drilled into their head...(and I was so glad) I don't wear something...drilled through the head".* However,

since he wanted to hear, his *"only solution was a cochlear implant".* P14 claimed *"I didn't think I had...other options"* and losing residual hearing was a major consideration.

Sacrificing residual hearing meant changing identity permanently, trading the last small amount of natural hearing for unknown electronic hearing. This was reported as a major barrier in the implant decision by Bierbaum et al. (2019) and Ebrahimi-Madiseh et al. (2020). P4, who identified as an *"in-betweener"* neither deaf nor hearing, had been hanging *"onto a tiny hope my hearing could be restored".* P14 said losing his residual hearing was *"holding me back"* because he would be completely deaf *"without my processors on",* and that idea *"took a little getting used to".* P2 was concerned about safety issues around having no residual hearing saying, *"I'm not going to hear something happen at night or not going to hear when (the children) are in trouble".* As reported by Ebrahimi-Madiseh et al. (2020) having a mentor at this stage in the process can help navigate the emotional and experiential aspects of having an implant.

Crossing the Hearing Divide

Although recipients were enabled to hear with a cochlear implant, they needed to go through a recovery process. As mentioned in the previous chapter, there is an argument that having a cochlear implant both returns the recipient to the hearing side of the divide while wearing the processor, and at the same time, actually firmly places them on the deaf side. Without the processor they hear nothing which aligns their understanding of disability around the social meanings of amplification technologies. This dichotomy creates a conundrum because as Kobosko et al. (2015) argued, they experience another hearing crisis not knowing whether they are now "deaf, hearing or half-deaf" (p. 606). Being deaf after implantation is discussed later in this chapter, but first a discussion on some key issues around regaining hearing.

Recovery: Regaining Hearing, Unlearning Negative Experiences & Changing Identity

Recovery involves a change in feelings, attitudes and values to develop a new, emerging personal identity (Fish, 2016). Through participant interviews, hearing recovery was found to be an active process with two major aspects: (1) regaining the ability to hear and understand, and (2) recovering from the impacts of the experiences of hearing loss, including how this may have impacted on identity.

Having a cochlear implant is a life-long commitment to technology and relearning to hear. One respondent commented, *"you have to learn how to communicate all over again"* [P13]. As Murray (2005) explains, although referring to people who had limb amputations, "becoming comfortable with, and accepting an altered body can often be a prolonged process, spanning months or years" (p. 428). As P9 mentioned, *"I knew I would have a long road...but I was more than willing to work at learning to*

hear" and as P3 explained *"it takes time for the brain to recognise and accept the new (stimulation) as sound".* S6 simply stated, *"it is challenging learning to hear again".* Ingrained habits had to be overcome and P3 said *"the biggest challenge I now have is looking at people's eyes instead of lips – no easy feat after years of lipreading".* This was similar to my own experience. I had to consciously change my focus; listening with my ears and not with my eyes. Negative experiences in particular environments needed to be reassessed, like the *"nagging sense of dread"* P1 and P5 had felt in being in social situations before their implant.

For some participants, regaining hearing was particularly difficult. P3 said she *"wanted to hear no matter how"* and underwent eight implant surgeries over 20 years to *"become successful in hearing with…two implants".* As P3 experienced, to maintain hearing may require further surgery, and to continue to maximise or improve hearing, the implant requires regular software/hearing level adjustments, and processors need upgrading and/or re-programming. P3 explained in 2014 she upgraded to the *"latest sound processor…and (found) it challenging hearing with this new powerful technology".* In 2018 and 2021 she upgraded to even later technologies. Besides P3, five other interview participants talked about upgrading their processors, and I personally have had five processor upgrades[19], numerous software updates and hearing level adjustments.

Regaining hearing begins when the implant is activated (switch-on[20]). Understanding may not occur instantly, and for many, it involves effort which impacts on the way they feel about themselves. P9 said *"there are life challenges with having cochlear implants just given the fact they don't provide perfect hearing".* Mauldin (2014) points out a cochlear implant is a conduit to the brain and the success of the implant is based on an "individual's ability to train his or her brain" (p. 130). P1 was told, when discussing implant brands, that hearing success is 10% technology (the brand) and *"90% your brain".* P14 also acknowledged the sensory experience is not really hearing because *"you don't hear with your ears…you hear with your brain".* As Mauldin (2014) argues, through technology the definition of deafness changes from one of sensory deprivation "to a neurological (processing) problem" shifting the "responsibility from the device to the individual" (p. 130).

Usually at switch-on, sound is not yet normal and involves a transitioning to hearing which causes emotional confusion. P3 commented *"people often do not realise that the sound we hear after being switched-on is not normal…(the sound) hearing people hear".* As P1 said it was *"really, really strange and robotic".* P14 said *"voices sounded strange…cartoonish"*, with P9 saying *"sound had an underwater quality".* However, almost all reported sound became normal, the way they remembered it, quite

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[19] In Australia, processor upgrades are covered under private hospital cover/prosthesis
[20] Switch-on is when a cochlear implant is activated, and new hearing commences

quickly. *"It took less than a week for sound and voices to…normalize"* [P9]. For others *"it took many weeks to recognise sounds for what they were"* [P11], and P14 said *"voices sounded strange…but after months of rehab, things improved".*

For some, just living life was the only rehabilitation they needed. Kobosko et al. (2018) reported, rehabilitation which addresses the psychological aspects of cochlear implantation is not readily available. Participants did not receive referrals for rehabilitation or support and needed to embrace a personal positive and pro-active approach to learning to rehear. P5 said rehabilitation *"is not how it's done in my (clinic)".* P1 stated "*there was no mention of any rehabilitation…they did nothing. I just did it on my own*". He pointed to his music equipment and said, *"my best rehab tools are right here",* although he mentioned using *"some apps on my phone and stuff".* P7 had a few lessons and P11 said two of the major brands now have rehab sessions or self-paced apps for use on smart devices. In my experience I found the more I played the piano, the greater the improvement in my speech perception, and this was an outcome also highlighted by Goldsworthy (2020). More research is needed to investigate aspects of rehabilitation.

Autonomy & Identity

An essential step in the recovery process is gaining independence and autonomy. In the cochlear implant context, increased hearing efficacy creates autonomy through better integration with the hearing majority. This resulted in greater independence and understanding of self. When answering a multiple-choice question in the survey, of the 38 participants, 35 said they were more satisfied with life, 32 were more positive and 31 had improved self-esteem. Thirty-six claimed they could now participate socially, and 22 said they were less reliant on others. Interview participants commented on regaining independence. P17 said she *"functions independently…(her) implants have been nothing short of a miracle!"* P5 linked independence to regaining identity saying "*I feel much more like myself"* because she can advocate for herself. Increased autonomy led to greater self-esteem and a positive outlook on life as P3 said, *"I no longer have to feel really challenged by deafness"*.

Re-enabling – Life Changing Technology

The importance of technological intervention, as found in the review of the existing literature (Dillon & Pryce, 2020; Saeedi et al., 2021), participants in this study suggested access to this technology dramatically changes life. Most participants compared their deafness-self to their cochlear implanted-self by commenting on what, and how, they could hear after implantation. There are too many comments to include but P1 is an example. *"I heard the first bass that I ever heard…I could locate sound…I can hear the chickens across the yard…the traffic on the highway…planes flying…above me…bugs over in the woods. It was the biggest difference in hearing"* [P1]. P1 continued saying his

cochlear implants had changed his attitude to life because they *"are a life changing event for me".* P6 described the differences by reporting word hearing tests saying she scored 100% in one ear and 98% in the other. She exclaimed *"I understand people",* whereas before she had struggled with expensive *"hearing aids that did not work".* She continued "*I feel like life began at age 50 when I received my first cochlear"* [P6]. P11 said *"getting a cochlear implant was like being reborn in a sense. I am now part of the world and have friends and can go places and be understood. I am no longer a lonely, isolated angry old man".*

Regaining Access to Phone Use

As discussed in the previous chapter, the inability to hear on a phone was one demarcation of the hearing line. Fourteen of the 16 people interviewed reported one of the enabling experiences was using a phone, which signalled regained access to hearing, resulting in increased self-sufficiency. One survey participant explained, *"I did not use a telephone for several years. After being implanted I have become much more independent (and) use a telephone without problem"* [S5]. As P7 declared, she was no longer *"eliminated from activities that require (phone) use"* and P10 claimed, I *"no longer rely on other people to make or take phone calls".* There were some participants who still preferred not to use the phone. P13, who after his implant considered himself as still *"somewhat disabled",* as *"hearing impaired"* and *"hard-of-hearing"* but part of *"hearing culture",* said *"I absolutely detest talking on the phone".* P7 identified the same way as P13, except she did not consider herself disabled, still said *"I don't enjoy using the phone".*

Career Identity Through a Cochlear Implant

Some participants had, after losing their hearing, experienced difficulties which threatened their career identity. In a study by Clinkard et al. (2015), it was found that having a cochlear implant resulted in a significant increase in employment and income. This was in line with survey answers showing 85% of those who had experienced difficulties were able to maintain or improve their careers after their implant. Comments include, *"Cochlear implants gave me access to work opportunities that I would not have had otherwise"* [S20]. *"I went back to work in a totally different field and have a better job than I ever had in my previous life"* [S33].

Interview participants' remarks underscore these findings. P6 stated her cochlear implant *"changed my life because I went from unemployed to employed".* When P4 became deaf she *"lost her job as a proposal engineer"*, but has *"bounced back. I received more responsibilities…and performed way better…because I could communicate better".* While the implant returned the ability for most to continue work, there were still some situations in which they struggled. P2 said the implants are *"helpful in certain situations"* but, as an example, found Zoom sessions without captions and, particularly break-

out rooms, difficult to understand. As indicated from participants' comments, after having a cochlear implant there are many experiences and emotional situations which forced most to re-think their identity.

Technologically Changed: A New Identity

Participants experienced their identity in different ways after their implant (Figure 10). Eleven interview participants said that before their implant they never lost their hearing identity despite their hearing loss. For them, a cochlear implant allowed them to maintain their hearing identity. P15 was deaf for only a few months and claimed, *"I was a hearing person and even now I identify as a hearing person not as someone with a cochlear implant"*. Others felt they returned to their hearing identity with P14 saying *"I identify myself as hearing again"*. P6 said *"I'm deaf when I want to be and hearing when I want to be"*.

Figure 10:

Survey Participants were Asked how they Identified after their CI.

Participants could say yes to any, or all, of the options. Some returned to or maintained their hearing identity. Others identified as disabled, neither deaf nor hearing and did not know how they identified.

Figure 10 shows the number of participants answering each of the options. Examples for interpreting the data:

1. Sixteen participants were part of hearing culture, which means 22 participants did not identify as part of hearing culture after their CI.

2. Seven participants identified as somewhat disabled therefore 31 participants did not identify as disabled after their CI.

During interviews, some participants described their identity in somewhat contradictory ways. P16 had been hearing but no longer knew who she was as she went deaf and offered a variety of explanations of her identity. She became part of Deaf community, and her position embraces a Deaf pride perspective, although claiming I *"stand out a little bit, but I am a member…and understand their culture".* However, unlike most people in this community, although she did not explain why, P16 thought of herself as *"disabled"*. After her implant her identity was mixed saying she was part of *"Deaf and hearing cultures"*, a *"cyborg[21]"*, *"hard-of-hearing"* but not *"hearing impaired"* or *"disabled"*. When asked did she consider herself a hearing person after her implant she said, *"No. I consider myself a Deaf person with technology".* P1 always had a hearing identity, although deafness changed him, but he never considered himself *"disabled"*. After his implant he still does not consider himself disabled but a *"cyborg"* and part of *"hearing culture".* P12 had a hearing identity as a musician. She had to change her career and no longer knew who she was because deafness changed her, but claimed she was *"not disabled"*. After her implant she still *"does not know how I identify"* although she is part of "*hearing culture",* is *"hearing impaired", "hard-of-hearing"* and now considers herself *"disabled"*.

In addition to no change in, or maintaining, a hearing identity, there were two significant findings around changes to identity after cochlear implantation. The first, was a number of participants identified as deaf even though they could now hear, and the second, was some identified as disabled even though they had not done so prior to implantation when they were less able to hear. It was hard to distinguish why some participants used the term disabled and others preferred to distance themselves from this label, but it may be because of the stigmatised nature of a disabled identity.

Biologically Deaf, Technologically Hearing

When participants had a cochlear implant they were once again forced to take on a hitherto unknown identity, one which relies upon technology to connect them to the world.

Identifying As Deaf

Around half of those interviewed identified as deaf (not hearing) after their cochlear implant. This is enigmatic because they had a hearing identity prior to implantation although they could not hear, and now after implantation they claim a deaf identity although they can hear. This finding is commensurate with Sam who had identified as "a hearing person who could not hear" and after her implant she understood herself as "a deaf person who could hear" (Adler, 2018, p. 803).

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[21] A cybernetic organism

The implant procedure was a major, single point of change and perhaps this is the point which allows many to acknowledge a deaf identity (although not a culturally Deaf identity). For some, this caused confusion. P17, who did not identify herself as *"deaf",* but as *"hearing-impaired"* when she could not hear, said *"I still question what the best identifier is for one in my hearing/deaf situation. Since being implanted, I now refer to myself as deaf, although I'm still not totally comfortable with that"*. So it would seem that even though participants can now hear, at least some do not necessarily embrace a hearing identity.

As discussed earlier in this chapter, without residual hearing participants can hear no sound when they remove their processors. However, most said they wear their processors from *"when I get up and (it) comes off when I go to bed"* [P11]. P14 identified as *"hearing impaired"* not part of "*hearing culture"* but said *"I don't really identify as deaf because I've always got these (processors) on, so I never really think of it much as an identity".* P7 said *"I identify myself as hearing (but with some limitations) and when (my processor is) off, I am deaf".* P12 acknowledged the same idea.

> *I'm still confused about my identity because when (my processors) are off, which is only in very private situations like going to sleep at night, then I don't hear, but that's only something that I and my husband appreciate because nobody else is exposed to that* [P12]*.*

P12 continued, saying that in social situations she is a hearing person although sometimes she may not hear, or may mis-hear, because her implant does not give her perfect hearing.

So why do some participants now identify as deaf? Is this because the solution returns hearing and therefore implant recipients make fewer awkward responses (as they may have before their implant), therefore being less likely to receive the social stigma associated with the label of deafness? While I offer some possible reasons in the following sections, there is room for more research to understand why some implant recipients identify as deaf after their implant when they did not before.

Processor as a Marker of Stigma

In order to hear, recipients need to wear the large, often visible cochlear implant processor, but this seems to be an acceptable signifier of deafness, when compared to a hearing aid, an often rejected technology (David et al., 2018; Domagała-Zyśk, 2019). Some interview participants discussed a disability or stigma surrounding a hearing aid, but none actually made similar comments about the implant processor. P12 had feared her internalised stigma of a hearing aid would carry over into wearing the large cochlear implant processor, but after regaining her hearing with the implant said *"I've become less precious about (people seeing) it. Oh, who cares really!"* The majority of the 38 answering survey questions did not feel stigmatised by others, however, six said they did, with five sometimes trying to hide their processor. In contrast, some participants proudly wore bright coloured processors or decorated them. Figure 11 shows P4 proudly displaying her *"bling"*. *"I wear it like a badge of honor"* [P7], and P6 quipped *"If they came out with big green antennas...I would wear them!"* P13 said *"If you've got it flaunt it"*.

Figure 11:

P4 sent a photo displaying her blinged-up processor Indicating she feels proud of her implant

Another enigma in identity after a cochlear implant, is a number of participants considered themselves disabled, where before they had not.

Identifying as Disabled after Implant

No specific questions probed participants' understanding of disability – whether they thought about it as decreased functionality, a consequence of social or economic barriers to equality including social stigma, as an identity or as some combination. It is possible that participants described themselves as disabled because none reported any residual hearing after implantation, meaning they were completely unable to hear whenever they were not wearing their processor. Goodley (2014) suggests "disability might be understood as an identity position" (p. xi), and another marker could be if those with cochlear implants need to access financial support, they have to accept the label of 'disabled' in official documentation. Most participants in this research lived in the USA and under USA law a cochlear implant recipient is considered disabled for one year after implantation[22] (Keefe & Hartwig, 2022). Treloar (2021) comments on a similar identity position in Australia. When d/Deaf people interact with the National Insurance

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[22] After which status of disability is assessed based on word recognition scores

Disability Scheme (NDIS) she notes applicants must adopt a disability label and "accept their wider community's framing of their…disability" (p. 4) so they can receive financial support.

Before their cochlear implant, 19 or 43% of those surveyed considered themselves disabled, and 13 or 34% still did after their implant. Conversely, before implantation 25 said they were not disabled but after implantation six of these same people now considered themselves disabled. When examining answers from these six participants, all said their cochlear implant had changed them and they had received the outcome they hoped for. Although, all six said their speech had improved, they still made some mistakes through mis-hearing, still needed to use lip reading, and three said they still bluffed or faked occasionally. With these answers it would appear they no longer felt a great degree of functional disability indicating they understood disability as separate from functionality.

Two possible explanations of disability, although this may not necessarily be seen as negative, are perhaps others treated or stigmatised these participants, and/or their cochlear implant became a marker of disability. Yet there was a consensus that the ability to communicate and socialise had improved and that their implant was a great help in their every-day life. All said they felt better about themselves, none felt any discrimination, and only one felt some slight stigma. Five of these six participants were women, and this might indicate an element of intersectionality (Bowleg, 2012), a theoretical framework which could be used to examine the intersection of gender and hearing loss. All five females reported trying to hide their cochlear implant and this could indicate they felt the processor was a marker of disability. This was certainly true, at least at first, for P12, who identified as disabled after her implant saying, *"I used to be very particular about looking in the mirror and making sure that nothing could be seen".* The intersection between gender, hearing loss and cochlear implantation was not explored in this research and is an area for future investigation.

For some, disability may be a positive attribute and many participants mentioned that when others noticed their processor it gave them a chance to advocate. For instance P9, who liked to add *"zing"* to her processor, said *"Yes, it draws attention to my processors…but it also leads to people asking questions about what I have on my ears".* P10 said *"when people ask me about them...I tell them how I hear and what it does for me".* P13 revelled in the chance to connect when people notice his processor. He said, *"I was at a hockey game and a little kid came up to me and said look, I have one too. So, it's also a conversation starter".*

Further understanding of the positive/negative connotations of technology in the discussion of disability in the context of a cochlear implant presents an opportunity for future research.

Cochlear Implant Role Models & Mentors

It became apparent from interviews that participants' support needs in the cochlear implant process were different than through the progression of hearing loss. P15 said, *"I wanted to know…what people experienced".* Shared experiences generally inspired hope for the benefits of a cochlear implant. P9, after talking to implant recipients at a conference, said *"even before getting evaluated at a cochlear implant centre, that meeting gave us HOPE"* that she might finally hear.

There were at least three participants who had family members with implants. P5's mother had an implant and encouraged her two late-deafened children to have one. P10 said his daughter, who always identified as hearing, had an implant, and the difference this made for her encouraged him to have one. One survey participant told he *"came from a family…where up to 16 of my…relations have at least one cochlear implant"* [S44]. This participant did not respond to an interview request so it is not known whether he drew on family members to understand himself through the cochlear implant experience. However, S44 became involved with CICADA and says he *"remains passionate in being an advocate for cochlear implantation",* which indicates a recognition of the need for mentors throughout this process.

Support was also needed to cope with the uncertainty and expectations of outcomes. P11 found help saying, *"Initially I was sent along to a CICADA meeting where you can talk with recipients about whatever you want and get to see the varying results people get. That was excellent and dispelled a lot of concerns".* P9 had a group of mentors, *"CI sisters"* she called them, who guided, supported, encouraged, and *"rejoiced with her in her new sound filled world".* A number of participants did not have the opportunity to meet anyone with related experiences and yearned for that support. P1, for example, said he *"went into the cochlear implant…pretty much blind…I would have loved to talk to somebody that had been through the process".*

Future Role Models & Mentors

A significant finding from the research is that at least 12 of the 16 interview participants have become mentors for potential cochlear implant recipients. While no participants specifically linked their advocacy with their identity some alluded to this. P3 said *"I have achieved more within the community (and) it is easier to be part of the community now that I have a CI, preferring the hearing community".* P12 indicated her mentor role was linked to her musician identity by saying, *"I participate actively in Cochlear research focused on technological developments for music perception and appreciation for recipients…Not only am I enjoying performing music as much as previously, but I believe I am a better musician due to my CIs"* [P12].

A common reason for becoming an advocate is they wanted to demonstrate the amazing change an implant made in their life and *"pay it forward"* [P15]. P1 wanted to *"give back a little",* and agreed to share his experience when his audiologist asked him to meet people. P3 provides counselling and said it was *"very rewarding seeing a person come out from a world of silence back into the world of sound".*

While interview participants may not be representative of all implant recipients, the large number who volunteered to become role models or mentors, indicates the value they placed on peer interaction around implantation.

Summary

Technology has the ability to produce widely varied outcomes (Wise, 2012) and while this study was not large enough to represent all cochlear implant recipients, almost everyone (86%) experienced an improved quality of life. Having a cochlear implant meant a life-long reliance on technology, one which could not be reversed and was a major decision, influenced by mentors and professionals. For some their implant reinforced or returned them to their hearing identity. However, some now identified as deaf and still others identified as disabled.

Participants' comments are in line with many other research studies and highlight the impacts of late-deafness on all aspects of their lives and how these experiences challenged their understanding of self. Their definitions of deafness linked to how they identified themselves, and those who had positive role models appeared to maintain a positive identity better than those who had to work it out for themselves. Understanding when and how to connect late-deafened adults to role models provides an opportunity for future research. Participants commented on issues which excluded them from the hearing world such as music appreciation, social communication, phone use and the need to wear a hearing aid.

Manchaiah et al. (2015) looked into positive experiences associated with acquired hearing loss, such as developing a greater empathy towards those who were differently abled. Two participants in the current research pointed to some positives such as meeting Deaf people *"showed me it was very possible to have great quality of life as a Deaf person"* [P9], or *"I learned how to advocate for myself"* [P4] and P16 made friends within the Deaf community. However, for all interview participants in the current research, the negatives of acquired deafness were frequently mentioned. All participants talked about their emotional response (*"feeling helpless"* [P2]), the socialisation difficulties (*"I couldn't always participate"* [P5]), often resulting in withdrawal *"isolating me away from people"* [all participants]. *"It was a daily challenge"* [P7] with communication issues such as *"missing things"* [P1, P3, P6, P16], and

the *"fear of being embarrassed by saying something inappropriate"* [P17]. All sought ways to regain hearing.

The impact of deafness on their quality of life became a trigger for exploring a cochlear implant, and this is discussed in Chapter 5. A discussion of the principal issues and research opportunities are covered in Chapter 6.

Chapter 6.
Discussion, Contribution & Future Research

There were three main purposes for my research.

(1) An in-depth understanding of the late-deafened adults' experiences through the progression of hearing loss and how this impacted on their identity.

(2) How receiving a cochlear implant created a new hearing status which impacted on, or changed identity for these late-deafened adults.

(3) The interaction participants had with hearing healthcare professionals and how this supported or undermined their experiences.

The majority of adults are hearing, and therefore late-deafness is a minority experience (Bedoin, 2019). These adults are "estranged from the hearing world…and are excluded from the traditional Deaf community" therefore "their deafness carries no cultural identity" (2014). A divide exists between experiences within Deaf culture and the late-deafened adult (Beckner & Helme, 2018) consequently, these people often feel between worlds (Barlow et al., 2007) struggling with the contradiction of a hearing identity while living with hearing loss. Chapters 4 and 5 highlight some of the inconsistencies in the way participants understood or described their identity both during the hearing loss experience and after cochlear implantation.

There were three Important findings in my research. The first was that positive, supportive role models during the progression of hearing loss helped these adults maintain their identity better than those who had no role models. A number of participants reported support was not provided or suggested by hearing healthcare providers. As Bennett, Barr, et al. (2021) reported "Research has elucidated infrequent provision of psychosocial support in the audiology setting" (p. S17). Some had supportive families but stated these family members could not really understand their experience and did not really know how to help. Due to this perceived lack of role models and mentors most participants in this research turned to social media for support and understanding both during their hearing loss and implantation. During the cochlear implant decision there was a need for mentors to share their personal experience. Current research supports the need for mentors (Ebrahimi-Madiseh et al., 2020) and a number of CI clinics, at least within Australia, provide a mentorship program. However, particularly for the participants in this research, there was no clear understanding of how to access these mentors because hearing health providers did not generally provide a connection with other cochlear implant recipients.

The second was some participants identified as hearing when they could not hear and deaf after receiving an implant even though now they could hear.

The third was some implant recipients identified as disabled after their implant, when they had not done so during their hearing loss.

Role Models & Mentors

Questions of identity are not the focus of hearing healthcare providers who generally concentrate on treating the symptoms of hearing loss. While there is recognition of the need for treatment of the emotional reactions to hearing loss (Bennett, Saulsman, et al., 2021), and a trend among around 50% of audiologists in Australia to treat psychological issues, as Bennett et al. (2020) argue, most of these professionals need more training to cover psychological and psychosocial concerns. While not focussing on identity research by Bennett, Barr, et al. (2021), found "Adults with hearing loss and audiologists recognise the importance of approaches that address the psychosocial impacts of hearing loss in audiological rehabilitation. However, both groups placed slightly greater value on the internal-based approaches (the clients own emotional response, empowerment, and responsibility), and slightly less emphasis on the external-based approaches (being supported by communication partners, support groups or other health professionals)" (p. S12). This recent research shows healthcare professionals are addressing some of the shortfall in audiology settings for counselling and rehabilitation.

Most participants had a negative perception of hearing healthcare providers during hearing loss. However, in contrast, participants had an entirely different attitude towards those professionals who helped them through cochlear implantation. No participant specifically explained the difference in their attitude to professionals and more research is needed to understand this.

The findings of my study suggest that having role models who were positive and pro-active about deafness, helped late-deafened adults cope with the impacts of their hearing loss while maintaining a positive sense of self. Academic literature, while suggesting the importance of connection and "the importance of community" (Dunn & Burcaw, 2013, p. 149) for people with disabilities (Fish, 2016; Sweet et al., 2020), was mostly silent on role models for those who do not identify with Deaf culture. However, unlike Deaf culture, which recognises the influence and importance of role models and mentors for a healthy identity (Cawthon et al., 2016; Sealy, 2015) late-deafened adults generally do not know anyone else who has acquired a hearing loss. Therefore, late-deafened adults do not have contacts or a community where they share common experiences. Furthermore, there is a difficulty in knowing how and when, the late-deafened should access support. As mentioned in the research by Dunn and Burcaw (2013), for those who acquired a disability it took time to acknowledge it. At what point in the progression of hearing loss, when these adults are struggling to maintain a positive sense of self, do they acknowledge they are deaf or have a disability, and need support? Participants in my research felt healthcare professionals lacked knowledge and understanding of their needs. This was in-line with

literature which acknowledged professionals were not providing support for real-life situations (Ferndale et al., 2016) for the psychological and sociological experiences encountered through late-deafness (Aguayo & Coady, 2001; Barlow et al., 2007; Fish, 2016; Rothschild & Kampfe, 1997). Recent research by Bennett, Barr, et al. (2021) while not focussing on identity, found

> Adults with hearing loss and audiologists recognise the importance of approaches that address the psychosocial impacts of hearing loss in audiological rehabilitation. However, both groups placed slightly greater value on the internal-based approaches (the clients own emotional response, empowerment, and responsibility), and slightly less emphasis on the external-based approaches (being supported by communication partners, support groups or other health professionals)" (p. S12).

Future research should investigate whether positive role models help late-deafened adults maintain a positive identity regardless of their hearing status. This should also investigate the role hearing loss professionals play in connecting these adults with appropriate support. Furthermore, while there is research into the impact of the role significant others play in the hearing loss experience (Bennett, Saulsman, et al., 2021; Wallhagen, 2009) it does not focus on identity. Future research should investigate how significant others impact on identity changes specifically within the cochlear implant experience.

The research revealed the support needed to make a cochlear implantation decision was different to that during hearing loss. There were two specific stages. The first was while the late-deafened adult was making the decision to have an implant and the second was living with the implant. During the decision and transition phases, late-deafened adults needed to understand the cochlear implant experience and manage their expectations of outcomes, which could be ameliorated through connection with mentors who had implants. However, particularly for the participants in this research, there was no clear understanding of how to access these mentors because hearing health providers did not generally provide a connection with other cochlear implant recipients. Reports by Dillon and Pryce (2020), Bierbaum et al. (2019) and Rapport et al. (2020) suggest healthcare professionals need improved knowledge and awareness of cochlear implants to better provide referrals and support. During the second stage, while relearning to hear, the need for the implant recipient is both managing their new hearing and also likely to be psychological (Kobosko et al., 2015). Mentors help these implant recipients to understand how to improve and manage their hearing. Many participants chose to become advocates indicating they valued mentors to provide understanding of receiving and living with a cochlear implant. Further research is needed into the role cochlear implant healthcare providers play in supporting the newly implanted adult, and how they could provide referrals to support groups.

Being Normal – Hearing, deaf or disabled after a Cochlear Implant

As Goodley (2014) says "medicalisation, dis/ability and identity merge in complicated ways" (p. 6), and this could not be more true for a cochlear implant recipient. There were unexpected findings in my research surrounding the way some late-deafened adults identified after cochlear implantation.

The findings suggest a cochlear implant provides hearing while wearing a processor, however it does not necessarily return a 'normal' hearing identity. Moser (2006) is critical about the promise of technology "to build an order of the normal and turn disabled people into competent normal subjects" particularly because it reinforces the "boundaries between abled and disabled, and normal and deviant" (p. 373). On the other hand, Mäki-Torkko et al. (2015) described cochlear implant recipients as going from "a state of alienation (not hearing) to a state of normality (hearing)" (p. 383). The view of my participants more closely matched the findings by Mäki-Torkko et al. (2015) as well as Dillon and Pryce (2020). They wanted a return of 'normalcy' through returned hearing, which in an audist environment, would allow them better social interaction and career prospects. Outcomes reported in studies by Boisvert et al. (2020) and Da Cruz (2021) corresponded with the outcomes reported by most of my participants who said their cochlear implants allowed them to return to a more 'normal' hearing life. However, there were seeming contradictions, with a number of participants claiming they were 'cyborg', resulting in confusion as to whether they were hearing, deaf or half deaf (Kobosko et al., 2015) and thus finding the technology blurred the boundary between "the (deaf) body and implant technology… merged…hybrid or cyborg body" (Snell, 2015, p. 349).

The research found that some late-deafened, implant recipients never lost their hearing identity and an implant simply allowed them to maintain this. For some who had lost their hearing identity through hearing loss, a cochlear implant allowed them to regain their hearing identity. Nevertheless, in seeming contradiction after their implant, some now considered themselves either deaf or disabled when they had not done so before.

Acknowledging a 'deaf' Identity

An unexpected finding was some participants had identified as a 'hearing person who could not hear', but after implantation they now identified as 'a deaf person who could hear'. This paradox was also reported in the case history by Adler (2018). For most late-deafened adults hearing loss is slow (Da Cruz, 2021) and there is therefore, no clear boundary between the old-hearing, new-deaf identity. Accepting a different identity "is likely to prove painfully slow and arduous, especially where the new identity lacks clear boundaries and must compete with well-established and deep rooted identities" (Malesevic, 2006, pp. 19, quoting Smith 1999). I suggest this may be one reason why, throughout hearing loss progression, late-deafened adults strive to maintain a hearing identity. Nevertheless, the implant procedure is a

major, single point of change because after surgery they have complete hearing loss when unaided. I argue this is a point which allows some to acknowledge a deaf identity, even though they can hear. Research is needed to understand why it no longer matters to claim a deaf identity even though they have regained hearing.

Understanding a Disabled Identity

Some participants' identity changed from not being disabled during deafness, to being disabled after their implant. No previous scholarship was found which commented on this. Participants were positively enabled by their implants, and as discussed in Chapter 5, appeared to have no functional impairment. It was hard to distinguish why some participants used the term disabled and others preferred to distance themselves from this label, but it may be because of the stigmatised nature of a disabled identity. Since all participants in my research had connected on-line with others who had cochlear implants, and many in these communities identify as disabled, this could be an influence on their claim to disability. This position was supported by Ellcessor (2018) who quoted several scholars who had "observed that online exchanges…allowed for understanding the social nature of a disability" (p. 259) and was an important step in claiming a disability identity. Future research could focus on why some recipients, after an implant, claimed a disability identity.

Study Limitations

There are a number of limitations in this study. The first was the size of the research population. It was a heterogenous group who had experienced deafness in different ways. Some had received cochlear implants years ago and others more recently, and this will have impacted on their perception of the process, particularly related to mentoring services. Secondly, all participants were sourced from social media groups on Facebook which favours older people. Their membership of these groups also indicated they had access to, and knowledge of, technology allowing them to participate. Other limitations include, participants could be considered educationally elite because almost all had completed undergraduate or post graduate studies. Almost all participants lived in either Australia or USA and there are very different healthcare systems between the countries. In the USA healthcare, and therefore access to a CI, is frequently attached to a job (or partner's job). However, in Australia a Cochlear Implant can be accessed through public hospitals and private health insurance. These differences may have impacted on participants' experiences. There were few opportunities to understand the impacts on significant others or for cross-cultural comparison, with only one Asian, and one African-American participant. The majority were aged between 50 and 69 years of age and the views of younger people may be different. Fewer men answered the survey and fewer men than women

were interviewed, which did not allow for gender comparison in the hearing loss/cochlear implant experience.

Participants sourced from different social media groups, through clinics or interviewed face-to-face may provide different results. Since all participants self-selected for the study, sampling bias may be present because it is possible those who answered the survey are those who want to be heard either because of their poorer hearing loss experiences or better CI experiences. A greater number of males, those who were not as well educated, or who live in other countries, particularly where health services are not as readily available, or those who do not have technological access, may also result in different findings.

The research cannot be generalised across all late-deafened/Cochlear Implant recipients, however, it could be validated through using a different research approach. For instance, testing the outcomes around mentoring and negative experiences of deafness could be undertaken by focussing on just one clinic, one which has more recently implanted recipients and has introduced a mentoring program. All ages and all genders, length of deafness and implantation plus participation and benefits of mentoring programs could be assessed.

The interview, while it could be repeated by a different interviewer, it may result in different stories being told by participants. It is probable my own insider experience influenced the way participants told their stories. This also probably impacted on my analysis, although during many discussions with my supervisor, I was challenged to reflexively think about comments and recognise differences from my own experiences.

Conclusion

This research provided so much more than expected and provides some insight into the identity impacts of the late-deafness and cochlear implantation experiences. There are several important areas where my research makes a novel contribution, such as role models during the progression of hearing loss for maintaining identity, and identifying as deaf or disabled after cochlear implantation. Other findings confirmed outcomes in studies highlighted in the literature review. These included many of the key issues of late-deafness including coping strategies, denial and acknowledgement of their hearing loss, communication issues, fatigue or withdrawal, as well as changes in experiences after cochlear implantation.

The research cannot be generalised across all late-deafened/CI recipients, however, it could be reproduced and validated by increasing responses to the questionnaire allowing for greater triangulation of data.

. The findings of the current research should offer insights into the subjective experience of becoming late-deafened and having a cochlear implant. There is little research about the meanings and social implications of technology in the cochlear implant context. While inferences can be drawn from other types of prostheses, such as that discussed by Murray (2005), cochlear implants are relatively recent technology and this could explain why there is little research about identity and social impact. Theories of technological acceptance and suitability (Šmahel et al., 2018) could be used to understand the acceptance and impact of cochlear implants.

This study enhances understanding of the experience of late-deafened adults and provides a base for future studies to advance how cochlear implants impact on identity.

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Appendix 1- Terminology

Assistive technology/devices – devices which help in listening situations (e.g., a phone or tv streamer, TTY - Telephone typewriter, etc).

Cochlear – spelled with an 'r' is commonly used in the literature to mean any brand of implant.

Cochlear implant – for a fuller understanding of a cochlear implant link to What Are Cochlear Implants for Hearing? | NIDCD (nih.gov). Briefly, a cochlear implant is two-part system one of which is surgically implanted, and the other worn externally. Unlike a hearing aid a cochlear implant does not amplify sound, but creates sound allowing recipients to hear frequencies they can no longer hear naturally.

Images from Google images showing the main components of a Cochlear implant

- **Internal implant** – surgically implanted, the receiver transmits the sound to electrodes.
- **Electrode array** – the electrodes are surgically inserted into the cochlea and when sound is received, stimulate the hearing nerve performing the work which hairs in the cochlea would do if the ear was healthy.
- **Processor/Speech processor** – the external part worn like a hearing aid and is the 'brains' of the implant. It 'hears' the sound and converts sound waves into electrical impulses. These are sent to the transmitter which connects to the internal receiver. The impulses are then conducted to the electrodes. From there the persons' normal hearing process takes over transmitting the impulses along the hearing nerve to the brain where sound is interpreted.

Hearing aid – a device which amplifies sound but does not create sound and mostly beneficial for those with a mild or moderate hearing loss but is less effective for those with a severe or profound loss.

Late-deafness/late-deafened/Adult acquired hearing loss– hearing loss or deafness acquired post-lingually, after the development of speech and language generally from adolescence onwards.

Phones – for the purpose of this report a phone means a device where communication is via voice and hearing. It does not mean the plethora of smart devices where communication is via text etc.

Appendix 2 – Invitations Posted to Social Media

The Invitation was approved by Ethics and a a link to the survey was included in the body of the post.

The invitation with the navy blue background was posted to two groups

1. Cochlear Implant Experiences Facebook goup (38.7K members as at 5 May 2022)
   https://www.facebook.com/groups/ciexperiences
2. Bilateral CI Warrior (829 members as at 5 May 2022)
   https://www.facebook.com/groups/325256355436065

The second invitation with the teal background was posted once to the Cochlear Implant Experiences Facebook goup approximately two weeks after the first one. It was not posted to Bi-Lateral CI Warriors.

Appendix 3 – LimeSurvey Instructions

Department of Media, Communication,
Creative Arts, Literature & Language
Faculty of Arts, MACQUARIE UNIVERSITY   NSW   2109

Chief Investigator/ Supervisors:
A/Prof. Nicole Matthews; Dr Rachael Gunn
Masters Student: Felicity Bleckly

Participant Information and Consent

Name of Project: **Hearing changes: an exploration into the identity challenges of deafness in adult cochlear implant recipients**

What is this survey about?

This survey aims to find out about the experiences of people who have gone deaf as adults and then had a cochlear implant and, in particular, whether both deafness and having a cochlear implant had any impact on their identity.

You are invited to participate in this research if you went deaf as an adult and have at least one cochlear implant or BAHA

Going deaf as an adult means going deaf after your teenage years. Having an implant can mean one or two implants of any brand, including a BAHA.

What will I be asked?

You will be asked about your age, your level of education and use of hearing aids. There will be questions about your experiences after going deaf, how losing your hearing impacted on your life, career, friendships and socialisation, and whether you experienced discrimination or stigma. You will also be asked similar questions about your cochlear implant and how this has impacted on your life.

Retelling your personal hearing loss story may be an emotionally charged experience. This may increase your risk of inducing or exacerbating emotional distress, resulting in anxiety, depression or embarrassment. Should unexpected distress occur while answering this survey please cease and contact a counselling service in your home country. A list of contacts is provided at the end of the survey.

Do I have to complete all of the survey?

No, participation is voluntary. If you are uncomfortable you can stop at any time. The survey will be anonymous. No identifying information about you will be collected.

How long will it take?

This survey will take approximately 10 to 15 minutes to complete.

How will my data be used?

Data collected in this study will be used to improve our understanding of how deafness affects personal identity and whether identity is again affected when someone has a cochlear implant. The data will be used to complete a Masters of Research thesis and, in addition, may be published in academic journals and presented at national and international conferences. If findings are published, you will not be personally identified in any results from this study.

Where can I get more information?

You can get more information about this study by an email to felicity.bleckly@hdr.mq.edu.au if you have any further questions.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics and Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome. ID: 520211031533992 29 October 2021

By clicking on the next button you are granting permission to use your responses in the research study and are ready to begin the survey.

Thank you so much for your help.

Felicity Bleckly (MRES student)
felicity.bleckly@hdr.mq.edu.au

Appendix 4 – LimeSurvey Questions & Descriptive Frequency Tables

The survey questions cannot be changed for this research. The following tables list the LimeSurvey questions and include SPSS frequency tables showing the number of the 44 answering each question. It should be noted that cross tabulations were run for all questions to examine whether there was any significant differences. These cross tabulations included:

1. Analysis by gender – some differences were noted and will be the subject of further research.
2. Analysis by Interviewed vs not-interviewed – little significant difference was noted.
3. Comparison of impact of deafness vs impact of cochlear implant. One table is included in the at the end of this appendix under **Comparing the Impacts of a Cochlear Implant – Before & After Implantation.**

#	Question	Frequency	
Survey Participant Demographics			
1.	What is your age range?	Age range	#
		30-39 years old	5
		40-49 years old	1
		50-59 years old	13
		60-69 years old	16
		70-79 years old	8
		Over 80 years old	1
		Total	44
2.	What country do you live in?	Country	#
		Other	7
		Australia	9
		USA	27
		UK	1
		Total	44
3.	Do you identify as….	Gender identity	#
		Female	27
		Male	17
		Total	44
4.	What is the highest level of education you have achieved	Education	#
		Other	4
		1. High school	10
		2. Undergraduate degree	12
		3. Post graduate degree	18
		Total	44

#	Question	Frequency
Hearing Loss History & Experiences		

#	Question	Frequency	
1.	Approximately at what age did your hearing loss begin	**Age hearing loss began**	**#**
		Under 20 years old	20
		20-29 years old	6
		30-39 years old	10
		40-49 years old	2
		50-59 years old	5
		60-69 years old	1
		Total	44
2.	Did you lose your hearing slowly or suddenly?	**Slow or sudden loss**	**#**
		Other	6
		Slowly - (over a number	32
		Suddenly - (a few days,	6
		Total	44
3.	Did you have a hearing aid either for one ear or both?	**Hearing aid**	**#**
		Left ear	5
		Right ear	6
		Both ears	31
		Total	42
		System	2
		Total	44
4.	How long did you have a hearing aid (approximately in years)?	**Years wearing hearing aid**	**#**
		Less than 1 year	3
		1-5 years	6
		6-10 years	3
		More than 10 years	29
		I didn't have a hearing aid	3
		Total	44
5.	Did you wear your hearing aid?	**Wear hearing aid**	**#**
		Never	2
		Sometimes	5
		Most of the time	9
		All of the time	27
		Total	43
		System	1
		Total	44
6.	If you did not wear your hearing aid(s) all the time, can you explain why?	Open ended question	
		Reason for not wearing	**#**
		Announced my disability	1
		Because I felt different	1
		Did not work	3
		Disliked loudness	2
		Except when asleep	4
		Give noise a rest	2
		It hurt	1
		Only wore them as I got older	1
		Too big	1
		TOTAL	16

#	Question	Frequency
Hearing Loss History & Experiences		
7.	I felt embarrassed by my hearing aid	Embarrassed by hearing aid — # Not answered — 1 Other — 15 Yes — 3 No — 17 Sometimes — 8 Total — 44
7.	I felt embarrassed by my hearing aid (other)	Embarrassed by hearing aid — # Afraid I would be made fun of — 1 Because I was different — 1 Everyone wants to be normal — 1 Made me look old — 1 More self conscious than — 1 People treat as stupid not deaf — 1 Self conscious about not being — 1 Stigma — 1 Too young to have a hearing aid — 1 Used to but no longer — 1 When it didn't work — 1 When my friends explained I wasn't stuck up just deaf — 1 TOTAL — 12
8.	My hearing aid was not visible	Hearing aid not visible — # True — 14 False — 29 Total — 43 System — 1 Total — 44
9a.	The reason my hearing aid was not visible is my hair covered it.	My hair covered it — # N/A — 26 Yes — 18 Total — 44 There is an apparent inconsistency between those who said their hearing aid was not visible (*n*=14) and the number who said their hair covered it (*n*=18). Respondents could answer each of Questions 9a, 9b and 9c and therefore the total number from these questions will not add to the number of those who said their hearing was not visible in question 8.
9b.	The reason my hearing aid was not visible is it was small	It was small — # N/A — 42 Yes — 2 Total — 44 Respondents could answer each of Questions 9a, 9b and 9c and therefore the total number from these questions will not add to the number of those who said their hearing was not visible in question 8 (*n*=14).

#	Question	Frequency
Hearing Loss History & Experiences		
9c.	The reason my hearing aid was not visible is my glasses hid it	<table><tr><td>My glasses hid it</td><td>#</td></tr><tr><td>N/A</td><td>43</td></tr><tr><td>Yes</td><td>1</td></tr><tr><td>Total</td><td>44</td></tr></table> Respondents could answer each of Questions 9a, 9b and 9c and therefore the total number from these questions will not add to the number of those who said their hearing was not visible in question 8 ($n=14$).

#	Question	Frequency
	Hearing Loss History & Experiences	

| 10. | Thinking about before you had your cochlear implant(s), did you have any of these experiences because of your deafness? (Choose all that apply)

44 participants | |

Q10 Impact of Deafness before cochlear implant	Yes	No
10. [I felt discriminated against because of my hearing loss]	19	25
10. [I felt discriminated against because of my hearing aid]	8	36
10. [I felt stigma because of my deafness]	21	23
10. [My hearing aid meant I experienced stigma]	7	37
10. [People told me my speech changed or was too loud]	19	25
10. [It became harder to socialise]	41	3
10. [I was embarrassed by my hearing loss]	16	28
10. [I made mistakes because I misheard what was said]	40	4
10. [I withdrew from social groups]	34	10
10. [I felt isolated from other people]	33	11
10. [I lost my job because of my deafness]	9	35
10. [I was passed over in my career because of my deafness]	12	32
10. [I had to change careers because of my deafness]	13	31
10. [I had to give up my education because of my deafness]	5	39
10. [I was teased or bullied because of my deafness]	7	37
10. [I no longer knew who I was]	10	34
10. [I learned/used lip reading]	37	7
10. [It was hard for me to remain positive]	19	25
10. [I had less satisfaction in life]	27	17
10. [I became (or was) part of the Deaf culture and community]	9	35
10. [I learned/used sign language]	11	33
10. [I bluffed when I didn't hear properly, to hide my deafness]	30	14
10. [Deafness impacted on my relationships with family and/or friends]	34	10
10. [I tried to hide my hearing aid]	6	38
10. [My hearing aid was little help]	16	28
10. [I felt I had lost something]	18	26
10. [I had communication difficulties]	33	11
people, someone had to come with me to appointments etc.)]	26	18
10. [I considered myself disabled]	19	25
10. [Deafness changed who I was]	22	22
10. [Some of my friends avoided me]	12	32
Total	613	751

Identity Effect of Hearing Changes in Late-deafened Adults

#	Question	Frequency
	Cochlear Implant History & Experiences	
	Note: 4 people stopped answering the survey at this point	

#	Question	Frequency
1.	How long were you deaf before you had your first cochlear implant?	Years deaf before 1st implant — # Less than 1 year — 4 1-2 years — 7 2-5 years — 4 6-10 years — 4 Longer than 10 years — 21 Total — 40 System — 4 — 44
2.	At what age did you have your first cochlear implant? (Ages merged into a range)	Age range — # Under 30 — 2 30-39 years — 2 40-49 years — 9 50-59 years — 17 60-69 years — 7 70-79 years — 3 Over 80 years — 0 Total — 40
3	How long have you had your FIRST implant?	Years 1st implant — # Less than 1 year — 8 1-5 years — 12 6-10 years — 12 More than 10 years — 8 Total — 40
4.	How long have you had your SECOND implant?	Years 2nd implant — # Less than 1 year — 12 1-5 years — 7 6-10 years — 6 More than 10 years — 3 I only have one cochlear — 12 Total — 40

#	Question	Frequency
5.	Open ended question - Now that you have a cochlear implant, how has your life changed when compared to while you were deaf?	Open-ended questions from the survey were coded in NVivo using codes identified in interviews
6.	Open ended question – What difference did having a SECOND (bi-lateral) cochlear implant make – as opposed to having just one implant? Tell me whether having a second implant made any differences in your life and your hearing	
7.	Open ended question - What is your definition of deafness?	

#	Question	Frequency
Cochlear Implant History & Experiences		
Note: A further 2 people stopped answering the survey at this point i.e., 6 people answered no further questions		

#	Question	Frequency
1.	Has your implant given you the outcome you hoped for?	**Outcome** — **#** N/A — 6 Other — 2 Yes — 32 Somewhat — 4 Total — 44
2.	See next page for question 2	
3.	Multiple choice Do you do any of these since you have had your cochlear implant(s)?	**Do you do any of these since your cochlear implant** — **#** I use lip reading — 33 I bluff to hide my deafness — 7 I try to hide my deafness — 5 I try to hide my cochlear implant — 3 I use sign language — 7 I uses none or do none of these — 4 Total — 59
4.	How do you identify yourself now you have cochlear implants	**How do you identify** — **#** Hearing culture — 16 Deaf & hearing culture — 10 Deaf Culture — 5 Hearing impaired — 18 Hard of hearing — 12 Cyborg — 12 Neither Deaf nor hearing — 4 I don't know — 4 Total — 81
5.	Tell me your hearing loss and cochlear implant story. I would like to know how life has changed for you. How were you challenged by deafness and how this has or if it has changed since you had a cochlear implant?	This question was coded in NVivo based on codes identified from Interviews.

#	Question	Frequency
		Cochlear Implant History & Experiences
		Note: A further 2 people stopped answering the survey at this point i.e., 6 people answered no further questions

2.	Multiple choice	
	How has your life changed because of your cochlear implant? When compared to deafness, please indicate whether these issues have changed for you, now you have a cochlear implant. **38 participants**	(table below)

Q2 Impact of Cochlear Implant	Yes	No
I feel discriminated against because of my hearing loss even though I have a cochlear implant	5	25
I feel discriminated against because of my cochlear implant	4	31
I feel stigma because of my deafness even though I have a cochlear implant(s)	6	27
My cochlear implant means I experience stigma	6	28
My speech has NOT improved (or I don't speak as loud) because of my cochlear implant(s)	7	26
It is harder to socialise because of my cochlear implant(s)	2	35
I feel embarrassed because I have a cochlear implant(s)	2	33
I make mistakes because I miss-hear even though I have cochlear implants	20	17
I am withdrawn or isolated from others even though I have a cochlear implant(s)	4	29
I do not feel connected to other people even though I have a cochlear implant	3	31
I have not been able to go to/continue to work because of my cochlear implant(s)	4	27
I do not have better career/work options because of my cochlear implant(s)	2	29
I have had to change careers because of my cochlear implant(s)	4	27
I cannot continue my study because of my cochlear implant(s)	3	23
I am teased or bullied because of my cochlear implant(s)	0	37
I do not know who I am because of my cochlear implant(s)	5	31
I still use lip reading/sign language even though I have cochlear implant(s)	8	26
It is still hard for me to remain positive	5	31
I am not more satisfied with my life because of my cochlear implant(s)	1	34
I am not part of the Deaf culture and community even though I have cochlear implants	6	25
I still use lip reading/sign language even though I have cochlear implant(s)	8	26
I still have communication difficulties even with my cochlear implant(s) (bluffing/faking hearing)	14	21
I am still dependent on family and friends even with my cochlear implant	4	29
I try to hide my cochlear implant	6	31
My cochlear implant(s) is not a great help in my every-day life	0	36
I still feel I have lost something	10	21
I still have communication difficulties even with my cochlear implant(s) (bluffing/faking hearing)	14	21
I am still dependent on family and friends even with my cochlear implant	4	29
I still consider myself disabled	16	20
My cochlear implant has not changed me	7	28
My friends still avoid me	6	17
I do not feel better about myself now I have a cochlear implant(s)	4	30

Comparing the Impacts of a Cochlear Implant – Before & After Implantation

This comparison table was developed to help understand some of changes which might impact on, and help to understand the meaning, of identity for participants.

Answers to two multiple choice questions (Q10 under Hearing loss experiences and Q2 under Cochlear implant experiences) allowed a comparison between hearing loss and cochlear implant experiences.

The first question (Q10) asked about the experiences and impact of deafness on respondents' lives and the second (Q2) was how having a cochlear implant impacted on similar issues. Some comparisons are included in the table below. It should be noted questions were multiple choice and any of the 38 participants could choose not to answer or could answer multiple times.

Comparing the Changes in Life Experiences Before & After a Cochlear Implant

Experiences of deafness	Before Implant	After implant	Experiences after cochlear implants	After implant
I feel isolated from others	33	3	I feel connected to others	31
I feel discrimination	19	5	I do not feel discrimination	25
It was/is harder to socialise	41	2	It is easier to socialise	35
I mishear and make mistakes	40	20	I no longer mishear	17
I withdraw from social groups	34	4	I no longer withdraw	29
I had to change careers	13	4	I did not have to change careers	27
I have less satisfaction in life	27	1	I am more satisfied in life	34
I lost my independence	26	4	I regained independence	29
I had communication difficulties	33	14	I no longer have communication difficulties	21
It was hard to remain positive	19	5	It is easier to remain positive	31

Appendix 5 – Interview Consent Form

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Email arts.hdr@mq.edu.au

Participant Information and Consent Form - Interview

Name of Project: Hearing changes: a qualitative exploration of the identity challenges of deafness in adult cochlear implant recipients

You are invited to participate in a study examining the identity challenges of deafness in adult cochlear implant recipients. The study is being conducted by A/Prof Dr Nicole Matthews and Dr Rachael Gunn, with Masters of Research student, Felicity Bleckly, of Macquarie University. (nicole.matthews@mq.edu.au; rachael.gunn@mq.edu.au; felicity.bleckly@hdr.mq.edu.au)

The purpose of the study is to understand how deafness and having a cochlear implant impacts on people's lives. The research will support clinicians' approach treatment; not just the hearing issues, but also the emotional consequences of deafness and cochlear implants.

Interview logistics: If you decide to participate, a time will be set for an interview of 30-90min duration, during which time you will be asked questions that relate to your experiences of deafness and getting a cochlear implant. Normally the interview will be conducted via Zoom and will be video-recorded, which will be used solely for transcription purposes.

Personal distress: Retelling your personal hearing loss story may be an emotionally charged experience. This may increase your risk of inducing or exacerbating emotional distress, resulting in anxiety, depression or embarrassment. Should unexpected distress occur during the interview, the interview will cease and you will be referred to a counselling service in your home country (refer the list at the end of this consent form).

Confidentiality: The recording is confidential and will only be heard by the research team. If you prefer to be interviewed in another way (for example, through live chat or via email) that can be arranged. Information or personal details gathered in the course of the study are confidential, except as required by law. You may select how you will be identified in any publication of the results: either by name or by pseudonym. Any future publications will acknowledge specific contributors by name or pseudonym.

Data access: Raw data will only be available to the research team.

Dissemination of results: A summary of the results of can be made available to you on request, please indicate if you would like a copy of the results. There are no expected risks associated with participating in this study and participation will not include any monetary payment.

Before the interview commences, participants will be emailed a written consent form which will be signed and emailed back to the researchers. At the start of the interview the project will again be described and confidentiality and anonymity assured. Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, consent to video and audio record will be stated at the beginning of the interview. You are free to withdraw at any time up until the report is being written (from January 2022) without having to give a reason and without consequence.

MACQUARIE University
SYDNEY·AUSTRALIA

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Participant Information and Consent Form - Interview

Name of Project: Hearing changes: a qualitative exploration of the identity challenges of deafness in adult cochlear implant recipients

Ethics approval #: 520211031533992 – November 2021

I,   *(participant's name)*   have read and understand the information on the previous page and any questions I have asked, have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Name: _____

(Block letters)

Participant's Signature: _____ Date:_____

Investigator's Name:_____

(Block letters)

Investigator's Signature: _____ ___Date:_____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics and Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Please email this completed and signed page to felicity.bleckly@hdr.mq.edu.au

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Retelling your personal hearing loss story may be an emotionally charged experience.

This may increase your risk of inducing or exacerbating emotional distress, resulting in anxiety, depression or embarrassment. Should unexpected distress occur during the interview, the interview will cease and you will be referred to a counselling service in your home country.

USA

- **Crisis Text Line**   Text: Type HOME to 741741 in the US Website: CrisisTextLine.org
  24/7 text free support line for anyone in mental health crisis anywhere in the US. Very useful for Deaf people.

- **SAMHSA's National Helpline**   Voice: 1-800-662-HELP (4357) TTY: 1-800-487-4889
  Website: samhsa.gov 24-hour free and confidential mental health treatment referral and information. Deaf people are welcome.

- **National Suicide Prevention Lifeline**   Voice: 1-800-273-TALK (8255) TTY: 1-800-799-4889
  Website: suicidepreventionlifeline.org 24-hour, toll-free, confidential suicide prevention hotline available to anyone dealing with emotional distress. This is the best option for Deaf emergency services.

Australia

- **Lifeline** 13 11 14, Lifeline text number 0477 13 11 14 www.lifeline.org.au
- MensLine Australia 1300 789 978 – includes an online form with email https://mensline.org.au
- Beyond Blue 1300 650 890 – includes an option to chat online www.beyondblue.org.au
- Suicide Callback service 1300 659 467 – includes phone and online counselling www.suicidecallbackservice.org.au
- MindSpot 1800 61 44 34 – includes online assessment would be helpful for ongoing treatment https://mindspot.org.au

Other countries

UK

o **Crisis Text Service – Specifically for the deaf** https://signhealth.org.uk/withdeaf-people/crisis-text-service/ Text DEAF to 85258

o **Shout 85258** https://giveusashout.org/get-help/resources/deaf-support/

USA, Canada, Australia, UK, NZ, Europe, South Africa, Japan (Global)

o **CheckPoint** https://checkpointorg.com/global/ - lists information for many stress issues Global

o **Befrienders Worldwide** https://www.befrienders.org

Appendix 6 – Researcher Interview Question Prompts

Hearing Changes: An exploration into the Identity Challenges of Deafness in Adult Cochlear Implant Recipients

MACQUARIE University
SYDNEY · AUSTRALIA

Interview questions – Ethics approval Ref No: 520211031533992

Contact: felicity.bleckly@hdr.mq.edu.au

Your story

I'd like to know your story. Can you tell me about your experiences of going deaf after being hearing? You could either write your story keeping in mind the questions below or you could answer each of the questions individually.

You can type in this document – or create your own document. Or if you prefer print and write by hand and then scan that and send it back to me.

Thinking about being deaf

1. What impact did hearing loss have on your life? Can you give some examples of the main things?
2. Did you know anyone else who had gone deaf like you?
   a. If yes, how did this help you understand what was happening to you? Would it have made a difference to the way you felt/understand yourself?
   b. If no, where did you turn for information and support?
3. Did you try to hide your hearing aid and if so why?
4. Did losing your hearing change your relationship with other people? In what way and how did this feel?
5. Did going deaf impact on your education or working life? And if so what was the impact?
6. Were there times when life was more difficult than other times because of your deafness and if so what were these?
7. Did your interaction with your partner, family and friends change because of your deafness and if so how did this change?
8. How did deafness cause issues with work or study?
9. Do you think there is a stigma about wearing a hearing aid? If so, why do you think that is?
10. Did you experience stigma when you were deaf and if so what was this stigma?
11. While you were deaf, how did you feel about yourself?
12. How did you identify?
13. Do you feel your sense of identity changed over the time you were deaf? And if so how did this change?
14. Do you think the way you were treated by hearing health professionals had an impact on your experiences of going deaf and the way you came to understand your identity? Please explain.

Thinking about your cochlear implant

1. You have a cochlear implant now. Can you tell me how that came about?
2. How did you find out about a cochlear implant and where did you find information about a cochlear implant?
3. Did your audiologists or other specialists talk to you about the process?
4. If so what kinds of things did they talk about with you?
5. Did you meet or talk to anyone who had a cochlear implant before you had your cochlear implant?
6. If so, how did this help you understand or what to expect when having an implant?
7. If no, where did you get information?
8. What has changed about your life since you got your cochlear implant?
9. If you have two cochlear implants is there a difference between the way you felt when you had one implant and now you have two implants? Please explain.
10. Do you feel a need to hide your cochlear implant? Why?
11. Do you feel a stigma is associated with your Cochlear implant? Please explain
12. Where do you go to find support and information about your experience now?
13. When compared with how you felt as a deaf person, has the way you feel about yourself changed now you have a cochlear implant? Please explain.

Comparing deafness with your Cochlear implant

1. What are the differences between being deaf and having a cochlear implant?
2. Compared to being deaf and now having a cochlear implant how has this impacted on your education, work and life? What are the differences?
3. Compared to deafness, are there times when life is easier because you have a cochlear implant? Please explain
4. When compared with being deaf, are there any times when life is more difficult because of your cochlear implant and if so please explain.
5. You had hearing and then became deaf so how did you identify throughout this process? Please explain
6. Do you feel your identity has changed since you've had your cochlear implant compared to the way you felt while you were deaf?

Health care providers

Do you think the way you were treated by hearing health professionals through going deaf and your cochlear implant process had an impact on the way you understand your identity? Please explain

How would you change things

1. Based on your own experience, what advice would you give to someone who was losing their hearing?
2. What advice would you give someone who was about to get a cochlear implant?
3. What advice would you give to audiologists, ENTs or other hearing health professionals about how they work with adults who lose their hearing?

Is there anything else you'd like to share? felicity.bleckly@hdr.mq.edu.au

We recognise that reliving memories of your hearing loss may cause distress. Should you find any of the questions difficult to answer or they raise emotional issues and you need to talk to someone please contact one of the care providers included in the consent form.

Thank you for your participation.

Appendix 7 – Examples of Coding

After all interviews were coded, codes were grouped into major themes, as outlined in the table below (pasted from the main thesis document). Refer Appendix 8 for full coding tree in table form

Major Themes, with Number of Child Codes, Showing Number of References by Theme

Major Themes	# of child codes	# of references
Identity	23	419
Hearing History	3	111
Consequences & impact of Late Deafness	75	1,005
Hearing Aids	9	227
Cochlear Implants	97	1,332
Implant Processor	11	78
The Hearing Divide	26	495
Peer/Family Support	5	114
Healthcare professionals	12	186

NVivo Coding Process

Codes were initially developed semantically from the words and terms participants used. Once all interviews and survey open-ended questions had been coded, these were grouped into major themes. The figure below is an example of the links between major themes and child codes after early interviews were coded. Additional themes and child codes were identified after more interviews were coded. To illustrate the way coding was undertaken samples of participants' comments are shown in the examples section.

Illustration from NVivo, mapping the interrelationship between major themes and child codes after early interviews

Examples of NVivo Coding

These examples of participants' comments throughout interviews, are chosen at random and are not all of the comments participants made about their identity.

Participants' Comments about Identity/Hard-of-hearing

Interview P01. zoom edited transcript, survey

"My identity. Ah I tell you what, I'll tell you what is my identity, was identified as being very hard of hearing for, you know, 20 years probably 15 or 20 years."

Interview P02. zoom edited transcript, survey

"I'm hard of hearing. I'm not really like wanting to be deaf."

Interview P05. zoom edited transcript, survey

"And how I identify myself I call my, I would call myself either I have hearing loss I wear hearing aids, or I'm hard of hearing. So I'm not overly sensitive. I know some people take offense towards like hearing impaired or, I personally think they're just words, and it really matters what your attitude is."

Interview P06. zoom edited transcript, survey

"Before I never identified as deaf or hard of hearing is what I would say but it was profound part of hearing is what I was told you are profoundly hard of hearing."

Participants' Comments Identity/Cochlear Implants

Interview P01. zoom edited transcript, survey

Answering survey question 4.
How do you identify yourself now you have a cochlear implant(s)? [Cyborg]   "Yes"

Interview P04. chat+email edited transcript, survey

I feel connected to the world again. Answering survey questions 2&4

Q2. [My cochlear implant has changed me]   "Completely true"

Q4. How do you identify yourself now you have a cochlear implant(s)? [Cyborg]   "Yes"

Interview P05. zoom edited transcript, survey

"So I don't call myself. I've never called myself deaf."

Interview P09. email, survey

"I identify as a deaf woman who uses and benefits greatly from cochlear implants but who is not fully hearing."

Interview P14. zoom edited transcript, survey

"I don't really identify as deaf because I've always got these on, so I never really think of it much as an identity but right now it's just natural."

Interview P16. zoom edited transcript, survey

"I consider myself a deaf person with technology."

Interview P17. email, survey

"Since being implanted, I now refer to myself as deaf, although I'm still not totally comfortable with that. In any case, I definitely have never felt I was a part of or identified with the Deaf community."

Appendix 8 – Coding Tree Table, Showing all Child Codes & Number of References

Major themes/codes	Child codes	# of references
Identity (419 references)	aging	3
	changed who I am	24
	cochlear implant identity	31
	Deaf community	77
	deaf hard of hearing identity	26
	defined by deafness - master identity	7
	didn't know it impacted on identity	2
	disability	25
	don't know identity crises	28
	feeling part of the world	5
	hearing identity	59
	hearing impaired hard of hearing or hearing loss	23
	hybrid in-between	11
	in both worlds	20
	intersectionality	3
	just different	2
	lost myself	4
	medical model of deafness	3
	music identity	1
	not deaf or hearing	18
	oral deaf	3
	pre-deafness self	8
	role models	36
Hearing history (111 references)	hearing history	85
	slow loss	23
	sudden loss	3

Major themes/codes	Child codes	# of references
Hearing aids (227 references)	hearing aids	27
	aging	5
	cost	8
	didn't use a hearing aid	2
	discrimination	12
	embarrassment, shame or stigma	29
	hearing aid problems	74
	hide hearing aids	44
	wear hearing aids	26

Identity Effect of Hearing Changes in Late-deafened Adults

Major themes/codes	Child codes	# of references
Music (95 references)	expectation from implant	5
	feelings about music	22
	hearing music	37
	lyrics	1
	music history	10
	pitch perception	20

Major themes/codes	Child codes	# of references
Professionals (186 references)	Professionals	3
	counselling	9
	rehabilitation	32
	cost	4
	counsel close others	3
	defensive	3
	lack of continuity	2
	lack of knowledge	1
	opinion of professionals	38
	professionals helping	54
	professionals not helping	34
	referral to help groups	3

Major themes/codes	Child codes	# of references
Cultural issues		5

Major themes/codes	Child codes	# of references
Support (114 references)	participants asking for my experiences	21
	peer support	77
	remote programming	1
	social media	4
	support services	11

Identity Effect of Hearing Changes in Late-deafened Adults

Major themes/codes	Child codes	# of references	Child codes	# of references
Deafness impacts (1005 references)	communication difficulties	71	communication difficulties	48
			connection cut off from world	4
			constant challenge	3
			forgetting language	1
			group environment	1
			missing things	12
			too much listening	2
	coping methods	199	coping	17
			acceptance	9
			assistive devices	15
			blaming others	1
			bluffing	18
			bullying	14
			controlling the conversation	3
			counselling	3
			denial	12
			disclosing hearing loss	2
			hearing dog	12
			lip reading & sign language	66
			more aware of things other than sound	2
			rehabilitation	5
			self-advocate	6
			self-blame	10
			self-motivation	4
	dependency, disempowerment	68	dependency, disempowerment	61
			lack of accessibility	2
			life plans change	3
			privacy	2
	emotional response	64	emotional responses	25
			didn't feel accepted	2
			frustration, confusion	12
			hearing tests	2
			lost something	17
			repeating things	3
			stress	3
	life impacts	199	authority challenged	4
			career	114
			covid impact	2
			driving	2
			education	40
			financial impact	1
			impact on all life	4
			phone	32
	mental & physical health	122	health	36
			co-morbidities	24
			lack of confidence	1
			misdiagnosed	7
			positive attitude	3
			self-esteem	29
			tired	10
			vulnerable, safety & quality of life	12
	other people's reactions attitudes	40	people's reaction	22
			expectation of others	3
			misunderstanding of hearing loss	4
			people did not believe had a hearing loss	7
			private & sensitive	2
			set an example	1
			understanding hearing loss	1
	socialisation withdrawal isolation	150	socialisation withdrawal isolation	96
			exclusion	1
			relationships	53
	stigma	92	stigma	9
			discrimination	16
			embarrassment	25
			speech change mispronunciation mishearing	40
			labelling	2

Identity Effect of Hearing Changes in Late-deafened Adults

Major themes/codes	Child codes	# of references	Child codes	# of references
Cochlear implants (1332 references)	before Implant	114	cochlear implants	7
			accessibility to cochlear implant	10
			choosing a brand	8
			cochlear implant referral	20
			cochlear role model	11
			cost-insurance	12
			fear, frustrated, grief	5
			knowledge of implant	12
			losing residual hearing	3
			making the decision	8
			might hear again	7
			size of processor	2
			surgery	2
			what have I got to lose	3
			which ear	4
	advocacy lobbying	55	advocacy lobbying	52
			advice	2
			cochlear implant research	1
	career	60	career	14
			phones	46
	cochlear implant history	95	history	3
			bilateral hearing	82
			bi-modal hearing	10
	communication improvement	86	communication improvement	51
			accents	4
			continual improvement	3
			direction	2
			missing things/mishear	26
	connection to people	116	connection to people	21
			relationship improvement	30
			socialisation	65
	coping methods	176	assistive devices, direct connection, captions	15
			bluffing faking	16
			body language	1
			hide deafness	15
			hide/not hide processors	49
			hiding deafness	1
			lip reading & sign language	41
			noisy environments	31
			technology transcriptions	7
	difficulties with cochlear implant	22	difficulties with cochlear implant	17
			horrible sounds	1
			reimplant	4
	feelings about outcome of cochlear implant	250	feelings about outcome of cochlear implant	133
			ashamed embarrassed	17
			belief about cochlear implants	11
			feeling overwhelmed	1
			getting used to hearing	2
			learning to hear again	2
			no longer lost something	14
			outcome from cochlear implant	3
			self-advocate	2
			self-confidence	16
			self-esteem	19
			speech improvement	23
			too much stuff with CI	2
			understanding the cochlear implant experience	5
	life impacts	149	COVID impact	12
			disclosing hearing loss - hearing aid - cochlear implant	14
			education	13
			empowerment, dependence	55
			fatigue	13
			no hearing without processors	10
			quality of life	24
			safety	6
			taking over life	2
	mental health	26	mental health	23
			co-morbidities	1
			stress decrease	2
	processors	78	a tool	7
			CI programs	2
			decorating processors	3
			fear of losing processor	2
			smaller processors	4
			switch-on	16
			upgrades new technology	18
			using the processor/ app connection problems	22
			wearing the processor	4
	sound quality	50	quality	30
			recognising sound	20
	stigma	55	stigma	19
			discrimination	18
			teased, bullied	18

This additional theme was identified to clarify adjustments. It should be noted these themes may also appear in other themes.

Major Theme	Child codes	# of references	Child Codes	# of references
The Hearing Divide	Phone	32		
	Music	95	Lyrics	1
			Expectation from implant	5
			Music history	10
			Pitch perception	20
			Feelings about music	22
			Hearing music	37
	Connection to people	116	Connection to people	21
			Relationship improvement	30
			Socialisation	95
	Feelings about outcome of cochlear implant	252	Feelings about outcome of cochlear implant	106
			Feeling overwhelmed	1
			Self-advocate	2
			Getting used to hearing	2
			Learning to her again	2
			Too much stuff with CI	2
			Understanding the cochlear implant experience	5
			Belief about cochlear implants	11
			No longer lost something	14
			Ashamed embarrassed	17
			Self-confidence	18
			Self-esteem	19
			Speech improvement	23
			Outcome from cochlear implant	30

Appendix 9 – Ethics Approval

Office of the Deputy Vice-Chancellor (Research)

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MACQUARIE
University
SYDNEY·AUSTRALIA

29/10/2021

Dear Dr Nicole Matthews,

Reference No:520211031533992

Title: 10315 Identity effect of hearing changes: a qualitative exploration of the experience of deafness in adult cochlear implant recipients

Thank you for submitting the above application for ethical and scientific review. Macquarie University Human Research Ethics Committee HREC Humanities & Social Sciences Committee considered your application.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by Dr Nicole Matthews and other personnel: Felicity Bleckly, Dr Rachael Gunn.

Approval Date: 29/10/2021

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007, updated July 2018) (the *National Statement*).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement,* which is available at the following website:
   http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All significant safety issues, that adversely affect the safety of participants or materially impact on the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC Humanities & Social Sciences Committee Terms of Reference and Standard Operating Procedures are available from the Research Office website at: https://www.mq.edu.au/research/ethics-integrity-and-policies/ethics/human-ethics

The HREC Humanities & Social Sciences Committee wishes you every success in your research.

Yours sincerely,

Dr Karolyn White
Chair, HREC Humanities & Social Sciences Committee

This HREC is constituted and operates in accordance with the National Health and *Medical Research Council's (NHMRC)National Statement on Ethical Conduct in Human Research (2007, updated July 2018)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*