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# Family Oriented Communication Assessment and Solutions – Motivation and Experience (FOCAS-ME)

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*A Qualitative Analysis of a Family-Centred Tool*

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**2019**

*A thesis submitted in partial fulfilment of the requirements for the degree of Master of  
Audiology, The University of Auckland, 2019*

## **Abstract**

*Objective:* To compare the Family Oriented Communication Assessment and Solutions: Motivation and Experience (FOCAS-ME) tool with current standard adult audiology practice. Themes relevant to service provision, including family-centred-care and third-party disability, were explored through the qualitative analysis of case records.

*Introduction:* Hearing loss impacts the quality of life of individuals, as well as those close to them through the impact of third-party disability. This can be addressed through family-centred care (FCC). The FOCAS-ME tool aims to incorporate FCC, as well as address recently identified gaps in adult audiology service provision. For the purposes of this study, the term “family member/s” will be used to represent any person who is a main communication partner of hearing-impaired individuals, including caregivers and friends.

*Methods:* A sample of Hearing Aid Discussions (HADs) from the University of Auckland Hearing and Tinnitus Clinic (UoA HATC) and completed FOCAS-ME forms from a pilot study in Australia, were collected and qualitatively analysed. This was conducted through the classification of FOCAS-ME themes, and identification of their occurrence in the HAD cases, as well as additional elements determined to be relevant to service provision. General themes relating to audiological service provision were also analysed.

*Results:* The FOCAS-ME tool shows promise regarding the exploration of the emotional impact of hearing loss and third-party disability. Family member involvement was intrinsic to the FOCAS-ME appointments. Current standard practice does not preclude family member involvement. Tinnitus, sound sensitivity, and physical limitations such as dexterity or vision problems are not part of the FOCAS-ME tool. All cases showed similar themes regarding the impact of hearing loss on hearing-impaired people and their families.

*Conclusions:* This research reinforced existing literature regarding the emotional, psychosocial, and third-party impact of hearing loss. Further investigation into the benefits of implementing FCC in adult audiology is encouraged. In order to establish the efficacy of the FOCAS and FOCAS-ME tools to incorporate FCC and address the recent gaps in adult audiology service provision identified in the literature, ongoing validation is required.

## **Acknowledgements**

Dedicated to my mother Beverly, without whom none of this would have been possible.

I would like to express my special thanks to my supervisor Grant Searchfield, for all his support and guidance through this process, and whose innovation and creative thinking saved my thesis from what seemed an almost certain demise!

Heartfelt thank you to my co-supervisors David Crowhen and Bettina Turnbull for your time, advice, contributions and dedication.

A huge thank you to the wonderful clinicians from the UoA HATC for providing access to cases for the research, and for your input, encouragement, and helpful ideas along the way, and over the past two years. Much appreciation is owed to the anonymous clinicians from the FOCAS-ME pilot study for providing us with completed forms for the research.

The amazing proof readers Coralie Nelson, Ruth Berry, and my mother Beverly Collins, are owed a debt of gratitude for their feedback and helpful corrections of spelling and grammar.

I would like to thank all the brilliant lecturers at The University of Auckland Master of Audiology programme for giving us so much of their time, wisdom, energy and support as we made our way through the course.

Finally, an enormous thank you to my fabulous classmates, whose intellectual and moral support, spirit, drive, inspiration and love kept me going through the challenging times. I greatly admire you all and it has been truly an honour to share this journey with you.

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## List of Abbreviations

ALD	Assistive Listening Device
BGN	Background Noise
BTE	Behind-the-Ear hearing aid
CIC	Completely-in-the-Canal hearing aid
COSI	Client Oriented Scale of Improvement
FCC	Family-Centred Care
F-M	FOCAS-ME
FOCAS	Family Oriented Communication Assessment and Solutions
FOCAS-ME	Family Oriented Communication Assessment and Solutions-Motivation and Experience
HA	Hearing Aid
HAD	Hearing Aid Discussion
ITE	In-the-Ear hearing aid
QoL	Quality of Life
RIC	Receiver-in-the-Canal hearing aid
RM	Remote Microphone
UoA HATC	The University of Auckland Hearing and Tinnitus Clinic
WHO	World Health Organization

## **Introduction**

Communication is an essential part of our existence as social beings, contributing to psychosocial and emotional wellness (Danermark, 2005; Krauss, 2002). Hearing loss can disrupt one's ability to engage in effective communication with others (Danermark, 1998). The effects of this can adversely impact the quality of life, not only of those with hearing impairment, but also those around them, which is known as third-party disability (Grenness, Meyer, Scarinci, Ekberg, & Hickson, 2016; Scarinci, Worrall, & Hickson, 2008, 2009, 2012; World Health Organization, 2001a). Family-centred-care can be applied clinically to help address the third-party disability impacting on family members of those with communication disorders (Ekberg, Meyer, Scarinci, Grenness, & Hickson, 2015; Grenness et al., 2016; Scarinci, Meyer, Ekberg, & Hickson, 2013).

The Family Oriented Communication and Assessment Solutions (FOCAS) tool is proposed for use as a clinical tool to efficiently incorporate family-centred-care in adult audiology practice (Crowhen & Turnbull, 2018a). The intention is to address the impact of third-party disability, and directly involve family members in the rehabilitative treatment of hearing loss, in order to improve outcomes (Crowhen & Turnbull, 2018a). FOCAS also aims to address further gaps in audiological service provision that have been identified in recent literature (Crowhen & Turnbull, 2018a) such as the emotional impact of hearing loss, and the exploration of far-field hearing needs. The Family Oriented Communication and Assessment Solutions: Motivation and Experience (FOCAS-ME) tool adds elements to FOCAS which aim to address potential barriers to hearing aid (HA) uptake (Crowhen & Turnbull, 2018b).

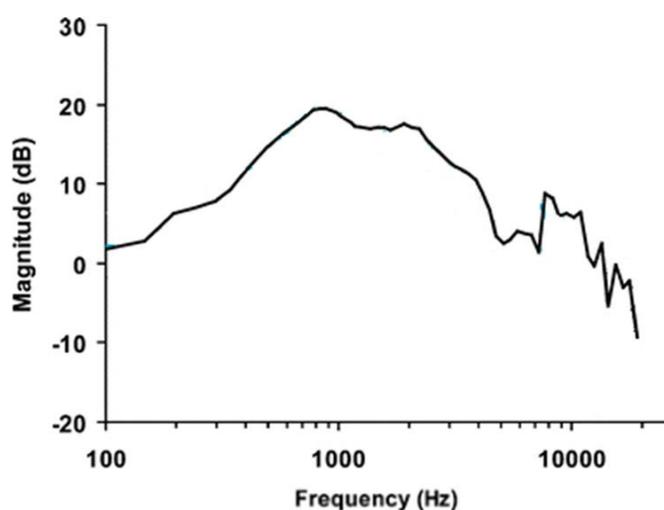
This research will investigate the clinical application of the FOCAS-ME tool as compared to current standard audiological practice, represented by HAD appointments at the UoA HATC. The aim is to discuss the benefits of introducing FOCAS-ME as a clinical tool to address the gaps in adult audiology service provision identified in recent literature. The information gathered in FOCAS-ME and HAD appointments will be analysed, with a focus on rehabilitative service provision in adult audiology, in order to contribute to the enhancement of audiological service provision for adults with hearing loss, and their families. This was conducted through qualitative analysis of case records from HAD appointments at the UoA HATC, and case records of adult audiology appointments using the FOCAS-ME tool.

## Chapter 1: Literature Review

### 1.1 Hearing: The Human Auditory System

Humans can hear sounds that range in frequency from 2–20,000 hertz (Hz) (Schlauch & Nelson, 2015). The most important frequencies for human speech perception range between 125–8000 Hz (Amlani, Punch, & Ching, 2002; French & Steinberg, 1947). The human auditory system is designed to enhance certain frequencies that fall in this range of important speech sounds (Pickles, 2013). This begins with a filtering process starting with the outer ear's pinna, which is the externally visible cartilaginous portion of the ear, and the external ear canal, which terminates at the ear drum (Pickles, 2013). A good portion of low frequency noise that comes into contact with the pinna is deflected away, effectively being filtered out by the system before it hits the ear drum (Ballachanda, 1997). The external ear canal increases the sound pressure level of a range of frequencies, particularly the frequencies between 2000–7000 Hz, which strike the eardrum and cause it to vibrate, transmitting the sound pressure to the middle ear (Ballachanda, 1997).

The filtering process continues when the acoustic energy travels through the middle ear and into the hearing organ, or cochlea (Pickles, 2013). The middle ear is an air-filled cavity on the interior side of the ear drum, in which reside the three tiny ear bones, called ossicles (Rosowski, 2012). The ossicles form a chain that connect from the interior surface of the ear drum to a membrane leading to the inner ear organ, the cochlea, which is filled with fluids (Rosowski, 2012). When the ear drum vibrates, the movement transfers to the ossicles, and their connection to the inner ear's membrane causes this vibrating energy to be transmitted to the cochlear fluids (Pickles, 2013). The highest concentration of acoustic energy transferred through the middle ear to the cochlea occurs at



**Figure 1: The transfer function of the human middle ear. Adapted with permission from Nakajima, Dong, Olson, Merchant, Ravicz, & Rosowski (2009).**

around 1000 Hz, with gradually less energy being transmitted towards the lower and higher frequencies (Figure 1).

Inside the cochlea are thousands of tiny nerve cells, which move back and forth when the cochlear fluids vibrate (Pickles, 2013). Through this movement the cells send signals along the auditory nerve, and up pathways to the brain, where the signals are processed and interpreted as sound (Pickles, 2013). The information being transmitted along this pathway is very complex, involving not just the frequency of sounds, but also intensity and timing (Pickles, 2013). Intensity is perceived as loudness, and timing cues help to locate sounds in space, and importantly, to separate speech sounds from other environmental sounds (Musiek & Baran, 2018).

## **1.2 Hearing Loss**

A variety of factors can cause hearing loss. These include genetic disorders, illness, disease, loud noise, and trauma (Sataloff & Sataloff, 2005b). Medicines that are potentially harmful to the inner ear, called ototoxic, can also cause hearing loss, such as some drugs used in cancer treatment (Schlauch & Nelson, 2015). Hearing loss may be congenital, appearing at birth, or acquired, appearing later in life (Virag, Hawkshaw, & Sataloff, 2005). The loss can be temporary, such as in the case of an illness like otitis media with effusion, also known as ‘glue ear’ (Browning, Rovers, Williamson, Lous, & Burton, 2010). This is when the middle ear cavity becomes temporarily filled with a thick fluid that interferes with the movement of the ossicles, impeding the transfer of acoustic energy and causing hearing loss (Browning et al., 2010). When the fluid resolves, either through surgical intervention or spontaneously, the ossicles can move freely again and hearing is restored (Browning et al., 2010).

Permanent hearing loss occurs when there is irreversible damage to auditory structures or nerves (Musiek & Baran, 2018). For example, structural damage can occur from head trauma, and nerve damage can be caused by excessive noise or ototoxic medications (Sataloff & Sataloff, 2005a). Permanent hearing loss may also occur if there is an unresolvable chemical imbalance in the inner ear, as in the case of Ménière's disease (Paparella, 1985). Depending on the nature and location of the damage, hearing loss can affect the ability to hear some frequencies while leaving others intact, or can affect the entire frequency spectrum (Dillon, 2012).

Two common causes of acquired permanent hearing loss are long-term noise exposure and aging, both of which primarily affect older adults, and cause a similar type of hearing impairment (Rabinowitz, 2011). The resultant damage is mainly to the sensitive inner ear nerve cells, higher frequencies being generally affected first, and the effect tends to be gradual (Hong, Kerr, Poling, & Dhar, 2013). When there is damage that impacts the processing of higher frequency sounds, this affects the ability to hear consonants, which are extremely crucial for understanding speech (Amlani et al., 2002; French & Steinberg, 1947). The problem is exacerbated in the presence of noise, which is largely made up of low frequencies (Dillon, 2012). Distance will also be more of a detriment to people with high frequency hearing loss, as high frequency acoustic energy dissipates faster over time (Emanuel & Letowski, 2009).

### **1.3 The Impact of Hearing Loss**

#### **1.3.1 The World Health Organisation and Hearing**

Since the 1990s, the World Health Organization (WHO) has increasingly recognised hearing loss as a global public health priority (Chadha & Cieza, 2018). The 2000 Global Burden of Disease Study, published in the 2001 World Health Report, estimated adult-onset hearing loss as globally the second leading cause of years lost due to disability (YLD) (Mathers, Smith, & Concha, 2000; World Health Organization, 2001b). The WHO International Classification of Functioning, Disability and Health (ICF) classifies hearing loss as a disability that affects multiple aspects of a person's health, including participation, environmental and personal factors (Grenness et al., 2016; World Health Organization, 2001a). In 2006 the WHO created resources to provide training on primary ear and hearing care at a community level (World Health Organization, 2006).

In 2015 the WHO created the Make Listening Safe initiative, to combat noise-induced hearing loss, especially amongst youth populations, of whom it is estimated more than 1 billion are at risk of recreational noise-induced hearing loss (Chadha & Cieza, 2018). The WHO's programme for prevention of deafness and hearing loss was approved and adopted by the 70th World Health Assembly on May 30, 2017, in Geneva, Switzerland (Chadha & Cieza, 2018; World Health Organization, 2017a, 2017b). According to latest estimates by the WHO on deafness and hearing loss, an estimated 466 million people have hearing loss that can be classified as disabling, and this figure could almost double by the year 2050 (World Health

Organization, 2018). Of these, 432 million are adults, including one third of all people over the age of sixty-five (Stevens et al., 2013; World Health Organization, 2018).

### **1.3.2 The Psychosocial Impact of Hearing Loss**

The use of linguistic communication is an intrinsic part of the social behaviour of human beings (Danermark, 2005; Krauss, 2002; Mead & Morris, 1967). A disruption of that faculty, like that caused by hearing loss, will therefore affect social habits and interactions, affecting a person's confidence and their willingness to engage in the rituals of social communication (Danermark, 1998). This can lead to avoidance behaviours and social isolation (Christian, Dluhy, & O'Neill, 1989; Danermark, 1998; Hallam & Corney, 2014; Mulrow, Aguilar, Endicott, Tuley, et al., 1990). Early research on the social impact of hearing loss often focused on the loneliness that isolation caused in elderly people (Chen, 1994; Christian et al., 1989; Pronk et al., 2011). Correlations have been found between the extent of hearing loss and the amount of loneliness felt, so long as the hearing loss was experienced as a handicap (Chen, 1994; Limburg, 1990; Perlman, Gerson, & Spinner, 1978).

Unlike members of the Deaf community who use Sign Language, those with acquired hearing loss only have written forms of communication to fall back on when verbal communication is disrupted, so are more likely to be deprived of social interaction due to their disability (Magilvy, 1985). Additionally, the presence of a second sensory impairment such as visual impairment, which often occurs simultaneously in older people with hearing loss, can mitigate the utility of coping mechanisms, for example lip-reading (Heine & Browning, 2002). Social withdrawal is therefore a common sign of hearing loss (Mulrow, Aguilar, Endicott, Tuley, et al., 1990; Yueh, Shapiro, MacLean, & Shekelle, 2003), particularly amongst older adults (Brink & Stones, 2007; Mick, Kawachi, & Lin, 2014).

Avoidance behaviours are not limited to physically withdrawing, but also include tactics such as dominating conversations by doing all the talking to avoid having to listen, and similar strategies (Meister, Walger, Brehmer, Von Wedel, & Von Wedel, 2008; Williams, Falkum, & Martinsen, 2015). These defensive forms of behaviour may stem from a desire on the part of the hearing-impaired person to regain some control, mandating the structure of communication to maintain contact on their terms, or as an attempt to hide the impediment (Danermark, 1998; Hallberg & Jansson, 1996; Hallberg & Carlsson, 1991). The psychosocial impact of hearing

loss is prevalent among the elderly, being proportionately the population most affected by hearing loss (Stevens et al., 2013; World Health Organization, 2018).

However, avoidance behaviours and social isolation occur in hearing-impaired adults of all ages (Hallam & Corney, 2014; Hallberg & Barrenäs, 1995; Héту, Riverin, Lalande, Getty, & St-Cyr, 1988; Nachtegaal et al., 2009; Thomas & Herbst, 1980). For example, avoiding auditory communication while at work, changing employment because of the impairment, and earlier retirement from the work force (Danermark & Gellerstedt, 2004; Ruben, 2000; Thomas & Herbst, 1980; Williams et al., 2015). Hearing loss can affect work-related participation, both social and professional, which may negatively affect relationships, performance and progress (Danermark & Gellerstedt, 2004; Kramer, 2008).

Having a hearing loss can result in fatigue due to the extra listening effort required to overcome the existing communication deficit (Alhanbali, Dawes, Lloyd, & Munro, 2017; Bess & Hornsby, 2014; Héту et al., 1988; McGarrigle et al., 2014). The need to ask for repeats and pay attention at a level of sustained concentration causes additional weariness (Héту et al., 1988). The resultant fatigue can impinge upon on one's ability to participate in social activities. For example, always needing peace and quiet after work, or feeling too tired to take part in the regular activities of family life (Héту, Jones, & Getty, 1993). The association between low energy and fatigue to the person's psychosocial wellbeing doesn't necessarily depend on the extent of the hearing loss, but rather on the extent of the communication difficulties experienced by that individual, and its social and emotional impact on their life (Hornsby & Kipp, 2016).

Denial can arise as a reaction to any illness or disability, including hearing-impairment (Armero, 2000; Erler & Garstecki, 2002; Goldbeck, 1997). This can be exacerbated by the gradual nature of acquired hearing loss, such as noise-induced hearing loss or age-related hearing loss (presbycusis), meaning those affected may start to instinctively or unconsciously develop coping strategies before they even realise there is a problem (Héту et al., 1993; Rolfe & Gardner, 2016). Some of this is a result of lack of awareness of the early warning signs, which alleviates the need for immediate acceptance, and can also lead to a delay in seeking treatment (Héту, Getty, & Waridel, 1994; Rolfe & Gardner, 2016; Yueh et al., 2003). Another factor is the perceived stigma associated with hearing loss, which may lead to a reluctance to acknowledge the reality of the situation, and therefore to seek needed help (Héту et al., 1994; Héту, Riverin, Getty, Lalande, & St-Cyr, 1990; Monzani, Galeazzi, Genovese, Marrara, &

Martini, 2008; Saunders, Cienkowski, Forsline, & Fausti, 2005; Southall, Gagné, & Jennings, 2010; Van den Brink, Wit, Kempen, & Van Heuvelen, 1996).

This unwillingness to accept that there is a problem is potentially exacerbated by the act of social withdrawal, because removing oneself from situations that expose the disability may therefore allow the person to ignore or minimise its existence for that much longer (Armero, 2001; Hallberg & Barrenäs, 1995; Héту et al., 1990). Essentially, hearing loss can impact negatively on a person's social functioning, especially in the case of the elderly population (Heine & Browning, 2002; Mulrow, Aguilar, Endicott, Velez, et al., 1990; Strawbridge, Wallhagen, Shema, & Kaplan, 2000; Wallhagen, Strawbridge, Shema, Kurata, & Kaplan, 2001; Weinstein & Ventry, 1982). Much of this behaviour can be related to the emotional impact of hearing loss (Brink & Stones, 2007).

### **1.3.3 The Emotional Impact of Hearing Loss**

Negative emotions associated with hearing loss often stem from a diminished self-image and low self-esteem. This can come from feelings of inadequacy caused by the adverse effect of hearing loss on the person's ability to participate in the everyday human communication they have grown accustomed to (Chen, 1994; Héту, Lalonde, & Getty, 1987; Magilvy, 1985). This may even include feelings of shame, despite hearing loss not being a deliberate choice (Danermark, 1998). A person with hearing loss can experience anxiety, caused by fear of how they will be perceived by others when unable to communicate properly. For example, the fear of being seen as 'stupid' or even 'crazy', which can lead to feelings of embarrassment (Hallberg & Jansson, 1996; Magilvy, 1985; Mohlman, 2009).

Anxiety can also relate to worrying that their listening needs, perhaps asking for conversational repeats, may be bothersome and annoying to others (Hallberg & Jansson, 1996; Héту et al., 1987). Anxiety can further be caused by the knowledge that a hearing loss results in less capability of responding to emergency warnings such as alarms, or things like the telephone ringing (Héту et al., 1987; Héту et al., 1988). Stress is a natural consequence of the constant anxiety, especially if the hearing loss, and particularly the negative emotional and psychosocial impacts of hearing loss, are not addressed (Héту et al., 1988; Hogan, Phillips, Brumby, Williams, & Mercer-Grant, 2015; Jayakody, Almeida, et al., 2018; Jayakody, Friedland, Eikelboom, Martins, & Sohrabi, 2018).

Depression is another detrimental emotion often associated with hearing loss (Brewster et al., 2018; Brink & Stones, 2007; Chen, 1994; Kramer, 2008; Kramer, Kapteyn, Kuik, & Deeg, 2002; Monzani et al., 2008; Wallhagen, Strawbridge, & Kaplan, 1996; Yueh et al., 2003). This is significant because depression can be very debilitating to a person's overall health and wellbeing (Murray et al., 2012; Wells et al., 1989). Late life depression, the risk of which is heightened by presbycusis, can also be a significant public health burden (Brewster et al., 2018; Hesel et al., 2018). Other negative emotions associated with hearing loss include frustration, anger, and feelings of being dismissed or left out, or as one person put it "...being 'neverminded' to death!" (Convery, Meyer, Keidser, & Hickson, 2018; Magilvy, 1985).

#### **1.3.4 The Quality of Life Impact of Hearing Loss**

The World Health Organization describes quality of life (QoL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (Whoqol Group, 1998). When assessing QoL measures, several factors may be considered. These include activities of daily living, such as basic mobility needs and toileting, versus more subtle functions like personal shopping or talking on the phone (Dalton et al., 2003). Other measures can include mental and physical status and social satisfaction, as well as encompassing psychosocial and emotional components, for instance depression and self-esteem (Dalton et al., 2003; Mulrow, Aguilar, Endicott, Tuley, et al., 1990). Generically, QoL measures can aim to assess overarching concepts, including a person's general perception of their overall health, or of life satisfaction (Ciorba, Bianchini, Pelucchi, & Pastore, 2012). The partly subjective nature of QoL measures can provide a more accurate assessment of the true handicap associated with hearing loss in the individual's life, than audiological data alone (Chen, 1994; Mulrow, Aguilar, Endicott, Tuley, et al., 1990; Polku et al., 2016).

It is not surprising that the extensive psychosocial and emotional impacts of hearing loss may adversely affect a person's quality of life (Agrawal, Platz, & Niparko, 2008). This recognition has led to the development of audiological assessment tools which include quality of life measures, such as the Hearing Handicap Inventory for Adults (HHIA), the Hearing Handicap Inventory for the Elderly (HHIE) and the International Outcomes Inventory – Hearing Aids (IOI-HA) (Ciorba et al., 2012; Cox et al., 2000; Newman, Weinstein, Jacobson, & Hug, 1990; Weinstein, Spitzer, & Ventry, 1986). The Hearing Impairment Impact – Significant Other Profile (HII-SOP) was developed to assess the potential impact hearing loss can have on the

QoL of family members (Preminger & Meeks, 2012). The negative impact hearing loss may have on QoL can be heightened by associated conditions like tinnitus or vertigo, for example in the case of sudden sensorineural hearing loss (Carlsson, Hall, Lind, & Danermark, 2011), or following surgery to remove vestibular schwannomas (Grauvogel, Kaminsky, & Rosahl, 2010). The links between decreased QoL and hearing loss are concerning and may affect large portions of the population, particularly older adults (Ciorba et al., 2012; Dalton et al., 2003; Kamil et al., 2016; Mulrow, Aguilar, Endicott, Velez, et al., 1990; Tseng, Liu, Lou, & Huang, 2018).

### **1.3.5 Public Understanding of Hearing Loss**

Despite the severity and widespread nature of the condition, there is little research investigating the general public's knowledge of hearing loss (Manchaiah et al., 2015). However, anecdotal evidence indicates there are significant misconceptions that hearing aids (HAs) are like glasses, creating an almost instantaneous, complete correction of sensory deficit. Many websites and online articles try and correct this misconception. The existence of the problem is evidenced by the experience of some audiologists when encountering newly diagnosed persons and their family members (Meyer, Scarinci, Ryan, & Hickson, 2015). The phenomenon therefore seems to persist, despite concerted efforts to educate the public, from children to working adults, about acquired hearing loss such as noise-induced hearing loss.

These include the aforementioned resources from the World Health Organisation, as well as the Dangerous Decibels® programme and other efforts (Martin, 2008; Martin, Griest, Sobel, & Howarth, 2013; Martin, Sobel, Griest, Howarth, & Yongbing, 2006; Reddy, 2014; Thorne, Coad, Reddy, & Welch, 2013; Welch, Reddy, Hand, & Devine, 2016; World Health Organization, 2006, 2017a, 2017b). This is not to say that these measures are not worthwhile or effective and should not continue. Rather, it illustrates the insidious nature of so called 'invisible' or 'hidden' disabilities like hearing loss, on people's awareness and perception of it, both those afflicted with the impairment and those who come into contact with them (Chen, 1994; Héту et al., 1994; Rolfe & Gardner, 2016).

There is a definite need for education to continue in all areas, building on the research that has come before (Griest, Folmer, & Martin, 2007; John, Grynevych, Welch, McBride, & Thorne, 2014). The aforementioned initiatives tend to target younger populations and will not necessarily reach older retired adults who have presbycusis, which is another population that

would benefit from targeted educational programmes (Hildesheimer & Muchnik, 1992; Li-Korotky, 2012; Öberg, Marcusson, Ngga, & Wressle, 2012; Peer, 2015; Southall, Gagné, & Leroux, 2006). One advantage of this would be tackling the common view that hearing loss is an inevitable part of ageing, just to be put up with, a view which may persist to this day (Chien & Lin, 2012; Scarinci et al., 2008; Van den Brink et al., 1996). Additionally, emerging research on the relationship between hearing loss and dementia reinforces the need to educate people about presbycusis (Gates & Mills, 2005; Gurgel et al., 2014; Lin, Thorpe, Gordon-Salant, & Ferrucci, 2011; Lin et al., 2013; Lin, Metter, et al., 2011; Panza, Solfrizzi, & Logroscino, 2015; Yuan, Sun, Sang, Pham, & Kong, 2018). This includes the need to educate primary care physicians on the prevalence, risks and signs of presbycusis (Bainbridge & Wallhagen, 2014; Davis et al., 2016; Gates & Mills, 2005; Lustig & Olson, 2014; NHS England and Department of Health, 2015).

The lack of knowledge about the nature of acquired hearing loss as permanent nerve damage, leading to the anticipation of similar results as those obtained from wearing glasses, often results in unrealistic expectations on the part of those affected by hearing loss. These include expecting a complete cure from the affliction, and recovering the full sensitivity of the auditory system, even in complicated listening environments such as discriminating speech in noise (Bille & Parving, 2003; Kricos, Lesner, & Sandridge, 1991; Meister et al., 2008; Meyer et al., 2015; Schum, 1999). These unrealistic expectations can also come from family members, who also may expect HAs to essentially cure the hearing loss, rendering listening strategies no longer necessary (Convery et al., 2018).

Therefore, one of the main issues for audiologists regarding the intervention and treatment of acquired hearing loss, if treatment using hearing technology is to be successful, is appropriately managing expectations, and fully preparing hearing-impaired individuals and their family members for the adaptation process that is required (Jerram & Purdy, 2001; Saunders, Lewis, & Forsline, 2009). Efforts to assist audiologists to achieve this in their practice have been ongoing, with the development of tools, including the ECHO questionnaire (Expected Consequences of Hearing Aid Ownership inventory) and the COSI (Client Oriented Scale of Improvement) (Bille & Parving, 2003; Cox & Alexander, 2000; Dillon, James, & Ginis, 1997). These tools are patient-centred, but do not overtly take into account the expectations of family members, hence the initiative towards that aim by later tools, for instance the Goal Sharing for Partners Strategy (GPS) worksheet (Preminger & Lind, 2012), and the current FOCAS tool initiative (Crowhen & Turnbull, 2018a).

## 1.4 Hearing Technology

The next section will explore two kinds of hearing technology: hearing aids (HAs) and accessory systems such as remote microphones (RMs) and other assistive listening devices (ALDs). The aim will be to investigate the potential benefits of their use, some of which are improved psychosocial and emotional wellbeing, and therefore quality of life, of people with hearing loss and their family members (Chisolm et al., 2007; Hyams, Hay - McCutcheon, & Scogin, 2018; Jerger, Chmiel, Florin, Pirozzolo, & Wilson, 1996).

### 1.4.1 Hearing Aids

Hearing aids (HAs) are designed to amplify sounds to ameliorate the problems caused by hearing impairment to as far an extent as possible (Dillon, 2012). There are essentially two methods that HAs can use to amplify sound for the wearer: air conduction and bone conduction



**Figure 2: Four examples of air conduction hearing aids. (a) In-the-ear (ITE). (b) Completely-in-the-canal (CIC). (c) Behind-the-ear (BTE). (d) Receiver-in-the-canal (RIC). From Moore & Popelka (2016). Used with permission.**

(Mylanus, Van Der Pouw, Snik, & Cremers, 1998). Air conduction HAs use a microphone or microphones to capture the sound, which is then directed into the ear canal via tubes and/or in-the-ear speaker systems (Dillon, 2012). Larger aids can be worn on the body, such as a unit that is carried in a pocket, connecting to the earpiece via lengthened wires. Most air conduction HAs are small devices that are worn behind the ear or inside the ear canal (Dillon, 2012). Figure 2 shows some examples of air conduction HAs.

Bone conduction HAs also use microphones to capture sound, however the sound is transferred to the hearing organ/s through a transducer directly vibrating the skull, either through the skin via an entirely external device, or with the aid of a surgical implant in the bone (Dillon, 2012). Refer to Figure 3 for an example of a surgically implanted bone conduction HA. One reason for prescribing bone conduction HAs is in the case of a middle ear issue that would prevent amplified air conducted sound from being efficiently transferred to the inner ear, requiring a more direct stimulation that bypasses the middle ear system (Lustig et al., 2001; Stenfelt & Goode, 2005). Another reason to use bone conduction instead of air conduction may be in the case of someone who suffers chronic

ear infections that are exacerbated by the constant presence of tubes and/or devices in the ear canal (Lustig et al., 2001; Mylanus et al., 1998; Snik, Mylanus, & Cremers, 1995).



**Figure 3: Example of a surgically implanted bone conduction hearing aid. From Westerkull (2011). Used with Permission**

The primary purpose of all modern HAs is to improve speech perception, and specialised algorithms have been designed, which are based upon the main frequencies of human speech, to optimise that effect (Byrne & Dillon, 1986; Moore & Glasberg, 1998; Seewald, Moodie, Scollie, & Bagatto, 2005). The aim is to mitigate the communication deficits that

hearing loss causes, and the subsequent impact on people's lives. An important part of successfully managing this outcome may be to go beyond whichever level of speech-in-noise improvement that HAs can provide to a wearer, by exploring the response of that wearer in terms of their personal ability to cope with the effects of background noise, which can vary between individuals (Nabelek, Tampas, & Burchfield, 2004). That is to say, hearing aid (HA) outcomes can vary between users, even those whose hearing losses have the same audiometric configuration, depending on a number of factors, such as where the damage is located in the person's auditory system (Lopez-Poveda et al., 2017).

#### **1.4.2 Remote Microphones and Other Assistive Devices**

The biggest issue faced by HA wearers and other people with hearing loss, is the presence of background noise interfering with the speech signal (Dillon, 2012). While there are specialised algorithms in HAs that have been designed to alleviate this as much as possible, another effective way to manage this problem is with the use of remote microphone (RM) systems (Dillon, 2012; Lewis, Crandell, Valente, & Horn, 2004; Thibodeau, 2010). These can be combined with HAs, or used alone, in order to increase the ratio of speech signal to noise in more clamorous environments (Dillon, 2012; Lewis et al., 2004; Thibodeau, 2010). Another problem for people with impaired hearing is that caused by distance. Listening situations where the source of sound is further than one metre away can be said to be in the far-field of hearing (Culling & Akeroyd, 2012). Being in the far-field means that the signal is impacted by the attenuating effect that distance has on sound waves, and decreases in intensity before it reaches the listener (Culling & Akeroyd, 2012). For example, the sound of a television located across the other side of the room, or the voice of someone sitting at the other end of a long table. A

more extreme example is a speaker giving a presentation in an auditorium or large meeting room.

This effect, coupled with the results of reverberation on the signal caused by the environment, makes it even more difficult for hearing-impaired people to hear sounds coming from the far-field, even when wearing HAs (Boothroyd & Iglehart, 1998; Culling & Akeroyd, 2012). RMs and other ALDs, such as TV and phone streamers, can help to overcome these issues by directly inputting the source signal into the HA (Boothroyd, 2004; Boothroyd & Iglehart, 1998). Modern devices use wireless technology to achieve this. RMs can use frequency modulation (FM) (Boothroyd, 2004; Dillon, 2012), or digital wireless radio transmission, as used by the Phonak Roger system, to transport the signal (Wolfe et al., 2013). Television and mobile phone streamers are devices that can directly access the TV or phone's audio output, using similar technology to wirelessly stream the audio directly into the HAs (Johnson, 2017; Smith & Davis, 2014). This streaming ability can be carried out via an intermediary Bluetooth device, or alternatively, built directly into the HA capabilities using a 2.4 GHz protocol that is comparable to Bluetooth (Johnson, 2017).

### **1.4.3 The Positive Impact of Hearing Technology Use**

It has been established in the previous sections that the consequences of hearing loss and its nature as a communication disorder, can negatively impact the psychosocial, emotional, and quality of life status of the hearing-impaired person and their family members. The previous two sections discussed how hearing technology such as HAs and ALDs are designed to improve upon the communication deficits caused by hearing loss. There is evidence that the use of hearing technology can improve the psychosocial and emotional effects of hearing loss, leading to better quality of life (Chisolm et al., 2007; Hyams et al., 2018; Joore, Potjewijd, Timmerman, & Anteunis, 2002; Mulrow, Aguilar, Endicott, Tuley, et al., 1990). For example, reducing depressive symptoms suffered by elderly populations with presbycusis, thereby improving the social functioning of hearing-impaired people and their family members (Cacciatore et al., 1999; Mulrow, Aguilar, Endicott, Tuley, et al., 1990), and combating loneliness (Weinstein, Sirow, & Moser, 2016).

Wearing HAs can actually provide comfort to the wearer, and may help to overcome the desire to conceal the impairment, leading to more confidence in asserting their needs (Backenroth & Ahlner, 2000). There is also evidence that using hearing technology can help improve tinnitus,

leading to greater health and wellbeing for those afflicted (Hodgson, Herdering, Singh Shekhawat, & Searchfield, 2017; Searchfield, Kaur, & Martin, 2010). The use of HAs and other assistive devices can help reduce stress in a relationship that has been adversely affected by hearing loss (Yorgason, Piercy, & Piercy, 2007). More research is needed into the effect hearing technology may be able to have on reducing the listening fatigue experienced by those with hearing loss (Hornsby & Kipp, 2016; McGarrigle et al., 2014), although some benefits have been demonstrated in this area (Hornsby, 2013; Picou, Ricketts, & Hornsby, 2013).

Kochkin (2007a) highlights “multiple environmental listening utility” as being an important factor in hearing technology benefit for the wearer, and links wearer satisfaction with the amount of different environments in which the technology provides sufficient utility. Increasing satisfaction for the wearer in a variety of environments may require the use of remote systems in those situations where HAs alone cannot provide enough signal to noise benefit (Dillon, 2012; Kochkin, 2007a; Lewis et al., 2004; Thibodeau, 2010). The effects of hearing loss can be cumulative, therefore the earlier the intervention, the better the impact may be on long-term QoL outcomes (Ferguson et al., 2017; Joore et al., 2002; Maharani et al., 2018; Timmer, Hickson, & Launer, 2017; Yamada, Švejdíková, & Kisvetrová, 2017). This is even more important in the case of people with a dual vision and hearing sensory impairment (Erber & Scherer, 1999; Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Lin et al., 2004).

#### **1.4.4 Stigma as a Barrier to Hearing Technology Uptake**

As discussed in the previous sections, the use of HAs and/or ALDs has the potential to improve the lives of hearing-impaired people. However, before these benefits can be experienced, the hearing-impaired person has to be willing to try the technology in the first place. A possible barrier to this is the stigma attached to the use of hearing technology. Stigma can be described as a social condition in which one’s identity is perceived to be lessened or devalued, based on the possession, or perceived possession, of a certain attribute or characteristic (Crocker, Major, & Steele, 1998). The attribute or characteristic in this case is hearing loss, but often the stigma around hearing loss is an association with aging, which is frequently viewed very negatively in modern Western societies that tend to be rather ageist (Southall et al., 2010; Wallhagen, 2009). This stigma can manifest as a reluctance to take any measures that may call attention to the hearing loss, in particular wearing HAs, out of fear of the wearer being seen as “old” (Hétu et al., 1994; Kochkin, 2007b; Rolfe & Gardner, 2016; Van den Brink et al., 1996).

Other stigma attached to hearing loss is the perception that one has become “weak” or “flawed”, due to the reduction in hearing ability (Hétu et al., 1994; Kochkin, 2007b; Southall et al., 2010; Wallhagen, 2009). As with ageism, this stigma reflects societal attitudes towards disability, and often emerges from attitudes previously held by the affected person him or herself prior to being hearing impaired, manifesting as a form of self-stigmatisation (Erler & Garstecki, 2002; Hétu et al., 1990; Southall et al., 2010). This can then be exacerbated by others, even significant others, who in lieu of being supportive, reinforce the stigma with their own attitudes, including perhaps a fear of being associated with a stigmatised group (Rolfe & Gardner, 2016; Van den Brink et al., 1996; Wallhagen, 2009). Therefore, reservations about the risk of being stigmatised and treated differently if one is identified as hearing impaired are not entirely unjustified (Hétu et al., 1994; Hétu et al., 1990; Southall et al., 2010; Wallhagen, 2009).

In regard to assistive devices, for example RM systems which used to be very bulky and cumbersome, visibility was an obvious factor in the reluctance of people to use them (Jerger et al., 1996). However, even as technology allows for smaller, more discrete systems, the stigma around calling unwanted attention to the device, and therefore the associated condition, may still be deterrent to some people in the same way that HAs have been (Bakke, Bernstein, Bally, & Pray, 2008; Lesner, 2003). Unfortunately, hearing technology industries can inadvertently perpetuate the stigma associated with hearing loss (Rolfe & Gardner, 2016; Wallhagen, 2009). In their efforts to cater for those who demand the least-noticeable technology available, they produce advertising campaigns that aggressively market the “invisibility” of their products, which can be taken by some as reinforcing the need to hide the impairment as much as possible (Rolfe & Gardner, 2016; Wallhagen, 2009).

There are other barriers that prevent people from procuring hearing technology. For example, cost, physical limitations such as dexterity or cognitive impairments, perceptions that the technology will not be effective, lack of confidence with using new technology, and other psychosocial factors (Boothroyd, 2004; Davis et al., 2016; Ekberg, Barr, & Hickson, 2017; Jerger et al., 1996; Vestergaard Knudsen, Öberg, Nielsen, Naylor, & Kramer, 2010). These are things that all need to be addressed. However, the stigma related to hearing loss is an emotional issue that reflects widespread attitudes in Western society towards aging and disability (Hétu et al., 1994; Kochkin, 2007b; Southall et al., 2010; Wallhagen, 2009).

Addressing the emotional impact of hearing loss on the hearing-impaired person and their family member/s, all of whom may be suffering from, while simultaneously reinforcing,

stigmatising attitudes, is therefore an important part of the counselling process (Hétu et al., 1994; Hétu et al., 1990; Hétu et al., 1988; Van den Brink et al., 1996). Stigma may also reflect the community's general lack of knowledge about the nature of hearing impairment (Hétu et al., 1994). Addressing this, by including family members in the assessment and management process of hearing loss, can ensure that all critical parties receive the same education and instruction regarding its nature, as well as being given the opportunity to share a clear understanding of realistic expectations regarding hearing technology's benefits and limitations (Ekberg et al., 2015).

## **1.5 Third-party Disability and Communication Disorders**

Hearing loss can significantly impact a person's psychosocial and emotional wellbeing, and quality of life (Agrawal et al., 2008; Grenness et al., 2016; World Health Organization, 2001a). It is important to examine the potential effects on these same factors in the case of family members of those with hearing loss (Scarinci et al., 2012). This effect is known as third-party disability (World Health Organization, 2001a). Third-party disability is an acquired disability experienced by someone because of the health condition of a significant other (World Health Organization, 2001a). Communication disorders such as aphasia, and those caused by dementia and hearing loss, demonstrate significant third-party disability on the part of family members (Byrne & Orange, 2005; Grawburg, Howe, Worrall, & Scarinci, 2013; Grenness et al., 2016; Scarinci et al., 2008, 2009, 2012; Threats, 2010).

For example, spouses of persons with aphasia have been described as "hidden victims" because the communication impairment can have on their long-term wellbeing (Threats, 2010). The nature of aphasia as a communication disorder is the complicating factor separating it from the non-aphasic brain injuries caused by strokes (Threats, 2010). Communication impairment is also the most prominent feature highlighted by family members in regard to difficulties associated with dementia (Byrne & Orange, 2005; Murray, Schneider, Banerjee, & Mann, 1999; Orange, 1991; Small, Geldart, & Gutman, 2000; Watson, Aizawa, Savundranayagam, & Orange, 2012; Williamson & Schulz, 1993).

In regard to hearing loss, family members have also been characterised as victims of the condition (Armero, 2001). Hearing loss does not necessarily have the myriad of comorbid functional issues as do other disorders affecting communication, like aphasia (Hilari, 2011). For example, full speech and language function can be retained, and other functions such as

memory and physical bodily health can remain intact (Scarinci et al., 2009). However, the essential nature of hearing loss as a communication disorder is what causes third-party disability to feature so prominently (Danermark, 2005; Héту et al., 1993; Scarinci et al., 2012). This is exacerbated if there is any denial on the part of the hearing-impaired person about the extent of their loss (Armero, 2001).

Due to the disability affecting everyone involved in intimate or close relationships with the person with hearing loss, maladaptive coping behaviours can arise, among others misplaced blame, the unwanted curtailment of social activities, and the shouldering of additional undesired communication burdens on the part of family members (Armero, 2001; Scarinci et al., 2008, 2012). Furthermore, coping strategies employed by the person with hearing loss, for instance turning up the television loud enough to hear it, can directly affect family members' comfort and peace (Héту et al., 1987). These behaviours can lead to strong feelings of resentment and frustration held by the family member, and decrease their relationship satisfaction (Anderson & Noble, 2005; Scarinci et al., 2008). Additionally, the discreet nature of acquired hearing loss, and the lack of knowledge about its effects, can mean that the communication difficulties that arise are erroneously attributed to an unwillingness on the part of the hearing-impaired person to engage, which may lead to hurt feelings (Héту et al., 1987).

Depression can also affect family members of hearing-impaired persons (Wallhagen, Strawbridge, Shema, & Kaplan, 2004). The Hearing Impairment Impact - Significant Other Profile (HII-SOP) was developed to assess the potential impact hearing loss can have on the QoL of family members, as this is also important to assess (Kamil & Lin, 2015; Preminger & Meeks, 2012). Essentially, the third-party disability caused by hearing loss can negatively affect the emotional, mental, and physical wellbeing of the sufferer, and is therefore important to address when considering the treatment and management of hearing loss (Kamil & Lin, 2015; Wallhagen et al., 2004).

## **1.6 Family-Centred Care**

### **1.6.1 The History and Development of Family-Centred Care in Early Intervention**

Prior to the 1900s, the dominant Western health care model was the medical model of care, which emphasised the professional's role over that of the patient, who was often reduced to a

mere recipient (Allen & Petr, 1996). This model essentially reduced family members to obstacles to be overcome, lacking the ability to contribute anything meaningful (Dunst, Johanson, Trivette, & Hamby, 1991). A similar approach to the family could also be seen in child-focused models, in which, despite more recognition of the child as a person rather than solely an “illness”, the family remained merely an accessory (Ahmann, 1998). As early as 1917, however, the concepts behind what is now known as family-centred care (FCC) were being expressed by social work pioneers such as Mary Richmond (Allen & Petr, 1996). The emergence of family-centred practice meant a shifting away from the medical model of care that had dominated the early part of the 20th century (Allen & Petr, 1996).

In 1948, in St Paul, Minnesota, a study of families who were placing the highest demand on community social services confirmed that the largest share was going to a relatively small percentage of the community’s families (Birt, 1956). The conclusion was that families, especially those with multiple complex needs, were not benefitting from the disconnected, individually-oriented care being provided by the disparate agencies involved with them (Birt, 1956). It was decided that these families required a more holistic, multidisciplinary approach that focused on the family as a whole (Birt, 1956). This galvanised the formation in the 1950’s of the Family-Centered Project of St. Paul, Minnesota, who coined the term “family-centered” (Birt, 1956). The concept was also being used by other social work practitioners of the day. Scherz (1953) included family members in counselling and service delivery, recognising their role in the dynamics of the situation being addressed, and the need to actively involve them in the process, to improve outcomes for the child whose needs were being assessed (Allen & Petr, 1995).

Throughout the subsequent decades, the implementation of FCC into practice was continued by the social work profession, childhood education, and in nursing, especially obstetrics and paediatrics (Allen & Petr, 1995). In 1985 the US Surgeon General, Dr Everett Koop, pioneered initiatives that led to the formation of the 1987 Association of the Care of Children’s Health, which outlined eight key elements of FCC (Hostler, 1999). One of the main drivers of change came directly from families’ dissatisfaction with the services they were receiving (Hostler, 1999). In the United States, this led to the establishment of the Institute for Family-Centered Care (IFCC), which was formed in 1992 (American Hospital Association and the Picker Institute, 1997; Hostler, 1999). New Zealand has also been a pioneer of FCC in social work, with the formation of the Children, Young Persons and their Families Act of 1989, and the implementation of Family Group Conferences (FGCs), a collaborative approach involving

families in decision-making around the management of children in care (Allen & Petr, 1995; Levine, 2000).

In the last few decades, efforts have been made to form a specific definition of FCC, based on key elements, including: the family as the unit of attention; family strength; family choice; and collaboration or partnership between family and professionals (Allen & Petr, 1996; Epley, Summers, & Turnbull, 2010). Consensus has not been reached on an absolute definition, with conceptual differences still apparent between families and practitioners, and amongst the different professions administering FCC in their various practices (Hoffman, 2016). This may be partly because of the structural changes required to successfully establish FCC in a professional body, which has in the past been underestimated by leadership and practitioner alike (Hostler, 1999; Lawlor & Mattingly, 1998). Additionally, there is a need for more research, education and training (Bamm & Rosenbaum, 2008; Dunst, 2002; Epley et al., 2010; Lawlor & Mattingly, 1998). Despite the lack of consensus and varied application amongst disciplines, FCC is set apart from prior approaches to early intervention programmes, through its dedication to providing avenues for family involvement and empowerment. The motivation for this is that in doing so, the needs of the child may be more successfully met (Viscardis, 1998).

### **1.6.2 Family-Centred Care in the Adult Arena**

The previous section outlined the origins of FCC in child social work, education and health care. When moving into the adult arena, one encounters a myriad of centred care models. The main references found are patient-, person-, client- and relationship-centred care, as well as family-centred. Thematically, all centred care models share underlying fundamental concepts related to improving encounters between patients or clients, and their service providers (Hughes, Bamford, & May, 2008). Often, models are used interchangeably in the literature, in particular patient- and person-centred, although there have been attempts to make clear distinctions (Buetow, 2011; Starfield, 2011). Patient- and family-centred care are also often combined (Ewart, Moore, Gibbs, & Crozier, 2014; Frampton & Guastello, 2014; van Mol et al., 2017).

The Patient-centred care model applied to adult health had established viewing the patient as a person rather than solely an illness to be cured (Epstein, 2000). The Institute for Family-Centered Care (IFCC) encouraged and facilitated the expansion of FCC into adult care

(Johnson, 2000). However, in 2010 the IFCC changed its name to The Institute for Patient- and Family-Centered Care (IPFCC) to acknowledge the role adult patients play in their own care, while still taking into account the indispensable role that family plays in the collaborative treatment process (Institute for Patient- and Family-Centered Care, 2010). This section will explore Family-centred care as applied to adult health care, either as a single model or combined with Patient-centred care.

By the 1990s FCC had moved beyond paediatrics into such areas as geriatric medicine and adult oncology (Johnson, 2000; Shaw, 1999). The underlying core principles that had underlined FCC in paediatrics and early intervention remained, using the concepts of family strength, collaboration and partnership (Shaw, 1999). Institutions were discovering that involving families of chronically ill adults through FCC practices had the same benefits for the adult patients' care as it did for children (Shaw, 1999). Additionally, many adult patients have children and others who depend on them for primary care (Johnson, 2000).

Incorporating FCC into the treatment plan considered the burden on patients with dependents, by providing support not only for adult family members, but for the patients' children as well (Johnson, 2000). In the USA, the Institute for Family-Centered Care initially concentrated on hospitals, with an educational focus, prioritising academic medical centres (Johnson, 2000). The implementation of FCC practices in acute medicine such as ICU services has been a recent focus, leading to calls for more research and education regarding its practice in these areas (Boyd et al., 2017; Goldfarb, Bibas, Bartlett, Jones, & Khan, 2017; van Mol et al., 2017). The role of FCC in chronic adult care remains a priority also. This is bolstered by the shift from curative to palliative care, and reflects the growing role of family caregivers in conditions like heart failure and dementia (Deek et al., 2016; Eloniemi-Sulkava et al., 2009; Pressler et al., 2013), as well as stroke rehabilitation and aphasia (Creasy, Lutz, Young, & Stacciarini, 2015; Ekberg et al., 2015; Nayeri, Mohammadi, Razi, & Kazemnejad, 2014; Visser-Meily et al., 2006).

The benefits of applying FCC to adult health care include greater patient and family satisfaction with services, through enhanced understanding on the part of health practitioners about the needs of patients and their families (Eloniemi-Sulkava et al., 2009; Shaw, 1999). There is also evidence of improved physical and mental health outcomes, and better adherence to treatment (Deek et al., 2016; Goldfarb et al., 2017; Nayeri et al., 2014; Renshaw, Steketee, & Chambless, 2005). FCC also has the potential to provide economic benefit by reducing resource demand

for acute services, and reducing the amount of institutional care needed for chronic conditions (Eloniemi-Sulkava et al., 2009; Goldfarb et al., 2017).

A key element is the individualisation of services when FCC is utilised (Bliuc, Costea, Mihai, & Stratulat, 2018; Deek et al., 2016). This is the same principle as with Patient-centred care; that of the patient as a person with individual needs, simply applied in a context which recognises the family and patient as one individualised unit, whose needs ought to be tailored to accordingly (Eloniemi-Sulkava et al., 2009; Fleming et al., 2006; Goldfarb et al., 2017; Hughes et al., 2008; Rathert, Wyrwich, & Boren, 2012). Health practitioners have recognised the benefits of implementing adult family-centred care, taking a keen interest in learning about and implementing its approaches to health care delivery, to improve their practice and their communication with families (Johnson, 1999; Shaw, 1999). Family-centred care approaches may also result in reduced re-admission rates, which will help ease overburdened health systems and practitioners (Peter et al., 2015).

### **1.6.3 Family-Centred Care in Adult Audiology**

Family-centred care is not a new concept in audiology, due to its long-term application in paediatrics (Gravel & McCaughey, 2004). Recent research in audiology recognises the need for FCC in adult clinical practice, especially amongst older patients with co-morbid conditions (Ekberg et al., 2015; Grenness et al., 2016; Scarinci et al., 2013). Third-party disability is prevalent among family members of people with hearing loss, which can have significant consequences that ought not to be neglected (Armero, 2001; Kamil & Lin, 2015; Meyer et al., 2015; Scarinci et al., 2009, 2012; World Health Organization, 2001a).

The nature of hearing loss as a communication disorder means it inherently affects family members, as any disruption in communication will influence a wide range of daily activities and interactions for all involved (Wallhagen et al., 2004). This ultimately affects quality of life (Dalton et al., 2003; Grenness et al., 2016; Wallhagen et al., 2004). The communication aspect is shared with conditions such as aphasia, which also has prevalent third-party disability, and where there is recommendation for FCC practices (Ekberg et al., 2015; Visser-Meily et al., 2006; Worrall et al., 2010). In its policy document Preferred Practice Patterns for the Profession of Audiology, The American Speech-Language-Hearing Association (ASHA) acknowledges family member involvement for all patients as an integral part of services (American Speech-Language-Hearing Association, 2006).

As with dementia, stroke rehabilitation and heart disease, patients in the adult audiology population tend to be in the more advanced age range (Grenness et al., 2016; Huang & Tang, 2010). However, hearing loss can affect adults of all ages, including working adults with dependant family members (Hallberg & Barrenäs, 1994; Nelson, Nelson, Concha-Barrientos, & Fingerhut, 2005; Wilson, Tucci, Merson, & O'Donoghue, 2017). Therefore, the individualised approach of FCC, as consistent with the principles of patient-centred care, is an important aspect of its application towards a more successful outcome (Rathert et al., 2012; Visser-Meily et al., 2006; Worrall et al., 2010).

Further benefits of applying FCC to adult audiology include increased awareness by family members about the problems their hearing-impaired family member is experiencing, which leads to better understanding, and more productive application of communication strategies that may be suggested by audiologists (Hallberg & Barrenäs, 1994; Scarinci et al., 2008). With increased awareness comes increased acceptance, leading to improved relationships and a reduction in the negative impact hearing loss can have on family life (Backenroth & Ahlner, 2000; Scarinci et al., 2008). Involving family members in audiological rehabilitation enables goal sharing, which can increase motivation and commitment to treatment programmes (Jennings, 2009; Preminger, 2003; Preminger & Lind, 2012).

Directly involving family members may be helpful in overcoming any denial that the hearing-impaired person may have about their hearing loss, assisting in the resolution of conflicts that denial can cause in the relationship (Armero, 2001; Heine, Erber, Osborn, & Browning, 2002). Additionally, involving the family will help facilitate communication strategies that are age-appropriate, and consider any conditions the family member may have that may affect their ability to engage in certain strategies (Heine et al., 2002; Scarinci et al., 2012; Trychin, 2012). This family involvement in the rehabilitation process is supported by some audiologists, who recognise the important role family members must play (Meyer et al., 2015). FCC can impact positively on the success of audiological interventions like HAs, improving uptake and resulting in better patient satisfaction (Hickson, Meyer, Lovelock, Lampert, & Khan, 2014; Manchaiah & Taylor, 2017; Preminger, 2003).

#### **1.6.4 Factors Affecting the Implementation of Family-Centred Care in Adult Health**

While Family-Centred Care has long been the avenue of paediatric health and early intervention programmes, there remain important structural and conceptual issues across disciplines that need resolving (Dunst, 2002; Epley et al., 2010; Hoffman, 2016; MacKean, Thurston, & Scott, 2005). It is therefore worthwhile to discuss how similar factors may affect the implementation of FCC in adult health care, to ensure effectiveness and sustainability. To be sustainable, the implementation of FCC at an institution would ideally be a cultural change that is overarching and structural, integrated into the core mission, philosophies and beliefs of the institution (Ahmann & Johnson, 2001; Henneman & Cardin, 2002; Hostler, 1999; Johnson, 1999; Johnson, 2000). This requires commitment at every level, not just at an individual practitioner level (Hostler, 1999; MacKean et al., 2005). Without direct input from family members and patients, there may be a lack of effectiveness due to devolution back to a professional-driven model (Ahmann & Johnson, 2001; MacKean et al., 2005).

However, in allowing direct input from patients and family members, there is a need to manage the possible risk of service providers feeling threatened by a perceived loss of their authority (Rosenbaum, King, Law, King, & Evans, 1998). Therefore, proper avenues for regular reviews, debriefing and specialised training need to be put in place (Hostler, 1999; Lawlor & Mattingly, 1998). Cultural respect for the clinical population must not be overlooked either, as no modern society is homogenous, and cultural sensitivity is an obligation regardless (Deek et al., 2016; Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003; Lawlor & Mattingly, 1998; Ngui & Flores, 2006; Nogueira Peredo, 2016).

Clinical appointment time is another very important factor, and this is a significant occupational stress for audiologists (Severn, Searchfield, & Huggard, 2012). The significance in regards to clinical appointment time of directly involving not just patients, but their family members, in treatment decisions and in setting rehabilitation goals, needs to be considered when promoting the delivery of FCC (Hostler, 1999; MacKean et al., 2005). While this may be daunting to a practitioner who has a limited time to accomplish certain tasks, while being required to adhere to professional guidelines and practice standards, it is often a matter of time management and efficient information framing and sharing (Boisvert et al., 2017; Hibbard, Slovic, & Jewett, 1997; Hostler, 1999; Turnbull, 2016). Accordingly, this factor may be addressed without necessarily having to increase appointment times. For example, during

audiology appointments, time management practices facilitating FCC include a decrease in the amount of time audiologists talk during the appointment, to allow more input from not only the patients, but their attending family member/s (Ekberg et al., 2015; Meyer et al., 2015). This requires a shift in focus from a closed question, site-of-lesion, audiologist-driven dialogue, to more open-ended questions that facilitate FCC practice (Hickson et al., 2016).

Individual family dynamics also must be carefully negotiated and managed by clinicians who wish to practice FCC, such as those caused by mismatched needs and incongruent perspectives between the parties (Meyer et al., 2015; Saunders, Preminger, & Scarinci, 2017). Due to the third-party disability common in hearing loss, the requirement of direct family member input into treatment plans and rehabilitation processes may cause longstanding misunderstandings and resentments to arise, potentially complicating the appointment process (Armero, 2001; English et al., 2016; Kamil & Lin, 2015). Also required is knowledge about the family's culture of communication. For example, such concerns may have remained previously unvoiced due to cultural reluctance to discuss illness, or other factors (Deek et al., 2016; Kleinman, Eisenberg, & Good, 1978; Pasick, D'onofrio, & Otero-Sabogal, 1996; Whitley, 2009).

Another important consideration is scheduling issues that may arise, resulting from the requirement of family member attendance to audiological appointments, particularly amongst the working population and those with children (Meyer et al., 2015). This is especially significant when considering the multiple appointments often required for successful fitting and management of hearing technology like HAs, which are commonly prescribed for many types of hearing loss (Dillon, 2012).

## **1.7 FOCAS**

### **1.7.1 Development**

The Family Oriented Communications Assessment and Solutions (FOCAS) tool was developed by David Crowhen, MAud, Audiologist & Brand Manager at Phonak New Zealand; and Bettina Turnbull, MAud, Director of Audiology & Education, Sonova Asia-Pacific. FOCAS was developed in order to provide a tool that assists clinicians to more efficiently implement FCC in adult audiology appointments, and to more thoroughly address the far-field hearing needs of people with hearing loss (Crowhen & Turnbull, 2018a). Additionally, FOCAS aims to provide a useful way for clinicians to address the emotional impact of hearing loss on their clients with hearing impairment, and their families (Crowhen & Turnbull, 2018a). In

2015, Phonak convened experts in the field of hearing healthcare to provide recommendations regarding the implementation of FCC in audiological practice (English et al., 2016; Hickson et al., 2016; Saunders et al., 2017; Singh et al., 2016; Turnbull, 2016). Recent research has demonstrated the benefits of implementing FCC in the field of adult audiology (English et al., 2016; Hickson et al., 2016; Saunders et al., 2017; Singh et al., 2016; Turnbull, 2016), as well as exploring the emotional impact of hearing loss (Singh et al., 2017; Singh et al., 2016). Also demonstrated, was the link between wearer satisfaction and the amount of utility provided by hearing technology in multiple listening environments (Crowhen & Turnbull, 2018a; Kochkin, 2007a).

The FOCAS developers conducted a survey of 76 hearing healthcare professionals worldwide (Crowhen & Turnbull, 2018a). This showed a low attendance of family members to audiological appointments, and less than 50% of those surveyed reported regularly (i.e. either “mostly” or “always”) exploring the far-field needs of their hearing-impaired clients (Crowhen & Turnbull, 2018a). The survey showed the COSI (Dillon et al., 1997) was the preferred tool amongst clinicians who used a formal tool. The COSI was preferred due to its ease, concise administration, and high validity (Crowhen & Turnbull, 2018a). Additionally, the surveyed clinicians appreciated the provision of goal setting and ability to track the benefit that the COSI efficiently provides (Crowhen & Turnbull, 2018a).

The goal of FOCAS is to retain those aspects in a single tool that also includes family member involvement, explores the emotional impact of hearing loss, and has a more holistic assessment of hearing needs that includes addressing far-field needs (Crowhen & Turnbull, 2018a). A further insight gained from the survey was the desire for communication assessment tools to be available in different languages, therefore an additional goal of the FOCAS was to accommodate this, and presently the FOCAS has been translated into 21 languages (Crowhen & Turnbull, 2018a). There are current proposals underway to pilot the FOCAS tool in New Zealand. The Family Oriented Communication Assessment and Solutions – Motivation and Experience (FOCAS-ME) tool has also been developed (Crowhen & Turnbull, 2018b). The FOCAS-ME consists of all the identical FOCAS sections, but with added elements that explore any prior experience/perceptions of HAs, as well as the client’s motivation to do something to improve their hearing (Crowhen & Turnbull, 2018b). FOCAS-ME is currently being piloted in Australia.

## 1.7.2 Overview

### FOCAS tool

FOCAS was designed to address efficacy issues that have been identified as barriers to providing FCC in adult audiology, and in response to the feedback received from the survey of hearing healthcare professionals (Crowhen & Turnbull, 2018a). It is a single page, interactive pdf form, consisting of free fields to type or write in, drop down menus, and some drag-and-drop elements (Figure 4). Following the details section at the top of the form, there are two key sections, each broken up into parts (Figure 4).

Section one is where client, family member, clinician, and date details can be entered (Figure 4). Section two is for hearing and communication challenges, and section three is for shared and individual hearing and communication goals (Figure 4). There is a structured flow guiding the use of the FOCAS from beginning to end, which uses concepts from the Goal Sharing for Partners Strategy (GPS) guidelines developed by Preminger & Lind (2012) (Crowhen & Turnbull, 2018a). The idea is to use the FOCAS during the initial assessment appointment, and then track outcomes by revisiting it after a certain period of rehabilitation time has passed (Crowhen & Turnbull, 2018a). Section one of the form has two date fields: Assess date and Outcome date, for this purpose (Figure 4). The clinician can type into the form, store it electronically, and the form can be printed out and a copy provided for the client and family member/s to take home. If the clinician prefers to write by hand, the form would be printed out initially, and the electronic version could then be referred to if needed, for the drop-down menu options.

The final section is a diagram in which each goal can be plotted into either the near- or far-field, by dragging and dropping its associated number into the graph (Figure 4). The level of expected noise of each situation is marked on the vertical axis, and the anticipated technology required is indicated on the graph, beginning with the various levels of HA technology from Standard to Premium, to wireless accessories (Figure 4).

## FOCAS – Family Oriented Communication Assessment and Solutions

### 1. Details

Client name: \_\_\_\_\_ Clinician: \_\_\_\_\_  
 Family Member(s): \_\_\_\_\_  
 Assess Date: \_\_\_\_\_ Outcome Date: \_\_\_\_\_

### 2. Hearing and communication challenges

*Adapted from The Goal-sharing for Partners Strategy worksheet from Preminger and Lind (2012).*

#### (i) – Client

Client – challenging situations and impact		Client's perspective on Family's experience and impact	
1.	_____	1.	_____
2.	_____	2.	_____
3.	_____	3.	_____

#### (ii) – Communication partner / family member

Family – challenging situations and impact		Family's perspective on Client's experience and impact	
1.	_____	1.	_____
2.	_____	2.	_____
3.	_____	3.	_____

### 3. Shared and individual hearing and communication goals

*Once goals are set, please print and plot each on the graph in terms of Near/Far field to indicate best technology solutions*

What might you do more of if...? What would the family like to achieve?	Near/Far field	Importance	Optimal Solution	Outcome
1.				
2.				
3.				
4.				
5.				



**Figure 4: The FOCAS tool, an interactive pdf form. From Crowhen & Turnbull (2018a). Used with permission.**

### **FOCAS-ME tool**

FOCAS-ME is adapted from FOCAS, adding a third section called Motivation and experience. (Figure 5). This section contains five questions, the answers to which can be typed or written into the corresponding free fields (Figure 5). These questions address some common barriers to uptake of rehabilitation interventions, such as the client's prior experience of HAs, and their level of motivation regarding improving their hearing (Dillon, 2008), as well as the cost of HAs, which can be another barrier to HA uptake (Ekberg et al., 2017). The questions in this section aid the clinician to address these potential barriers to rehabilitation in a structured and transparent way (Crowhen & Turnbull, 2018b).

For example, regarding HA cost, Ekberg, Hickson, & Barr (2017) investigated how clinicians can approach clients regarding the issue of HA cost in a manner that led to a smoother interaction between them. They concluded that offering multiple price options at once, rather than one single cost option at a time, smoothed out the transaction, because this meant that clients were more engaged in the decision-making process (Ekberg et al., 2017). FOCAS-ME can be used if clinicians want to capture this additional information in the same place. The rest of the form is identical to FOCAS.

#### **1.7.3 Clinical Application and Proposed Benefits of Use**

Audiologists can use the FOCAS or FOCAS-ME at clinical appointments attended by a person with hearing loss and their family member/s, in which the clinician intends to assess listening needs, and discuss potential treatment and rehabilitation options. The second section, Hearing and communication challenges, consists of a client segment and a communication partner/family member segment (Figures 4 and 5). These segments provide each party an equal opportunity to explore the challenges and emotional impact of hearing loss from their own perspective, as well as their perception of the challenges and emotional impact being experienced by their family member/s. The aim is to gain insight into the other's experience, as well as into one's own, and if applicable, expose incongruences between different perspectives, that can then be addressed in order to find the common ground needed to enable shared goal setting (Crowhen & Turnbull, 2018a).

Family Oriented Communication Assessment and Solution – Motivation and Experience (FOCAS-ME)

**1. Details**

Client name: \_\_\_\_\_ Clinician: \_\_\_\_\_  
 Family Member(s): \_\_\_\_\_  
 Assess Date: \_\_\_\_\_ Outcomes Date: \_\_\_\_\_

**2. Hearing and communication challenges**

*Adapted from The Goal-sharing for Partners Strategy worksheet from Preminger and Lind (2012).*

<b>(i) – Client</b>	
Client – challenging situations and impact	Client's perspective on Family's experience and impact
1. _____	1. _____
2. _____	2. _____
3. _____	3. _____

<b>(ii) – Communication partner / family member</b>	
Family – challenging situations and impact	Family's perspective on Client's experience and impact
1. _____	1. _____
2. _____	2. _____
3. _____	3. _____

**3. Shared hearing and communication goals**

*Once goals are set, plot each on the graph in terms of Near/Far field to indicate best technology solutions*

	What might you do more of if...? What would the family like to achieve?	Near/Far field	Importance	Optimal Solution	Outcome
Client specific and shared goals	1. _____				
	2. _____				
	3. _____				
	4. _____				
	5. _____				

**4. Motivation and experience**

- Have you ever had a hearing test? \_\_\_\_\_
- What do you think of hearing aids? \_\_\_\_\_
- Have you done any research on hearing aids? \_\_\_\_\_
- Do you have any idea about prices of hearing aids? \_\_\_\_\_
- How ready are you to do something to improve your hearing? (scale) \_\_\_\_\_



- 1
- 2
- 3
- 4
- 5

Print

Figure 5: The FOCAS-ME interactive pdf. From Crowhen & Turnbull (2018b). Used with permission.

The third section, Shared and individual hearing and communication goals, consists of a segment where goals can be established, and are identified as near- or far-field hearing needs (Figures 4 and 5). Defining the goals as such was identified as important by the developers, as the results of their aforementioned survey indicated that catering to adult far-field needs may often not be considered by audiologists (Crowhen & Turnbull, 2018a). This is despite a prevalence of far-field needs being identified among adult clients (Crowhen & Turnbull, 2018a). Additionally, survey results indicated that many audiologists may not recognise the importance of attending to these needs in a targeted way that might necessitate moving beyond HAs, due to perhaps overestimating their benefit in this regard (Crowhen & Turnbull, 2018a).

Once outlined on the FOCAS, the goals are individually given a measure of importance between 0 and 10 (Figure 6). This has been designed so that instead of rating the goals in an overall order of importance, for example sequentially from 1-5, each is given its own measure in regards to the importance it has in the life or lives of those setting the goal (Crowhen & Turnbull, 2018a). Setting goals in this way can provide self-awareness regarding the issues experienced in different situations, and encourage a shared responsibility regarding adherence to rehabilitation strategies (Crowhen & Turnbull, 2018a).

3. Shared and individual hearing and communication goals					
<i>Once goals are set, please print and plot each on the graph in terms of Near/Far field to indicate best technology solutions</i>					
What might you do more of if...?					
What would the family like to achieve?		Near/Far field	Importance	Optimal Solution	Outcome
1.					
2.			Critical 9-10 Significant 7-8 Moderate 5-6 Occasional <5		
3.					
4.					
5.					

**Figure 6: Drop down options showing importance ratings between 0 and 10. Adapted from Crowhen & Turnbull (2018a). Used with permission**

Classifying each hearing situation identified as being either a near- or far-field need will provide information to help determine what hearing technology option/s or other solutions would provide the optimal benefit in that situation. If the recommended solution for a given situation is unobtainable for any reason, this resource will help create realistic expectations when the rehabilitation plan decided upon is formulated, and potential outcomes discussed (Crowhen & Turnbull, 2018a).

The Optimal Solutions field is not limited to hearing technology, as listening strategies and other solutions can also be entered here (Crowhen & Turnbull, 2018a). In order to track progress, the goals are revisited after a set time (to be decided upon as appropriate by the clinician), and a percentage outcome measure can be indicated via the Outcome drop-down menu (Figure 7). The percentage measure can be used by discretion, as for example the percentage of time the person is hearing better in that situation, or alternatively, the percentage of improvement they feel has been achieved since prior to treatment/intervention (Crowhen & Turnbull, 2018a).

3. Shared and individual hearing and communication goals					
<i>Once goals are set, please print and plot each on the graph in terms of Near/Far field to indicate best technology solutions</i>					
What might you do more of if...?					
What would the family like to achieve?					
		Near/Far field	Importance	Optimal Solution	Outcome
1.					
2.					80-100 60-80 40-60 20-40 0-20
3.					
4.					
5.					

**Figure 7: Drop down options showing outcome ratings between 0 and 100%. Adapted from Crowhen & Turnbull (2018a). Used with permission**

The FOCAS-ME tool contains a fourth section, which explores motivation and experience regarding hearing technology, including cost (Figure 5). This section was added by the developers to incorporate an exploration of the prior experience the person may have had with hearing assessment, as well as their knowledge and thoughts about HAs. It also provides opportunity to create an up-front dialogue about the price of HAs, and the person’s readiness to take action to improve their hearing. Questions 1-3 explore previous experience with hearing tests, and thoughts and possible prior knowledge about HAs (Figure 5). Question 4 opens the discussion about cost, by asking what ideas the person may have regarding prices of HAs (Figure 5).

Cost is often “the elephant in the room” when it comes to clinical audiology appointments, and if not appropriately addressed may compromise clinician-client interactions on the subject (Ekberg et al., 2017). During the discussion that arises from Question 4, clinicians are encouraged to use the approach suggested by Ekberg, Barr & Hickson (2017) to prevent such a compromise (Crowhen & Turnbull, 2018b). Question 5 broaches the subject of motivation

directly, by asking how ready the person is to take action on their hearing loss (Figure 5). Questions 2 and 5 were developed based on research regarding attitude and motivation that led to the development of the Wishes and Needs tool (WANT) used by the Australian Government Department of Health Hearing Services Programme (Figure 5) (Australian Government Department of Health, 2018; Dillon, 2008; Dillon, 2012). WANT assesses a client's attitude and motivation, which are crucial factors in how successful outcomes are for clients (Dillon, 2006; Dillon, 2008).

The diagram which makes up the final section of both forms will become a visual representation of the information recorded in the first segment of the Shared and individual hearing and communication goals section (Figures 4 and 5) (Crowhen & Turnbull, 2018a). Doing this will help to demonstrate the variety of listening environments and challenges faced, and the intervention required to better manage them, with the intent of making it easier for clients and family members to decide which option or options they feel are best suited to their needs (Crowhen & Turnbull, 2018a).

Essentially, what makes the FOCAS tool unique compared to other clinical tools in existence are the following factors: the rating of importance of each goal, rather than selecting the order of importance; encouraging exploration of near- and far-field hearing needs along with the visual tool that plots the goals into near- or far-field, illustrating the solutions that will be optimal for both; the availability in 20+ languages; as well as its incorporation of FCC, all into the one tool. FOCAS and FOCAS-ME are newly developed tools, currently being investigated regarding their utility in implementing FCC into audiology practice, and improving outcomes, through pilot studies in Australia, with further pilot studies proposed in New Zealand. Ongoing validation would be recommended, and there is a need for independent authors to engage in further research and conduct studies, and for the publication of evidence-based outcome measures regarding its efficacy and utility in general audiological practice.

## **Chapter 2: This Study: Purpose and Design**

### **2.1 Background**

Hearing loss has a widespread adverse impact, not just on the life of the person who has a hearing impairment, but also their family members through third-party disability. Hearing technology including HAs, and ALDs such as remote microphones and TV streamers can help address the communication deficits caused by hearing loss, and potentially improve the lives of people with hearing loss and their family members. Despite the potential benefits, the uptake of hearing technology is reasonably low, and adherence to treatment plans, and consistent use of the hearing technology prescribed, is not optimal. This can be because a lack of understanding of the nature of hearing loss results in unrealistic expectations regarding the capability of the technology, causing dissatisfaction and eventual abandonment of treatment. Additionally, the negative emotional associations between hearing and ageing, and other stigmatisation of hearing loss, can be a barrier to seeking treatment in the first place.

Recent literature has identified gaps in adult audiology service provision, which the FOCAS and FOCAS-ME tools aim to address. The FOCAS clinical tool has been designed to address the impact of hearing loss, not only on the hearing impaired, but on those affected by third-party disability, in the realm of adult audiology. FOCAS has also been designed to address the emotional impact of hearing loss and allow affected parties to gain insight on each other's experiences, possibly helping to resolve incongruences and misunderstandings. Through the exploration of far-field hearing needs, FOCAS intends to aid the clinician in setting realistic expectations regarding whichever solution is decided upon by the person with hearing loss and their family, and to provide the entirety of information around what is appropriate and available regarding those needs. The goal is to improve adherence to treatment plans and result in more long-term treatment success. FOCAS-ME expands upon the former to explore the motivation of the person assessed with hearing loss regarding trying hearing technology, including up-front discussions about the prices of hearing aids, and how much previous experience the person has had with hearing assessment and technology. The intention is to help overcome these potential barriers to the uptake of hearing technology, and further contribute to better outcomes.

## **2.2 Purpose**

This study will investigate how the FOCAS-ME tool compares to current standard clinical audiology practice, as represented by HAD appointments at the UoA HATC. To facilitate the comparison, the study intends to outline and present key elements as per the FOCAS-ME inherent structure and design, which consists of the entire FOCAS tool, with an added section encompassing further elements (Figure 5). The study will qualitatively analyse a sample of HAD case records from the UoA HATC and compare them with the key elements. Note that the generic name “Hearing Aid Discussion” is applied to the selected UoA HATC clinical appointments, however, this is an umbrella term for a hearing needs assessment in which may arise discussions about HAs, and/or other assistive listening devices, or the preference to not use any hearing technology and opt for different strategies.

The purpose of the above comparison is to explore whether any of the key aspects of FOCAS-ME may already be addressed in current standard clinical practice, and if so, how this may be occurring, as well as the significance of this not occurring. The information gathered through this study’s analysis intends to be relevant to discussion regarding the benefits of introducing a new clinical tool to address the gaps in adult audiology service provision identified in recent literature. This analysis also intends to evidence any potential gaps that may exist in service provision if the FOCAS and FOCAS-ME tools were to be adopted as an alternative to methods currently being used.

Additionally, themes related to rehabilitative service provision for adults with hearing loss, will be derived from the use of FOCAS-ME in clinical practice, to be analysed and compared with themes derived from the HAD cases. The former will be developed from a sample of completed FOCAS-ME tools used during audiology appointments, and the latter from the selected UoA HATC HAD cases. The purpose of this analysis is to compare the way information is gathered in the FOCAS-ME and HAD appointments, with a focus on rehabilitative service provision in adult audiology, in relation to the issues that were discussed in Chapter 1.

Ultimately, the goal of the research is to provide useful information that may contribute to the enhancement of audiological service provision for adults with hearing loss, and their families.

### **2.3 Worldview and limiting bias**

The author is informed by a worldview that emphasises fairness, possessing a strong sense of justice. This leads to a tendency to empathise with the perceived “underdog” of a given situation more often than not, and can result in a strong reaction to any perceived discrimination or oppression. These characteristics may be seen to belong to what has been defined as the transformative approach to research (Creswell, 2013). However, according to Mertens (2010), the transformative worldview in relation to a research project must have the agenda to confront the oppression itself, and address inequality and other social issues. This research does not have this agenda as such, despite being driven by the desire to help a marginalised group of people who may suffer from discrimination, namely those who have hearing loss. Rather, the aim of the research is geared towards problem-solving, and may be considered in line with a more pragmatic worldview, although perhaps with underlying transformative elements (Creswell, 2013; Patton, 1990).

The author has a history of being quite stubborn and can become fixated on what they perceive to be unfair. It requires an effort on my part to maintain objectivity in the face of perceived unfairness, and to view the situation from all sides. For example, I am deeply sympathetic to the extremely stringent time constraints that many clinical audiologists operate under in their appointments, often due to circumstances and restrictions outside of their control. It happens to be something that I personally view as not very fair, neither to the audiologists nor their clients, and is indeed something I am concerned about for myself, as a future audiologist. When reviewing cases, I cannot help but be aware of the time issue as a potential factor regarding what is covered during a given appointment, and the information that ends up captured and recorded. Notwithstanding, I believe strongly in honesty and integrity, and prefer overwhelmingly to remain truthful, even at the potential cost of my own reputation, rather than engage in a deceit of any sort. I have also had extensive opportunity to practice and apply objectivity to my work, and am much more capable of achieving this nowadays, having enjoyed plenty of life experience. Therefore, the analysis was objectively of the material as contained in the datasets, with no deliberate distortions made.

Consistent with the author’s worldview is the belief that FCC has an important role in adult audiology. The author has also taken part in clinical placements at the UoA HATC through the course of their studies and developed a great respect for the clinicians and practice observed there, including the robust history discussions and needs assessments protocols. The author has

no experience with the clinics or clinicians which provided the completed FOCAS tools for review. These factors were considered as potential inherent bias that the author attempted to avoid. A second coding by the thesis supervisor attempted to limit bias.

I hold a great respect and admiration for all practicing audiologists, and the audiology field as a whole, based on my observations and participation in clinical sessions as a student intern. I have had a tendency to put practicing audiologists “on a pedestal”, feeling quite in awe of their abilities, and suffer from a nagging sense of inadequacy about my own potential to perform as effectively to their standards, once I am fully out in the field. The author acknowledges that when putting people on a pedestal, one risks overlooking that they are also human beings with all the frailties of human nature, and forgetting that everyone, even the most highly achieved individual, makes mistakes. With that in mind, each case study was analysed at face value, without any attached preconceptions regarding length of clinical experience, or academic or personal achievement.

## **2.4 Methods**

This study was approved by the University of Auckland Human Participants ethics committee.

## **2.5 Data Collection**

In order to gather data for the research, a random sample of 20 HAD cases were sourced from records stored in the UoA HATC database. The cases were dated between 1 November 2017 and 1 March 2018 and were selected by accessing the UoA HATC patient management database which is called Medtech (patient management system). Medtech (patient management system) is a registered trademark of Medtech Global. At the time of data collection, the UoA HATC was using Medtech32 Version 22.10 (Build 5555). This database stores attachments in text and picture format, such as Word files and scanned documents, as well as having an internal mechanism to write and store case notes.

The database has a calendar which allows for the retrospective selection of individual calendar days. There is a drop-down menu available, by which any practicing UoA HATC clinician’s name can be selected, and all historical appointments that occurred on that clinician’s caseload on the selected calendar day will appear. The daily appointments of all the practicing clinicians can then be viewed individually and in full, with all their corresponding attachments and case notes. In order to obtain a random sample of cases, all HAD cases that occurred at the UoA

HATC between the dates of 1 November 2017 and 1 March 2018 were identified and selected in MedTech, starting with the earliest occurrence. The relevant data was duplicated into separate Word documents, and the duplicated data redacted all identifying details, including the clinician's name, patient and family member names, dates of birth, and any other identifying information like doctor or medical clinic names. The age of the clients was redacted in order to avoid biasing the analysis in regard to personal circumstances. For example, making an assumption that it was more likely that a person was widowed and living alone, based on how old they were. After redaction, the duplicated information was saved electronically, case by case, and each was numbered sequentially in date order, from the earliest dated case to the last dated case.

All but three of the HAD cases selected used essentially the same internal HAD template form developed by the clinic (Figure 8). It is normal practice to make use of COSI goals during UoA HATC HAD appointments, and the standard template contains a COSI goal section (Figure 8). HAD-02 incorporated the entire needs assessment in the client's history form, including COSI goals. Both HAD-05 and HAD-09 also did not use the HAD template, instead typing the entire hearing aid discussion into a case note, however COSI goals were incorporated herein also. The UoA HATC clinic also has available a diagram that can be used in HADs if the clinician chooses. This diagram is titled Your Hearing Needs (Figure 9). The Your Hearing Needs diagram outlines different technology levels and listening situations and provides space for price estimates for different levels of hearing technology (Figure 9). In the case of the selected HADs, if this diagram was used during the appointment, it was collected as part of the data.

Additionally, accompanying UoA HATC Adult History Guide forms and clinic notes were included in the data collection when available, solely due to the fact that in some of the cases, certain needs assessment information was recorded therein and referred to during the HAD. Audiology case histories generally consist of questions that assist towards assessing risk factors for hearing loss, and creating differential diagnoses of possible pathologies, and also ought to probe for medical red flags such as unilateral tinnitus (Beck, 2015; Zapala, Shaughnessy, Buckingham, & Hawkins, 2008). An example of a generic history question would be: "Is there is a history of hearing loss in your family?" Case notes can contain a range of information, perhaps outlining the plan for the next appointment, or a reminder about what paperwork the audiologist needs to complete.

## Chapter 2 – This Study: Purpose and Design

Hearing Aid Discussion: NAME. DATE. CLINICIAN.

(Copy over Needs assessment and COSI goals from History form if already done)

<b>Currently using HA's?</b>	
TYPE:	
AGE:	
LIKE/DISLIKE:	
DID THEY WORK WELL INITIALLY?	

<b>Needs assessment:</b>	
HOME:	
TV:	
TELEPHONE:	
WORK:	
SOCIAL:	
<b>COSI Goals:</b>	
1)	
2)	
3)	
4)	

<b>Pt limitations:</b>	
VISION:	
DEXTERITY:	
MEMORY/COGNITION:	
OTOSCOPY:	
SENSITIVITY:	
TINNITUS:	

### Funding:

#### ACCESSIBLE FUNDING:

- Childhood HL (m/s in btr ear). (Evidence).
- SSNHL (m/s in btr ear). 6m window. Stable 14 days. (ENT).
- Visual/physical/intellectual impairment from birth (optometrist report/IQ test <70/disability support evidence).

#### CSC

- + 30 hrs+ work p/w
- + 20 hrs+ voluntary work p/w
- + Seeking employment (WINZ registered)
- + Care for dependent person (child, partner with ailment) (GP ltr).
- + <30hrs work + disability
- + FT education

### ACC:

- TBI/Accident
- NIHL (if 'yes' stop discussion and apply for ACC via GP).

<b>Hearing Devices:</b>	
BINAURAL:	
TECHNOLOGY:	
STYLE:	

BATTERIES:	
DOMES/TUBING/ <u>EARMOULD</u> :	
COLOUR:	

<b>Special uses/features:</b>	
Programmes:	
Accessories:	
ALDs:	
T-coil	
Automatic phone switching	
BT capabilities	
FM	
Accessories:	
Other special needs:	

### To Do:

QUOTE:

EAR IMPRESSION:

GIVE EAR-NURSE LIST FOR WAX REMOVAL:

REQUISITION:

MAKE FITTING APPT:

### NOTES:

Figure 8: HAD template. The template is a two-page Microsoft Word document. Adapted with permission from the UoA HATC.

Hearing needs assessment questions relate specifically to management and rehabilitation options for a person with hearing loss (Dillon, 2012; Gatehouse, 2003). An example of a needs assessment question that contrasts with a generic history question would be: “How well do you hear conversation in the presence of background noise?” When information such as this, regarding a client’s listening needs or rehabilitative goals, was recorded in the Adult history guides or clinic notes, and referred to during the HAD, it was considered part of the HAD and relevant for inclusion in the study. Adult history guide records or clinic notes that did not meet criteria for analysis were those that qualified as generic history questions, or other miscellaneous information. For example, the client’s childhood history of diseases, or the fact that they completed a release of information form. UoA HATC HAD appointments are generally subsequent to the client history taking and a diagnostic assessment, which are usually conducted at the clinic prior to booking the HAD. An exception to this might be if the client is a current long-term HA wearer referred from another clinic, where diagnostic assessment was already completed.

**Your Hearing Needs** Name: \_\_\_\_\_ Date: \_\_\_\_\_

	Quiet Conversations	Outdoors	Watching TV	Telephone	Meetings Conferences Classrooms	Restaurants Cafes	Social Gatherings Parties	Music Live or Recorded	Conversation in the Car
Premium									
Advanced									
Standard									
Essential									

### Hearing Aid Styles

#### Custom Hearing Aids



**CIC** Completely In-the-Canal  
**ITC** In-the-Canal  
**Half Shell**  
**Full Shell**

#### Behind the Ear Hearing Aids



**BTE** Traditional  
**Thin Tube**  
**RIC** Receiver In-the-Canal

**Figure 9: Your Hearing Needs diagram. From the UoA HATC. Used with permission.**

There were fifty-three HAD cases in total that occurred at the UoA HATC clinic during the stipulated timeframe, receiving assigned numbers from 1-53, as per their selection in date order. The numbers from 1-53 were then entered into an online random number generator ([www.Random.org](http://www.Random.org)) which generated those numbers in random order sequence. The sequence of numbers was then applied, in the order provided by the random number generator, to the fifty-three cases in the same date order in which they were selected. The cases assigned numbers from 1 to 20 were then chosen out of the sequence, to be analysed for the research (Figure 10).

The case assigned the number 7 was an exclusively tinnitus assessment. As this study is focusing on hearing loss rather than tinnitus, this case did not meet the criteria for inclusion. To complete the twenty cases, number 21 from the random sequence of generated numbers was chosen as a replacement. Therefore, the final assigned numbers from the sequence were numbers 1-6 and 8-21 (Figure 10). These were assigned a data code from HAD-01 to HAD-20 in the order in which they appeared in the randomly generated list (Figure 10). These files were also printed and stored in hard copy format, where they could be reviewed, and notes written upon as needed. There is no existing record of which clinician each HAD case belonged to, as this was never noted down, and was never intended to be a part of the analysis.

Additionally, twelve completed anonymous FOCAS-ME forms, completed by external clinicians engaged in a pilot programme using the tool in their clinical practice, were provided for the purposes of the research. These were assigned data codes from F-M 01 to F-M 12 in the order in which they were received. I did not have access to any other client records from these appointments apart from the completed FOCAS-ME forms. It is not known if the FOCAS-ME cases were conducted prior to, or subsequent to, diagnostic testing. The twelve completed FOCAS-ME provided by the pilot clinicians were also redacted of all identifying information including whichever clinic or clinics they may have been working in at the time. These forms were also stored electronically, as well as being printed and stored in hard copy format, where they could be reviewed, and notes written upon as needed. There are therefore two datasets: the HAD dataset, comprising of the twenty HAD cases, and the F-M dataset, comprising of the twelve completed FOCAS-ME forms from the pilot study.

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## Random Sequence Generator

Here is your sequence:

7	N/A
5	HAD-01
25	
8	HAD-02
41	
17	HAD-03
50	
53	
32	
30	
6	HAD-04
16	HAD-05
4	HAD-06
28	
24	
21	HAD-07
49	
27	
36	
47	
10	HAD-08
42	
45	
3	HAD-09
22	
15	HAD-10
9	HAD-11
35	
11	HAD-12
44	
18	HAD-13
29	
48	
34	
2	HAD-14
39	
37	
46	
33	
14	HAD-15
31	
19	HAD-16
12	HAD-17
20	HAD-18
51	
38	
52	
13	HAD-19
23	
26	
40	
1	HAD-20
43	

Timestamp: 2018-10-17 00:57:14 UTC

Again!

Go Back

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Figure 10: Sequence of random numbers generated for the HAD case selection. Numbers 0-6 and 8-21 are highlighted yellow.

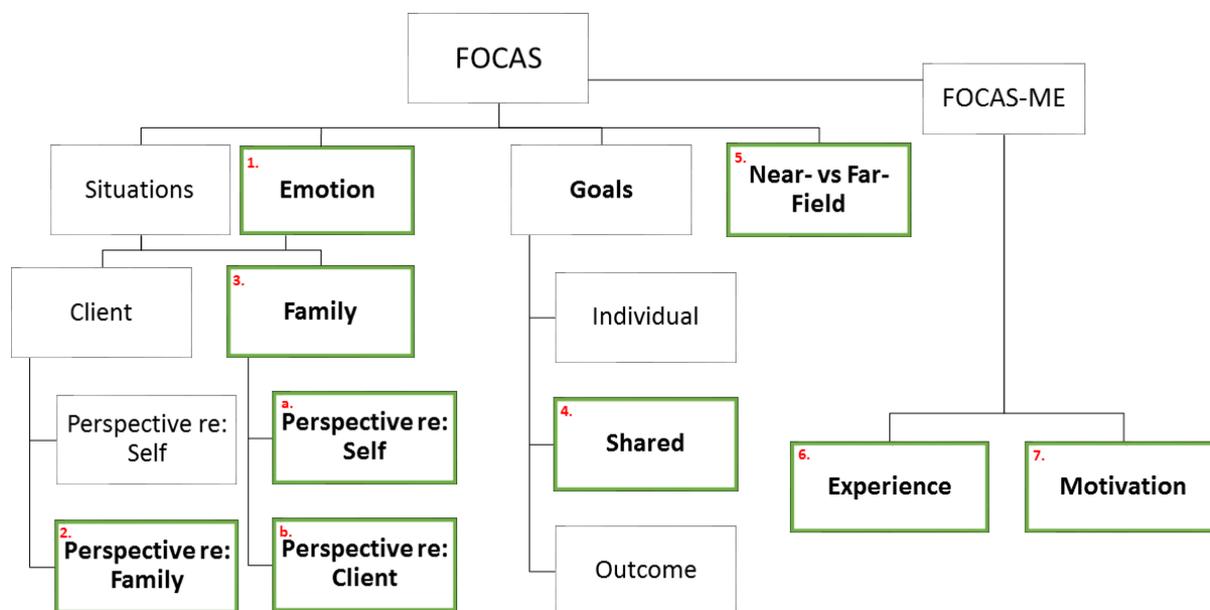
## 2.6 Study Design

The qualitative method chosen for this study was thematic analysis as outlined by Braun & Clarke (2006). The authors argue that thematic analysis can be a valid method on its own, rather than being solely an existing element of the more established methods of qualitative analysis, for example, grounded theory or discourse analysis (Braun & Clarke, 2006). Nevertheless, they advise that when choosing thematic analysis, one must clearly define the methods used, and the analysis ought to be based on a theoretical framework that can be demonstrated by the researcher, so as to make their decisions transparent, relevant and justifiable (Braun & Clarke, 2006). The nature and purpose of this particular study drives the analysis in a theoretically driven direction, rather than inductive, as the analysis was conducted with prior engagement with the literature (Braun & Clarke, 2006). Therefore, issues such as the impact of hearing loss, third-party disability, and family-centred care were influences on the analysis. Additionally, the data is principally being approached with specific questions in mind, as outlined in the study purpose.

The first part of data analysis was framed by seven key elements which were classified as themes, based on the key sections of the FOCAS-ME tool. They cover the key sections of the FOCAS tool: the emotional impact of hearing loss, the client's perspective on their family member's experience and vice versa, the family member's perspective on their own experience, shared goal setting, and the exploration of hearing needs as being near- or far-field (Figure 11). The FOCAS-ME adds the client's motivation towards taking action on their hearing loss, and their prior knowledge and experience of HAs, including cost (Figure 11). These elements were chosen as being pertinent to the study aim of comparing FOCAS-ME with current clinical audiological practice. Elements not chosen for comparison were: situations impacted by hearing loss, the client's perspective on their own experience, individual goals, and outcomes. The basis for these omissions is that they typically are elements of standard audiological needs assessments, for example as per the COSI.

This part of the analysis was conducted with a view to discover if the identified key elements, hereafter referred to as themes, appeared in the HAD cases selected, and in what forms they appeared. To record this information, a table was constructed consisting of the themes and the twenty HAD cases (Table 1). For each HAD case, a tick indicates whether each theme appeared (Table 1). The total amount of cases in which a theme appeared was also tallied, as well as the resultant percentage (Table 1). These results were then analysed on a case-by-case basis, and

the forms in which the FOCAS-ME themes appeared in the HAD cases were discussed. Additionally, elements of the HAD cases identified by the author as themes contributing to audiology service provision, that did not appear in the FOCAS-ME cases, were analysed and discussed.



**Figure 11: Diagram illustrating key elements of FOCAS and FOCAS-ME. The seven identified key themes of FOCAS-ME are numbered in red.**

The second part of data analysis comprised themes from the datasets that were determined to relate to rehabilitative service provision for adults affected by hearing loss and their families. This was in order to fully round out the study in regard to its overarching goal of contributing to the enhancement of adult audiological service provision. To do this, the analysis followed the six phases of thematic analysis as proposed by Braun and Clarke, 2006 (Figure 12). Codes were extracted and organised into themes as per the previously outlined theoretical approach. The themes were primarily identified at a semantic level, with regards to the explicit meaning of what was written, with the information taken at essentially face value (Boyatzis, 1998; Braun & Clarke, 2006). They were then interpreted with regard to the significance of any patterns that were established, and the broader meanings and implications underpinning the themes and patterns were theorised as they related to the research. Features not related to the purpose of the study were not coded. These included generic history questions or miscellaneous information not definitively related to a hearing needs assessment, as described in the previous section.

The technique of “mind-mapping” (Buzan, 1970) was utilised as an organic method of examining and collating the ideas that arose upon each review of the material. Mind mapping is a way of capturing ideas and information in a non-linear fashion, on a single horizontal plane (Mento, Martinelli, & Jones, 1999). This allows for a lot of information to be captured, and relationships between a multitude of ideas or items to be visually demonstrated on just one page (Mento et al., 1999). Associations can be made spontaneously, and the mapper can use any manner of creative visual cues to represent their ideas and the relationships between them, which can be personalised according to their preference and taste (Kokotovich, 2008).

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

**Figure 12: The six phases of thematic analysis. From Braun and Clarke (2006). Used with permission.**

For this study, the mind maps were initially created manually with coloured pencils and sheets of paper, then transcribed electronically. QSR International’s NVivo 12 Software (QSR International Pty Ltd., 2018) was used to manage the data electronically, creating codes (or “nodes” as they are described in the software), organising the codes into themes, and extracting and organising relevant quotes. The mind maps informed the extraction and coding of the data and helped to capture insights and ideas creatively, refining them in order to catalogue them in NVivo. The main function that the software was used for was the organising of relevant quotes for easy access and referral.

The information presented in the cases was analysed semantically which meant the written records were interpreted as being necessarily a representation of the way the clients and family members spoke about their experiences. While the data was not a verbatim transcript, nor an audio or visual recording of the appointments, it is presumed that the case records attempted to capture all parties’ points of view as accurately as possible. Therefore, what informed the thematic analysis was less the code titles and their subject matters, and more how the issues

## Chapter 2 – This Study: Purpose and Design

were discussed in the selected cases, in other words what direction they were deemed to go in, based on the information offered.

## Chapter 3: Results

### 3.1 Part 1

Part one of the analysis involved a comparison between the information recorded in the HAD cases and the seven key FOCAS-ME elements identified as themes (Figure 11). The results of this comparison are shown in Table 1. The themes of Emotion and Experience occurred most frequently, followed by Shared Goals. Client Perspective Regarding Family was next, then Near- vs Far-field. Motivation occurred in two cases, and no cases were counted under the theme of Family Perspective (Table 1). Notes qualifying how it was decided whether or not the themes occurred can be found in Table 2.

Emotions were generally in the form of anxiety, such as “concern” or “worry”. For example, in regard to an open-ended question about her hearing loss, it was recorded that HAD-03 ‘Misses grandchild which causes her concern.’ In HAD 18, under a section marked “Management”, it was stated ‘...unsure if he wants to trial hearing aids, but is concerned that he may struggle with hearing in the classroom.’ Under the section titled “Work” (Figure 8), HAD-07 recorded the following: ‘Lecturer... – teaches information systems. Sometimes misses what students in the lecture theatre are saying – worried about this.’ HAD-11 expressed anxiety in two of their COSI goals: ‘1) Reassurance that it will not get worse. Affects her work, is missing things that are said, pretends she can hear...’, and ‘4) Overall confidence in what is happening in the environment. In car worried that may not hear a fire engine, so put window down to make sure [to] hear car coming or be aware of environment.’

Other emotions recorded were hopelessness and being fed up: ‘More difficult if many people around; crowded room is hopeless...Music concerts hopeless, BGN is too much.’ (HAD-14); ‘Has given up being able to hear.’ (HAD-02); ‘Big, louder, family, 20 grandchildren (15 can be there at a time), always out of the loop, used to just want to go home, fed up concentrating.’ (HAD-04). Also mentioned were doubt, stress, and feeling uncomfortable. Frustration and irritation were emotions that were applied to family members and others.

**Table 1: FOCAS-ME key theme occurrences in HAD cases.**

FOCAS THEMES	HAD CASE NUMBER																				Total /20	%
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20		
1. Emotion	✓	✓	✓	✓			✓	✓		✓	✓		✓	✓			✓	✓		✓	13	65
2. Client Perspective re: Family	✓		✓	✓			✓			✓	✓				✓			✓		✓	9	45
3. Family Perspective																					0	0
4. Shared Goals	✓	✓		✓			✓		✓	✓					✓	✓	✓			✓	10	50
5. Near- vs Far-Field			✓		✓		✓			✓					✓	✓	✓	✓			8	40
6. Experience	✓	✓		✓	✓	✓			✓			✓		✓	✓		✓		✓	✓	12	65
7. Motivation																	✓		✓		2	10

**Table 2: Notes regarding FOCAS-ME key theme occurrences in HAD cases.**

FOCAS THEMES	NOTES REGARDING FOCAS THEME APPEARANCE IN HAD CASES
1. Emotion	Mentions of emotion seemed to arise spontaneously, as no questions in the HAD are geared towards this specifically. However, it is impossible to tell if an individual audiologist may have verbally prompted this perspective, as what is being analysed are the recorded case notes, and there is no audio or video from the actual appointments available.
2. Client Perspective re: Family	As above, despite there being no directive in the HAD format to discuss this, the perspective seemed to arise spontaneously, although interactions beyond what is recorded in the case notes are inaccessible. Additionally, refer to notes below under Family Perspective.
3. Family Perspective	Due to the fact that there was no clear indication of family member input, references to family members' feelings or experiences were necessarily attributed to client perspective.
4. Shared Goals	As per above, it is not known if possible family member presence may have contributed to any goal-setting. The author made the judgement about whether a goal was shared based on whether the goal was recorded as explicitly involving family.
5. Near- vs Far-Field	Listening situations were not delineated as near- or far-field, in any of the HAD cases. However, if ALDs that assist with far-field needs, such as remote microphones or TV streamers, were discussed, these cases were counted.
6. Experience	The HAD forms contain a prompt regarding current HA use. In cases of a negative response, with no subsequent recorded discussion about previous HA use or experience, these cases were not counted. If there was no previous or current HA use or experience discussed, yet the Your Hearing Needs diagram (Figure 9) was used in the appointment, these cases were counted as meeting the cost criteria, due to the range of cost estimates displayed for discussion.
7. Motivation	With regard to current HA wearers, motivation can somewhat be established. However as no discussion of motivation was recorded, these cases were not counted. Cases that indicated suggested HA makes and models for the client to trial, and/or quotes provided, were also not counted for the same reason.

Notes relating to the perspective of family members included emotional impact, as stated previously: ‘Her partner gets frustrated having to repeat things...’ (HAD-10); ‘Telephone ([wife’s] concern as she relies on him to hear on the phone) (HAD-01); ‘Sometimes get people to repeat 4 or 5 times and cause irritation.’ (HAD-11). With respect to the latter, “people” were not exclusively stipulated as being family members, as work colleagues were also mentioned. However, the quote is a component of the client’s first COSI goal: ‘1) To hear better in group situations and hear what others are saying. Not getting people to repeat themselves...’ which followed descriptions regarding group listening situations that included mention of family: ‘Live with daughter and cat. Get daughter to repeat herself, miss a lot of words in family gatherings. Family gatherings are around 4 people. Small groups...’

Other recorded instances of client’s perspective regarding their family were simply statements that family members felt that the client had a hearing loss: ‘... daughter feels he isn’t hearing on the phone.’ (HAD-01); ‘Wife feels his hg not so good.’ (HAD-18); ‘Has 2 daughters and 1 son and they feel she isn’t hearing well.’ (HAD-20). Further statements were in reference to TV volume: ‘TV higher than normal (not an issue for husband though).’ (HAD-03); ‘TV: Has it up more than wife would like.’ (HAD-15); ‘TV: Has it up louder than wife and daughter would like.’ (HAD-18). In the case of HAD-15, the client’s wife was reported as encouraging him to consider HAs, although TV volume was not specifically recorded as being the reason: ‘Because X is struggling to hear in social settings with BGN he booked in for a HAD to learn more about his options. Mentioned wife pressured him to consider aids.’

No cases were counted under the theme of Family Perspective i.e. statements made by family members themselves. Shared goals were qualified as any goals that included family, especially if they were related to quoted family member perspectives. For example: ‘Telephone ([wife’s] concern as she relies on him to hear on the phone.’ (HAD-1), and ‘To appease children.’ (HAD-20), the latter being the case in which it was recorded that the client’s children feel she ‘isn’t hearing well.’ HAD-10 had as their first COSI goal: ‘Wants to be able to hear her husband better in quiet at home particularly if he is not looking at her.’ This links to the frustration quoted as being experienced by the client’s husband: ‘Her partner gets frustrated having to repeat things...’

Other shared goals were not in relation to quoted family member perspectives, but still involved communicating with family. For example: ‘To hear wife at home.’ (HAD-07); ‘With family on weekly visits.’ (HAD-09); ‘Quieter Restaurants – to hear wife...’ (HAD-15). When a goal

involving family was mixed with other social communication it was still counted as being shared due to the involvement of family: ‘Would like to be able to hear in restaurants e.g., family party could be 10 people.’ (HAD-02); ‘Family get-togethers, coffee shops, café, as above.’ (HAD-04).

Eighteen HAD cases recorded having listening situations that would qualify as far-field. Fourteen out of the eighteen cases which recorded far-field needs were in reference to TV. This was based on the assumption that the distance from the television was more than a metre. Other far-field situations reported were meetings, classroom lectures and church. Cases that recorded discussion about assistive listening devices (ALDs) that categorically help with far-field needs, such as remote microphones or TV streamers, were counted under the theme Near- vs Far-Field, even if the listening situation was not explicitly classified as far-field in the needs assessment notes. Discussions regarding phone streamers alone were not included, as this is not a far-field need.

For example, in HAD 17 under the “Work” component of the needs assessment section (Figure 8), it was stated: ‘...Resource teacher of learning and behaviour. Goes into a classroom and do an observation – v diff b/c can’t actually hear what the students are saying, should be able to hear what they’re saying but she can’t – they aren’t looking at her...’ In this case, in the “Special uses/features” section, under “ALDs” (Figure 8) it was noted: ‘Discussed remote microphone as an option for hearing soft-spoken children in noisy classroom...would like HAS to be compatible with this in case it’s needed in the future.’ In HAD-05 the notes stated: ‘...doesn’t do well on the TV with dialects and accents even with volume loud enough. Has tried sound bar which didn’t work and headphones that plugged in. Headphones had to be plugged in and that didn’t work because then no one else could hear it. Would like to try wireless headphones.’

Cases recording discussions relating to this category of devices were included under this theme even if it was in a more general manner. For example: ‘Discussed Telephone streamer, TV streamer and RM. OK with talking on the phone now so not interested in phone streamer. Not a big technical person so not interested in wireless accessories either now or in the future.’ (HAD-03); ‘Discussed TV streamer and phone streamer. Wants Direct streaming.’ (HAD-07); ‘ALDs: Is not interested as 80% of her environments is only in the presence of her and her partner.’ (HAD-10).

In regard to the theme of Experience, three of the HAD cases were clients who were not currently wearing HAs, yet discussed their previous experience under a section dedicated to current HA use (Figure 8). For example, HAD-02's response was recorded as 'Doesn't wear aids at all. Used to wear them all day everyone [sic]. Stopped wearing them because she found she could hear better without them.' HAD-12's response indicated previous use was discussed '...Not sure what style it was, may have been a RIC... Didn't perceive much benefit.' HAD-17 stated: 'Had HAids 5-6 years ago...had it on one side (only needed in one side), never stayed in, it kept falling off. Even with retention tail. One day it fell out and was never found again. Very upset with experience of hearing aid. Had many adjustments at the audiologist but never felt the sound was quite right.' In the case of HAD-19, the client stated they had been trying out their brother-in-law's demo devices, which he had apparently been provided to trial in three different technology levels: '[client's] brother in law has been trialling the demo devices on 7px, 5px and 3px, so he already has some experience... felt premium was too loud...Advanced was clearest and gave him the most help in noisy restaurants and family gatherings... standard level helped with tinnitus...'

Seven of the other nine HAD cases counted under the theme of Experience were all current HA wearers. Of those seven cases, two also incorporated the Your Hearing Needs diagram, which provides a section for the audiologist to note a range of HA price estimates based on four technology levels (Figure 9). Therefore, these cases also met the criteria for discussing cost. The remaining two cases were not current HA wearers and no previous experience was indicated as being discussed, nonetheless they too incorporated the Your Hearing Needs diagram, with the range of costs displayed. Based on this they were also included under the Experience theme.

Motivation was referred to in HAD-17 in notes the clinician wrote at the bottom of the HAD, which stated: 'Is slightly on the fence about HAs after poor experience with last hearing aid trial but recognises that she needs to do something about hearing as she has been struggling with work.' The other case that was included under the theme of Motivation was that of the client who had tried his brother-in-law's demo HAs at three different technology levels: '...felt premium was too loud (this was the first one he tried) and advanced and standard were the best....Felt all levels made a huge difference when noise was present....Had 8 people over the other night, heard them perfectly with standard level trial. would struggle to hear in that situation without the hearing aids...advanced one was a lot clearer and he didn't have to

concentrate as much.’ (HAD-19). This was recorded as his response to the question of whether or not he was currently using HA.

When conducting the comparison between the HAD cases and the FOCAS-ME key themes, three elements were identified that the HAD cases consistently covered in the needs assessment section (Figure 8), for which there are no specific directives in FOCAS. These were: tinnitus, enquiry into sound sensitivity, and physical limitations such as dexterity or vision issues. Seven HAD cases recorded either bothersome tinnitus, sound-sensitivity, or both. Two of these cases had COSI goals that targeted improving the tinnitus. Nine HAD cases recorded physical limitations that could potentially impact the client’s management of HAs. Most were to do with dexterity: ‘Carpel tunnel in the right hand and has numbness in the right hand and is relatively ok at picking items up but is struggling to shave every day.’ (HAD-01); ‘Familial tremor – putting battery will be difficult.’ (HAD-07); ‘Good movement in hands, but isn’t sure if he could fiddle with something very small (particularly batteries).’ (HAD-15); ‘OK – sometimes numb feeling in fingers.’ (HAD-10); ‘Poliomoga?? [likely Polymyalgia Rheumatica], fingers tight in the morning and no numbness.’ (HAD-11). ‘Arthritis and numbness and both fingers. Still sews but is aware of the numbness.’ (HAD-20). Vision issues recorded tended to be cataract-related; either that they were in the process of forming or were scheduled to be removed.

Another factor, that was explored in four of the HAD appointments, was the issue of home safety, for example questions regarding whether the client is able to hear smoke alarms or other alerts. Questions about safety are not part of the standard template that is used in these appointments, however clinicians seemed to incorporate questions about safety when discussing the listening environment in the home. For example: ‘Can hear if someone knocks on the front door most of the time. Can hear alarms in the house, hasn’t checked the smoke alarm recently.’ (HAD-01); ‘Can hear someone knocking on the door and can hear smoke alarms in the house...feels she would be able to wake at night.’ (HAD-09); ‘Hears knocks on doors dependent on who is knocking and how loud. Can hear smoke alarms and it would arouse her from sleep.’ (HAD-10); ‘Able to hear the alarm, don’t hear the door knocking at home all the time but others can hear the knock in the house.’ (HAD-11).

## 3.2 Part 2

Part 2 of the analysis involved qualitatively analysing the HADs and completed FOCAS-ME forms, in order to extract themes that were determined to relate to rehabilitative service provision in adult audiology. Each dataset was analysed separately, and the themes extracted from each set were then analysed as a whole. Phases one and two of Braun and Clarke's six phase guide to thematic analysis (Figure 12) were completed first. The initial coding was broad and systematic, involving the entire scope of each dataset. This resulted in commonalities between the two datasets, with some codes identified more often in one dataset than the other.

Television was coded in almost every case in both datasets. Other codes common to both datasets were Background Noise (BGN), Missing Out, Avoidance, Clarity, Frustration, Struggle, Worry, Cosmetics and Strategies. Strategies refers to methods undertaken by the person with hearing impairment in order to cope with a deficit in hearing, and mostly pertained to the HAD dataset, while the FOCAS-ME (F-M) dataset had more instances of Frustration. There were also codes unique to each dataset. The code of Isolation was unique to the F-M dataset, while Safety was unique to the HADs.

After this phase was completed, the codes were collated into initial themes, which were then reviewed, according to phases three and four of the six phases of thematic analysis by Braun and Clarke (Figure 12). The results are shown in mind map form in Figures 13 and 14. At this juncture there are themes and sub themes. Some were common to both datasets, such as Third-Party Disability, Negative Psychosocial Impact, Conflict and Struggle. This stage was also where common coded elements were taken in somewhat different directions. For example, elements originally coded under BGN in the F-M dataset appeared under the various sub-themes of Emotion – Client, Avoidance, and Misinterpreting: 'bgnd noise can need repeats which can be embarrassing.' (F-M 09); 'noisy environments unable to hold conversation, withdrawn, avoidance.' (F-M 11); 'when in bgnd noise-misinterpreting.' (F-M 09). It also appeared under the theme of Isolation: 'When in bgnd noise in group up to 6 present-feels isolated.' (F-M 07). In the HAD dataset, BGN was its own sub-theme associated with Struggle.

There were also some parallels between the two datasets. For example, the sub-theme of Clarity was entirely associated with TV in both cases (Figures 13 and 14). However, in the F-M dataset there were multiple examples of clarity which were associated with emotions, whereas in the HAD dataset there was just one quote relating to clarity, which was associated with struggle: 'Needs clarity with most TV programs- Frustrated and feels not capable to understand. (F-M

01); ‘To have clarity and not need volume as high-gets frustrated.’ (F-M 05); ‘Has to turn the TV up quite a bit for DVDs but can still struggle with clarity.’ (HAD-01). This example also illustrates that while frequency of occurrence was an element of the coding process, it wasn’t the main driver behind deciding what qualified as a code. The fact that clarity was only mentioned once in the HAD dataset did not preclude its being coded, as clarity was deemed to be an important part of hearing rehabilitation and management, and therefore important to distinguish.

This is not to say that frequency of occurrence did not have some influence on how elements were coded and on the development of the themes. For example, the HAD dataset contained many references to strategies used by the client to deal with their hearing impairment, therefore Strategies became a theme of its own (Figure 13). In the F-M dataset there were less references to strategies, and what there were related to emotion, hence Positive Strategies and Negative Strategies became sub-themes associated with the theme of Emotions (Figure 14).

Conflict is another example. This was given its own theme in the F-M dataset, as there were several instances where the wording was interpreted as denoting conflict in regard to differing perspectives about the impact of the client’s hearing loss: ‘...feels client cuts himself off...feels hearing is selective.’ (F-M 05); ‘feels wife mumbles.’ (F-M 06); ‘causes problems.’ (F-M 09); ‘...feels he cannot understand and wife is not making an effort to raise voice over car noise... feels wife is talking softly and doing so on purpose at times.’ (F-M 11); ‘...have to make sure adapt to her, she is not seeking solution...family is impatient, ignoring her, doing things 'on purpose'... arguments...tired of repeating.’ (F-M 12). In the HAD dataset there was just one instance that denoted conflict, which was made into sub-theme under the theme of Family Mentioned: ‘Wife only struggles to hear when she’s talking from the other end of the house, and she believes he should be able to hear her.’ (HAD-18).

Some of the coded elements appeared in more than one place. For example, the following quote: ‘wife is not enjoying situation as he is not listening, frustrated.’ (F-M 11) was included in the sub-theme Conflict – Incongruence, but also in the sub-theme Emotions – Family, and the theme Third-Party Disability. The quote: ‘Doesn’t want to tell them ever.’ (HAD-13) refers to a client’s employer, regarding the fact that the client entirely lost their hearing in one ear. This was included in both the sub-theme Negative Psychosocial Impact – Professional, and Negative Psychosocial Impact – Stigma.

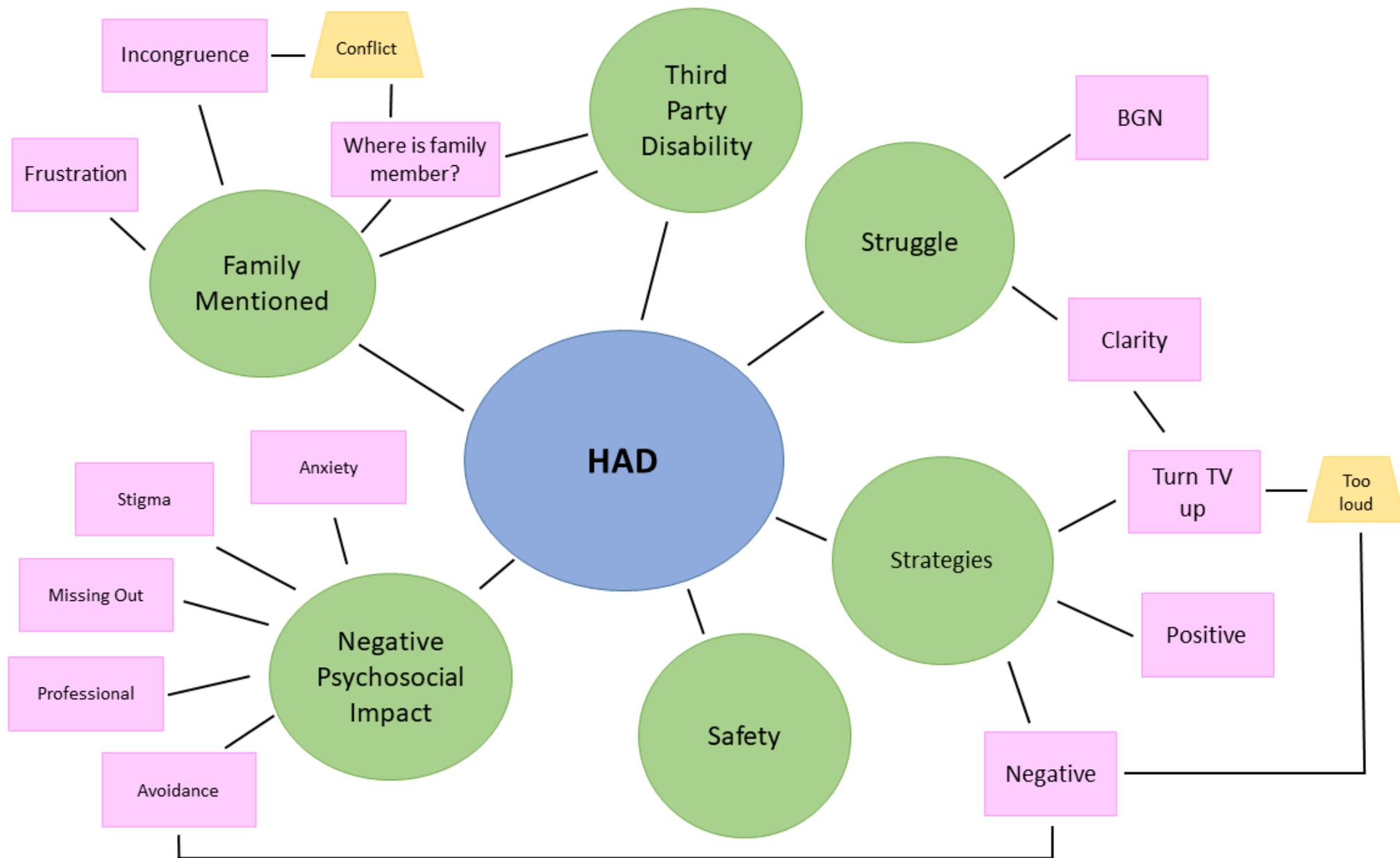


Figure 13: HAD mind map

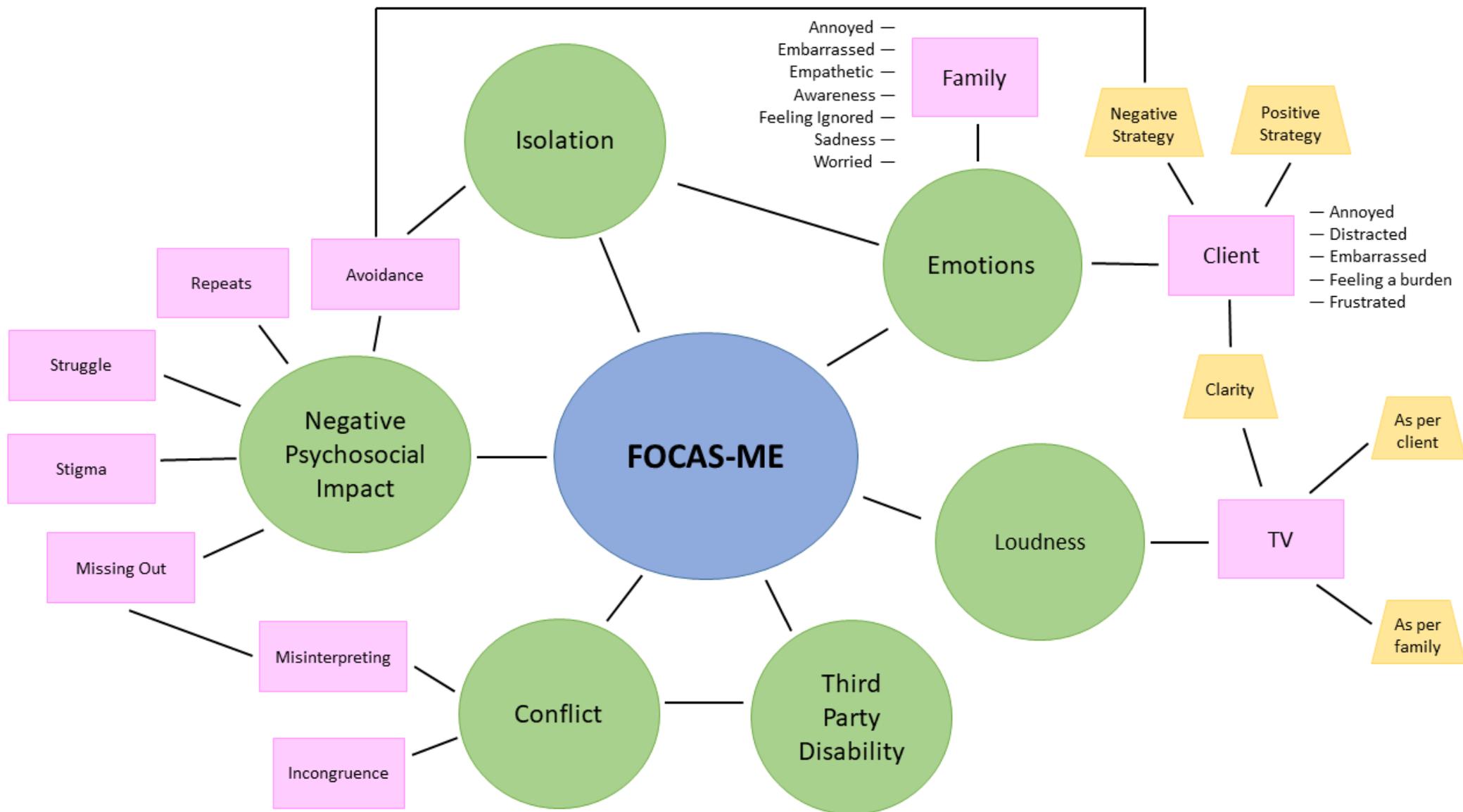


Figure 14: FOCAS-ME mind map

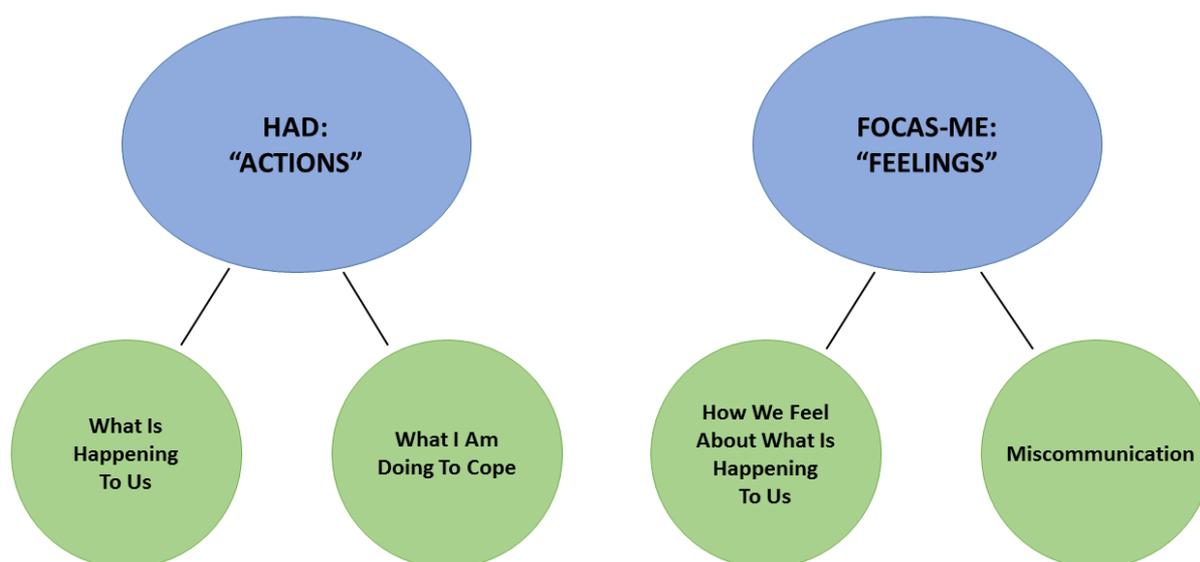
In phase five, the overall stories began to take shape, and the result was that each dataset was allocated a central idea with two main themes (Figure 15). The HAD dataset had the central idea of “Actions” and consisted of what could be considered the complimentary themes of What Is Happening To Us and What I Am Doing To Cope (Figure 15). The F-M dataset had the central idea of “Feelings” and consisted of the themes How We Feel About What Is Happening and Miscommunication (Figure 15). “What is happening” refers to the impact of hearing loss, and as there were references to the experiences and/or perspectives of the clients as well as their family members, therefore involved “us” and “we”. The latter HAD theme is the singular “I”, due to the fact that the data in this theme focused on what the client alone was doing to cope with the impact of hearing loss. The FOCAS-ME Miscommunication theme consisted of perspectives from both clients and their family members.

The central idea of the HAD cases reflects the nature of the recorded discussions as being primarily statements about actions. For example, in the case of TV, the HAD cases disclosed what the client is doing in regard to the TV, and in some cases, the practical impact this had, i.e. whether the action made it easier to hear, or whether it remained difficult. For example: ‘Has to turn the TV up quite a bit for DVDs but can still struggle with clarity.’ (HAD-01); ‘TV higher than normal.’ (HAD-12); ‘Needs to turn the volume up. Hears fine if turned up’ (HAD-16); ‘Has it up louder. Follows ok if vol raised.’ (HAD-19). There were three instances where the client acknowledged it was either louder than others would normally have it (HAD-12), or louder than family members “would like” (HAD-15 and HAD-18). Nonetheless, in these instances there was no direct mention of how the others actually felt about the fact that the TV was louder than they would normally have it or like to have it. This is not to say that there were no feelings recorded in the HAD cases. Evidence of this can be seen reflected in initial themes such as Anxiety and Frustration (Figure 13). However, in general it was determined that the HAD data focused on actions.

In contrast, the FOCAS-ME data, while also necessarily discussing actions, was determined to relate mostly to how the parties felt. To once again use the example of TV volume, this was reflected especially in the case of the family members: ‘Gets frustrated with high volumes that [client] needs, feels car radio is also high.’ (F-M 05); ‘TV and radio is too high - used to it now.’ (F-M 09); ‘TV is up too high for her...’ (F-M 11). In F-M 02, both the client and the family member acknowledge that the TV volume is too loud for the family member. The client states: ‘[family member] feels it is too high in volume’, and the family member is noted as

‘reporting TV is too loud.’ In regard to their perspective on what their family is experiencing, F-M 10’s client stated that ‘TV is up, constantly asking for repeat, tiring.’

There were other references to loudness and feelings in the F-M dataset also, as seen in the previous quotes which included references to radio. There were also allusions to the impact of loud talking. F-M 01’s client stated: ‘when family visit, I talk too loud for the family...’, and they believe their family member also ‘feels [client] talks too loud. ‘Their family member stated he or she ‘prefers quieter life’, which appears to confirm the client’s statements. F-M 04 showed that the family member reported being ‘aware needs to raise her voice especially over the phone’, yet also reported that they thought the client felt she, the family member, was ‘shouting’. The initial theme of Loudness was created in the F-M dataset to encompass these different situations of TV, radio and talking (Figure 14), and these elements were then incorporated into the final theme How We Feel About What Is Happening To Us.



**Figure 15: Final themes**

The final themes were accordingly formed based on the central ideas. The first HAD theme comprised of actions that were considered to be “happening to” the clients and their family members. A big component of this theme was the idea of struggle: ‘Can struggle to hear female voices on the phone and can struggle with dialects sometimes.’ (HAD-01); ‘Finds it hard to hear grandchildren and great children. Struggles to hear them when they come to visit.’ (HAD-02); ‘Struggles to localize.’ (HAD-05); ‘Struggles to hear colleague who speaks quietly...Struggles pubs and bars partly because of hearing.’ (HAD-07); ‘Struggled when she

used to work when talking on the phone.’ (HAD-10); ‘Restaurants and cafes, struggles in restaurants which are noisy.’ (HAD-15).

Missing out on sound, especially conversation, was also part of this theme: ‘TV higher than normal, misses clarity...Misses grandchild (3 years old, quiet voice) which causes her concern. Misses what others are saying when speaking from another room or when back is turned...Misses parts of conversations...misses soft speech, misses clarity.’ (HAD-03); ‘Sometimes misses what students in the lecture theatre are saying – worried about this.’ (HAD-07); ‘Missing subtle temporary and timing factors.’ (HAD-08); ‘Sometimes misses the details of the story.’ (HAD-15); ‘Sometimes misses what daughter in law is saying. Even 1:1 or in quiet.’ (HAD-16); ‘Misses parts of sentences of husband at home even in quiet. Just with husband...Misses the moreporks.’ (HAD-17). HAD-03 and HAD-07 mention feelings of concern and worry, however overall the data was analysed as being principally action-related.

Another example from the What Is Happening To Us theme is in the case of background noise (BGN) which was a subject for discussion in almost every single HAD case. Primarily, the focus was on the effect that background noise had on the client’s ability to hear, which was interpreted as being an action that was happening to them: ‘The hearing aids magnify the sound but when there’s other sounds finds it v hard to hear the TV.’ (HAD-02); ‘Has issues hearing speech in noise... Manages fine with work phones unless there’s BGN in the room...if someone calls from downstairs, sometimes hears perfectly fine, but other times doesn’t hear well if other noise going on.’ (HAD-03); ‘He finds he has trouble hearing what someone says when noise in bg... If any bgn in the home e.g., music, then struggles to hear wife over the music... his office has air conditioning uses headphones to listen to videos otherwise the ambient noise in the office interferes.’ (HAD-07); ‘Background noise find it difficult to understand.’ (HAD-08).

Background noise was analysed differently in the F-M dataset. There was an example of BGN in the Miscommunication theme: ‘when in bgnd noise-misinterpreting.’ (F-M-09). However, most of the references to BGN in this group was in relation to how the effect of BGN on their hearing made them feel, such as distracted, isolated, embarrassed or annoyed. These were enclosed in the theme How We Feel About What Is Happening To Us and are demonstrated by the following quotes: ‘When in crowded rooms (pubs and restaurants)-distracted by louder bgnd noise.’ (F-M 06); ‘When in bgnd noise in group up to 6 present-feels isolated.’ (F-M 07);

‘bgnd noise can need repeats which can be embarrassing.’ (F-M 06); ‘can’t understand in noisy environment like car, annoying specially on long trips.’ (F-M 11).

Isolation was also encompassed in the FOCAS-ME How We Feel About What Is Happening To Us theme: ‘when family visit, I talk too loud for the family and need a lot of repeats, I feel isolated.’ (F-M 01); ‘When in a group of 6 present to misinterpretations when Y can hear next to me-feels isolated when this happens.’ (F-M 05); ‘When in bgnd noise in group up to 6 present-feels isolated.’ (F-M 07); ‘needs repeats of dialect-feels he is isolated.’ (F-M 09). Other feelings encompassed in this theme are illustrated in Figure 14 under the theme Emotions. Additionally, instances classed as indications of third-party disability also conveyed feelings: ‘distressing for family...[family member] feels sad for mum.’ (F-M 07); ‘TV is up, constantly asking for repeat, tiring.’ (F-M 10); ‘social gatherings, client avoids conversation so leaves all communication to wife - tired of having to speak for husband... wife is not enjoying situation as he is not listening, frustrated.’ (F-M 11); ‘...tired of repeating themselves.’ (F-M 12).

Regarding the HAD cases, it was the action of avoidance that was discussed: ‘rarely goes to restaurants or cafes because of how loud all the environmental noises are.’ (HAD-01); ‘Don’t go often to restaurants want to avoid situations like that...HL can make her tired which has limited her in hanging or talking with friends.’ (HAD-11); ‘No longer goes out b/c of his hearing.’ (HAD-16); ‘Avoids restaurants and pubs b/c can’t hear what people saying to him.’ (HAD-19). The aforementioned examples are included in the HAD What I Am Doing To Cope theme. This theme was comprised mostly of strategies, as the HAD cases featured plenty of reports of clients disclosing different actions they engage in to cope with their hearing loss. Some strategies were classed as negative, for example the avoidance examples mentioned above. Other negative strategies included the following: ‘...Does a lot of guesswork.’ (HAD-03); ‘...is missing things that are said, pretends she can hear.’ (HAD-11). One example of a negative strategy that had quite serious implications was again in the case of HAD-11, who reported that in their work, medical tests which required listening (for example through a stethoscope) would often have to be repeated as they were unable to be confident in the result at the first listen. Additionally, they were resorting to conducting medically unnecessary tests to overcome the hearing deficit, as well as extra tests that likely would not have been needed if their hearing was optimal.

Strategies classed as positive included being comfortable asking people for repeats or to speak up, lip-reading, and advising other people about the best place physically for them to be in

relation to the hearing-impaired person, in order to facilitate communication: ‘...can struggle with dialects sometimes but is comfortable asking for repeats.’ (HAD-01); ‘Social events – asked people to step outside to talk. Watches peoples lips...Asks wife to be nearby if she is going to say something.’ (HAD-07); ‘...ask wife to face him when speak softly or out of the room.’ (HAD-08); ‘...does have some training situations but keeps trainer on the right...’ (HAD-12); ‘Tends to move people to her left side.’ (HAD-13). HAD-11 stated: ‘most of the time lip-reading.’ In this case, while the strategy is useful, in this particular instance it was interpreted as being more a report on how difficult things were getting for the client, rather than sharing a positive strategy.

There was one example that referred to feelings in the HAD strategies documented: ‘...is comfortable asking for repeats.’ (HAD-01). However, in general the HAD strategies were statements of actions, as seen in the preceding quotes. Even with regard to HAD-11 and the quite serious negative strategies being resorted to at work, there was no mention of how the client felt about the situation. Also featuring in the HAD What I Am Doing To Cope theme were the examples of turning the TV volume up, as quoted previously, which is also considered a strategy, and may be negative or positive, depending on the potential effect it has on others. The example classed as a positive strategy that was found in the F-M dataset was a reference to feelings: ‘...-feels is easy to ask to speak up.’ (F-M 04).

The FOCAS-ME Miscommunication theme consisted of references to misinterpreting, asking for repeats and struggle, particularly in the goal setting section: ‘To minimise repeats needs from others when in the shop.’ (F-M 03); ‘To minimise misinterpretations in a group of 6 present facing me at 1-1.5m distance.’ (F-M 05); ‘To minimise misinterpretations when at the theatre and follow the storyline and dialect when person next to me can understand and follow the performance without a struggle.’ (F-M 07); ‘To minimise repeats on the phone with people with accents to minimise misinterpretations.’ (F-M 08); ‘when in bgnd noise-misinterpreting...in a group of 4 present mis understanding.’ (F-M 09).

As illustrated in the examples above, this theme contained more statements of actions than the How We Feel About What Is Happening To Us theme. Nevertheless, overall the theme chiefly comprised of references to feelings. For example, in relation to asking for repeats, there were references to embarrassment, frustration, isolation and being tired: ‘bgnd noise can need repeats which can be embarrassing... needs repeats of dialect-feels he is isolated.’ (F-M 09); ‘can't hear in the car - ask for repeat, frustrating...family is frustrated when they have to repeat

on a regular basis...client has to ask for repeat a lot and gets frustrated - family gets frustrated.’ (F-M 10); ‘understanding at home or in family environment tired of repeating themselves.’ (F-M 12).

There was also quite a bit of conflict recorded in this theme: ‘[wife] feels hearing is selective.’ (F-M 05); ‘feels wife mumbles.’ (F-M 06); ‘when in bgnd noise-misinterpreting...causes problems.’ (F-M 09); ‘would like to hold a conversation even in the car, but feels he cannot understand and wife is not making an effort to raise voice over car noise... feels wife is talking softly and doing so on purpose at times.’ (F-M 11); ‘understanding in group/family environments family is impatient, ignoring her, doing things 'on purpose'...client starts to withdraw from group activities, arguments tired of repeating.’ (F-M 12). Finally, with regard to missing out, there were also references to feelings: ‘To attend the theatre and not miss out-feels annoyed.’ (F-M 07); ‘going to church, missing out a lot there doesn't see the point of going.’ (F-M 12).

## **Chapter 4: Discussion**

The main aim of this research was to investigate how the Family Oriented Communications Assessment and Solutions-Motivation and Experience (FOCAS-ME) tool compared to current standard clinical audiology practice as represented by HAD appointments at the UoA HATC. The key themes of the FOCAS-ME tool were identified, and examples of their occurrence were examined in a sample of clinical HAD cases. Additionally, elements of HAD appointments determined to be important to rehabilitative service provision, which are not part of the FOCAS or FOCAS-ME tools, were identified. Further analysis explored the way information was gathered in HAD and FOCAS-ME appointments, with an emphasis on rehabilitative service provision for adults with hearing loss and their families. This was executed using the same sample of clinical HAD cases, and a sample of completed FOCAS-ME tools.

### **4.1 Findings Part 1**

The main findings of the first part of the analysis showed that all but one of the FOCAS-ME key identified themes were classed as having occurred to some extent in the HAD cases. This is despite the latter not containing directives targeting those particular subject matters, with the exceptions being HA prices in the Your Hearing Needs diagram (Figure 9), and the ALD section and the question regarding present HA use in the standard HAD form (Figure 8). Considering the subject matters arising spontaneously during the appointments, this suggests that they were relevant enough to the clients to warrant mentioning at the time, although it is also conceivable that they could have been verbally prompted by the audiologist through follow-up questions. Inevitably, the manner in which the subjects arose was not in exact accordance with the FOCAS-ME tool, which is designed to target the issues directly in the assessment questions. This meant that a HAD case's inclusion under a specific theme was generally based on whether the issue arose, even in a peripheral way, with the manner of its discussion being a necessary part of the analysis.

For example, the HADs do not contain explicit questions about emotion, yet clients expressed emotion about the impact their hearing loss was having on their lives, and in some cases, on their family members. How these expressions of emotions were addressed by the clinician at the time can only be speculated, as it is presumably not standard practice for clinicians to record how they choose to respond to all of their clients' statements. Additionally, to do so may not

be practical due to time constraints (Severn et al., 2012). The recorded clinician contributions to the HAD discussions took the form of suggesting hearing technology and/or listening strategies, or recommending referrals to hearing therapists and ear, nose and throat (ENT) doctors. This may indicate that the focus was on practical resolution of the primary cause of the negative emotions, namely the hearing impairment.

This direction is extremely important, given that any improvement to the impairment ought to help with the emotional impact and potentially lead to better quality of life (QoL) (Chisolm et al., 2007; Hyams et al., 2018; Joore et al., 2002; Mulrow, Aguilar, Endicott, Tuley, et al., 1990). It is also the role of audiologists to provide this service, which is a fundamental component of the audiology scope of practice in New Zealand (New Zealand Audiological Society, 2009). However, it is possible to acknowledge emotional impact while simultaneously suggesting a solution to help with the cause. One cannot promise that the emotional impact will be completely resolved, but acknowledging emotion can validate a client's feelings, and potentially foster a strong therapeutic alliance (Singh et al., 2017). The FOCAS and FOCAS-ME tools invite discussion of emotional impact as part of the initial questions in section 2: Hearing and communication challenges (Figures 4 and 5). The manner in which an audiologist administering the tool responds to the expression of emotion would likely also be verbal and unrecorded due to the aforementioned reasons, and the format of the tools. However, having this aspect as an integral part of the assessment process may encourage clients and family members to express their emotions when they otherwise might not do so (Singh et al., 2017).

Irrespective of the fact that there are no set questions asking the client for their views on the experiences of their family members in relation to the impact of the client's hearing loss, the format of the HAD needs assessment segment consists of open-ended questions. This allows for a range of responses, including statements respecting client views in this regard (Figure 8). Clients did volunteer information regarding their family members' perspectives, which suggests they were aware at least to some extent of the impact that the hearing loss was having on them, and that it was important enough to them to make mention of it. It is likewise conceivable that the perspective offered by clients was pure conjecture on their part. The best way of knowing would be if the family member were present and able to speak on their own behalf.

The fact that there was no recorded information directly attributed to family members in the HAD cases does not preclude family member presence or involvement, as recording whether

family is present for the appointment or not is up to individual UoA HATC clinician discretion. Regarding, for instance, the statement ‘her partner gets frustrated at having to repeat things...’ [HAD 10]; in the absence of a direct reference to the source of the statement, it is impossible to ascertain whether this information came from an actual family member being in the room and contributing to the discussion, or if it was the client’s perspective. Due to the standard format of the HAD appointments consisting of questions directed at clients, any contribution by family members themselves would be incidental, or perhaps verbally prompted by an audiologist veering from the written format. For the present analysis, with regard to the statements indicating the experience and perspective of family members, lack of specificity necessitated the assumption that any such statements were attributable to the clients.

There were instances in the HAD cases when it may have been beneficial to have the family member present, either to provide input, or receive counselling by the audiologist. For example, HAD-05’s client stated: ‘Entertains at home and really struggles (4 people) to hear even in the same room if her husband is also talking as her husband has a very loud voice but can hear 4 in a group with no noise, without her husband fine.’ It is possible that the client has already attempted to address the issue of her husband’s loud voice in these circumstances, without success. Alternatively, she may not have advised him, and was just putting up with it. In either case, if her husband were present, the audiologist would be able to offer him guidance as to how to speak in a manner that takes into account his wife’s hearing loss, thus providing support for her client as well as inviting input from her husband regarding his view of the situation.

Further instances where family presence may have been useful were the cases in which it was reported that family members felt the client’s hearing was impaired, and in the cases where TV volume was mentioned as being too loud for family members. For example, in HAD-18 it was stated that the client’s wife pressured him to consider aids, and that the TV was ‘up louder than wife and daughter would like’, yet previous case notes from the associated adult history guide form had stated: ‘Because at the moment he does not feel he is struggling much with his hearing, he is unsure if he wants to trial hearing aids...’ This incongruence could be important to investigate, and having the wife present for the subsequent HAD appointment might have been advantageous in addressing the possible denial that her husband was exhibiting about the extent of his hearing loss (Armero, 2001; Heine et al., 2002).

Another case where the family member’s presence could have been desirable is in the case of HAD-10, where it was noted: ‘Her partner gets frustrated having to repeat things, ok 1:1 but

only if he faces her. LE is bad ear, and husband tends to talk towards the TV.’ The frustration on his part qualifies as potential third-party disability, which is important to address regardless (Scarinci et al., 2012). Furthermore, it would be beneficial for the audiologist to educate the client’s husband on why he needs to face his wife when he is talking to her, rather than looking towards the TV, as this is clearly creating problems, and even more so if he is sitting on his wife’s left side. While audiologists are not expected to be marriage counsellors, involving the family member in the clinical appointment may help facilitate better communication (Ekberg et al., 2015; Scarinci, English, & Lemke, 2017).

A family member’s absence does not prevent the audiologist from providing advice to their client to help resolve the situation, perhaps offering guidance on how to broach the subject with their partners or learning what happened if their client already tried to broach the subject. Additionally, the presence of a family member does not guarantee automatic benefit, as much can depend on the dynamics of the parties’ relationship (Preminger & Lind, 2012; Scarinci et al., 2017). Notwithstanding, participation of family members can be valuable both in terms of understanding the impact of hearing loss, as well as their own responsibility as the communication partner of someone whose hearing is impaired (Ekberg et al., 2015; Jennings, 2009; Meyer et al., 2015; Preminger & Lind, 2012).

Regarding shared goals, an alternative approach to the analysis was taken. Despite no written record of family member contribution to the discussion, and the possible, or likely, absence of family member attendance, it was decided that goals involving family communication ought to be considered shared, based on their nature. The presumption here was that if a client reported communication difficulties with their family member/s, and stated a goal that involved bettering that communication, it was reasonable to expect that the family member/s in question shared the goal. The important distinction to note is that if the family member was not present at the appointment, they would be unable to contribute their input, perhaps in the form of adding to the goal, or modifying it. Additionally, the family member/s may have other goals that they would bring up during the discourse and propose as shared. For instance, they may have a goal in mind to address a situation that the client was not aware of but would be willing to include as a shared goal after consideration. The multiple examples of HAD clients having goals that included family communication indicates that sharing goals with a family member present in the appointment is a possibility that might be amenable to them.

In the case of far-field listening needs, most of the HAD cases studied contained an end section dedicated to special uses/features, which includes a space for discussion of ALDs, including those required for far-field listening needs (Figure 8). The Your Hearing Needs diagram can also facilitate discussion of ALDs, and notes regarding any such discussion can then be handwritten on the form by the audiologist (Figure 9). The Your Hearing Needs diagram illustrates situations that would qualify as far-field (e.g. Meetings/Conferences/Classrooms), although they are not explicitly labelled as such, with the focus geared towards the HA technology level deemed to be most appropriate to manage them (Figure 9).

Notwithstanding, in HAD-20 the audiologist did note “distant speech” under the “Meetings/Conferences/Classrooms” example (Figure 9). The inclusion of these sections allows for the discussion of ALDs for far-field needs, although in HAD-20 the ALD section of the HAD form was left blank. That may be indicative of a reliance on the more advanced HA technology level to address the issue of distant speech that would be presented in those listening situations. This was an issue that the Crowhen & Turnbull (2018a) identified as a potential concern, regarding overestimating the efficacy of HAs, which was part of their motivation for developing the FOCAS tool.

If television were being watched from further than one metre away, it would meet the criteria as a far-field listening need (Culling & Akeroyd, 2012). In the interests of qualifying this with accuracy, the distance the client sits from their television would have to be established. This depends on many factors, such as the size of the TV screen, the size of the room, and a person’s visual acuity. However, it is more common for people to watch TV from further than one metre away, in the case of both adults and children (Nathan, Anderson, Field, & Collins, 1985; Tanton, 2004), especially as screen sizes have increased with the widespread use of flat-screen devices (Lachat, Gicquel, & Fournier, 2015; Lee, 2012).

Fourteen out of the eighteen HAD cases discussed listening needs in reference to TV. Out of these fourteen, six discussed the use of TV streamers. In some of the cases, there were notes recommending sound bars and external speakers for the TV to assist with sound quality. In cases where ALD solutions were discussed, some clients presented viewpoints that reflected a reluctance to deal with any added technology on top of HAs, essentially wishing for the solution to remain as simple as possible: ‘Not a big technical person so not interested in wireless accessories either now or in the future.’ (HAD-03); ‘Not really fussed about the extra technology, wants something more simple.’ (HAD-08); ‘Prefers not to do anything with it. Just

to wear it throughout the day.’ (HAD-13). This may have been a reflection of an older demographic of client to whom the cost, as well as apprenticeship and management of additional devices, might be less appealing (Czaja et al., 2006; Lesner, 2003; Southall et al., 2006).

For example, HAD-15 recorded issues with TV volume and missing out on content: ‘Has it up more than wife would like. Mostly follows things if volume is up. But sometimes has more trouble hg e.g., films when music in the background. Sometimes misses the details of the story.’ Yet, in the Special uses/features section it was stated: ‘Not interested in Bluetooth streaming for phone or TV streamer either now or in the next 6 years.’ HAD-16 had as their second COSI goal: ‘TV – to hear at a normal volume’, yet under the Special uses/features section it was recorded: ‘Discussed phone and TV streaming but not interested.’ It is important to work with a client and respect their wishes, but it is also equally important to present the consequences of such decisions in regards to expectations and projected outcomes (Saunders et al., 2009), although there is not necessarily any reason to believe that this was not accomplished verbally in the HAD cases in question.

The FOCAS theme of Experience incorporated the questions from the FOCAS-ME tool relating to the client’s previous knowledge and experience regarding hearing assessment and hearing technology, including the price of HAs (Figure 5) (Crowhen & Turnbull, 2018a). The UoA HATC form has a section containing questions about current HA use, which does not involve a specific question regarding previous experience (Figure 8). This would not preclude the audiologist making that enquiry and noting it down, although, in theory, if a person answered “no” to that question, and provided no more information, this could mean they have had experience with HAs but are just currently not using them.

Three of the HAD cases were clients who were not currently wearing HAs yet discussed their previous experience under the section dedicated to current HA use. This indicates that either the audiologist prompted the follow up question about previous HA use verbally, or the client provided the information voluntarily in answer to the original question. Important information was provided in the case of HAD-17, in which the client reported a very negative experience with HAs: ‘Had HAids 5-6 years ago...had it on one side (only needed in one side), never stayed in, it kept falling off. Even with retention tail. One day it fell out and was never found again. Very upset with experience of hearing aid. Had many adjustments at the audiologist but never felt the sound was quite right.’ Additionally, HAD-02 stated she stopped

wearing her HAs because ‘she found she could hear better without them’, and HAD-12 stated, in regard to their previous HAs, that they ‘didn’t perceive much benefit’. These examples also show potentially useful information for the audiologist to have.

The investigation into previous knowledge and experience regarding hearing assessment and hearing technology aims to assist the clinician to gain more understanding of their client’s current situation (Australian Government Department of Health, 2018; Crowhen & Turnbull, 2018b; Dillon, 2008; Dillon, 2012). For example, discovering why a client did not go ahead with previously recommended treatment may help the clinician address concerns that were not resolved in prior assessments (Crowhen & Turnbull, 2018b). Asking a client what they think of HAs can uncover negative attitudes related to issues like cosmetics, or expose fears and misconceptions the client may hold about having to wear them, and managing these factors appropriately may help lead to better outcomes (Australian Government Department of Health, 2018; Dillon, 2006; Dillon, 2008).

Another aspect of the Experience theme is cost. It is standard practice for a client to be given a quote for trial HAs in audiology appointments in NZ, including at the UoA HATC clinic, and quotes were provided in most of the sampled HAD cases. However, notes that a quote was provided was not considered as sufficient for inclusion under the Experience theme in relation to the cost aspect. This is because training for use of the FOCAS-ME specifically involves broaching the subject of cost by presenting a range of prices rather than just one option (Crowhen & Turnbull, 2018b). This may overcome cost as a potential barrier to HA uptake, through establishing the client’s attitude towards the price of HAs, and providing more information for them to process (Ekberg et al., 2017). Additionally, reimbursement options that the client may or may not be aware of can also be discussed at this time. The Your Hearing Needs diagram, has a dedicated section for a graduated price scale of hearing instruments, providing a range of options, meaning HAD cases that included it were included under the theme of Experience. However, a senior audiologist from the UoA clinic advised that use of this diagram during HAD appointments is optional, and just four out of the twenty sampled HAD cases incorporated it.

Regarding the theme of Motivation, seven out of twenty of the HAD cases were current HA wearers, looking to upgrade or adjust their devices. Out of the remaining thirteen cases, all were either provided a quote for HAs to trial, or a suggested HA make and model was discussed in the appointment. The FOCAS-ME incorporates a question that explores the client’s

motivation and readiness to act on their hearing loss. Clients are likely to show better adherence to treatment plans, and experience better outcomes, if their attitude and motivation are positive (Australian Government Department of Health, 2018; Dillon, 2006; Dillon, 2008). While some level of motivation may be assumed based on the willingness to consider a HA trial, or discuss a potential HA make and model, this does not necessarily assume a discussion about the client's motivation. Consequently, it was decided that in order for a case to be considered under this theme, a discussion about motivation needed to be documented.

Motivation was referred to in HAD-17 in notes the clinician wrote at the bottom of the HAD, which stated: 'Is slightly on the fence about hearing aids after poor experience with last hearing aid trial but recognises that she needs to do something about hearing as she has been struggling with work.' This may have been the audiologist's opinion regarding the client's motivation based on their interactions during the appointment, or it could be actually reporting what was discussed with the client. Without any way of knowing, it was included in the theme of Motivation at face value. In the case of HAD-19, who had been borrowing his brother-in-law's demo HAs to try, the notes reflected that he seemed keen to trial some of his own, based on those experiences: '...Felt all levels made a huge difference...Had 8 people over the other night, heard them perfectly...would struggle to hear in that situation without the hearing aids... he didn't have to concentrate as much.'

There were three factors determined to contribute to rehabilitative service provision which were identified as part of standard protocol in the HAD appointments, which are not components in the FOCAS or FOCAS-ME tools. These were: tinnitus, sound sensitivity, and physical limitations. The UoA HATC offers dedicated tinnitus and hyperacusis appointments with a clinician specialised in these areas. However, in standard UoA HATC HADs it is protocol to enquire about a client's tinnitus and sound sensitivity. These aspects can potentially impact the appropriateness of prescribed hearing technology. For example, whether a tinnitus masker is provided (Hoare, Searchfield, El Refaie, & Henry, 2014), or how much a benefit a sound-sensitive person may be able to gain from the use of HAs (Formby, Sherlock, Hawley, & Gold, 2017).

Physical limitations such as arthritis can impinge upon a client's ability to manage hearing technology. For example, changing HA batteries or filters, which are quite fiddly tasks and require some level of dexterity in the fingers (Erber, 2003). Vision similarly impacts on whether a patient can see clearly enough to manage these requirements, as well as other

maintenance, such as ensuring filters or tubes are not blocked (Erber, 2003). Cataracts would not necessarily impact as much on vision as would a more serious progressive disease such as macular degeneration, and vision can be restored through surgery (Alio et al., 2012; Erber, 2003). However, it is important to understand whether the patient will be able to visually manage their hearing technology at the time of prescription, and if and when there will be any progression or improvement over the course of technology use (Erber, 2003).

Regarding safety in the home such being able to hear smoke alarms or other alerts, audiologists can provide counselling and advice. These are important aspects to take into consideration when assessing a client's needs, as there may be a requirement for specialised equipment like vibrating smoke alarms or door bells. Audiologists in NZ can also help the client apply for funding (Ministry of Health NZ, 2016). However, if a client has a need for this kind of equipment, a referral to a hearing therapist would be beneficial, as they can also provide assessment in this area. This service is free, which means that an entire appointment could be dedicated to addressing this particular issue if needed (Life Unlimited, 2015).

## **4.2 Findings Part 2**

The initial findings of part two of the analysis demonstrated many common themes across both datasets. There were correspondent listening challenges described by the clients, for example issues with TV volume and clarity. There were common emotions expressed, such as frustration. Both datasets had themes relating to the negative psychosocial impact of hearing loss and third-party disability, as well as positive and negative strategies the clients used to manage their hearing impairment. The discussions in the HAD cases tended to be more action-oriented, in other words more matter-of-fact statements explaining what was happening to the clients and their family members, and reports of how this impacted their behaviour, largely in the form of coping mechanisms. The F-M dataset was more feelings-oriented, consisting of reports of the emotional impact the hearing loss was having on clients and family members, and exposing the conflict and miscommunication that this was causing in relationships. Despite these variations, the mutual themes indicate a commonality of experience shared by those who were seeking assessment at the clinics, and by hearing-impaired people worldwide (Agrawal et al., 2008; Chadha & Cieza, 2018; Mathers et al., 2000; World Health Organization, 2001b).

Cosmetics were also discussed in both datasets, with examples contributing to the creation of the shared theme of Stigma (Figures 13 and 14). Simply expressing a cosmetic preference

cannot be definitively relegated to concerns about stigma, without establishing why the client held this preference. For example, in relation to choosing a HA colour, HAD-19 stated: ‘Sandy brown...to blend in with skin and hair.’ Other comments concerned discreteness: ‘Wants RICs because cosmetics are important to him, understands that there is more cleaning/maintenance required and he would need to replace the receiver annually and cost.’ (HAD-18); ‘wanting discrete if needed’ (F-M 09). It is possible these people simply prefer discrete accessories as part of their aesthetic, and this may be reflected in all their choices, including items not generally associated with stigma, such as wristwatches or earrings.

Nevertheless, such cosmetic concerns could potentially relate to the stigma associated with wearing HAs (Rolfe & Gardner, 2016; Wallhagen, 2009). Audiologists can help to address the possible effects of stigma by responding appropriately to their clients’ concerns (Wallhagen, 2009). However, the stigma towards hearing impairment can stem from ingrained societal attitudes towards disability and age, as well as possibly the effects of some HA advertising (Hétu et al., 1994; Kochkin, 2007b; Rolfe & Gardner, 2016; Southall et al., 2010; Van den Brink et al., 1996; Wallhagen, 2009). Consequently, overcoming it will likely have to be a holistic societal effort, and cannot be feasibly expected to be solved by audiologists alone, irrespective of clinical tools used.

One client expressed that they didn’t care what the HAs looked like, but this seemed to be because they would be covered by her hair, rather than that cosmetics were not any concern: ‘Usually wears hair down, doesn’t care what the HA’s look like.’ (HAD-13). This same client had also made a statement that may be indicative of the stigma that can be felt by those who are hearing-impaired. They had entirely lost their hearing in one ear, and regarding their employers stated: ‘Doesn’t want to tell them, ever.’ This may stem from a fear of being viewed as less professionally competent (Hétu et al., 1994; Kramer, 2008). Another client seemed to feel that gender was a concern, possibly worrying about social acceptance: ‘Initially preferred ITE style, feels for males they are more socially acceptable.’ (HAD-14).

Stigma may also be a potential contributor to some of the negative strategies that were related by clients (Southall et al., 2010). These included avoidance behaviours like no longer going out to restaurants and cafes, pretending to be able to hear things when they couldn’t, resigning from a position or hesitating to apply for a position due to the hearing loss, or in one case, engaging in unnecessary medical tests instead of addressing the hearing loss at work. Most of these negative strategies were found in the HAD dataset, although there were no questions

recorded specifically asking for this information. The same applies for any positive strategies related by clients. This circumstance contributed to the “action” idea assigned to the HAD dataset, and the theme What I Am Doing To Cope was created based on the prevalence of strategies mentioned (Figure 15). It is helpful to have information regarding clients’ coping strategies, as this can provide insight into how the hearing-impairment is impacting on their lives, and can supply the clinician opportunities for counselling, in the case of negative strategies, and positive reinforcement, in the case of positive ones (Bennion & Forshaw, 2013).

Communication with family was discussed to a large extent in both datasets, in describing challenging listening situations, as well as in goal setting. The ways family communication was discussed in each dataset was also in line with the ideas of “actions” versus “feelings”. The HAD dataset had many statements of fact regarding communication with family members: ‘Can hear his wife most of the time if she’s in the same room but not if she’s out of the room.’ (HAD-01); ‘Finds it hard to hear grandchildren and great children. Struggles to hear them when they come to visit.. Usually family come to visit with their children...’ (HAD-02); ‘If she can’t see her daughter and her daughter is in another world [sic] then can’t hear her.’ (HAD-11); ‘Lives with wife, his daughter in law and son. Sometimes misses what daughter in law is saying. Even 1:1 or in quiet.’ (HAD-16).

The F-M dataset largely consisted of references to family that were emotional, and often denoted conflict as discussed previously: ‘when family visit, I talk too loud for the family and need a lot of repeats, I feel isolated.’ (F-M 01); ‘feels wife mumbles.’ (F-M 06); ‘gets annoyed.’ (F-M 09); ‘family nagging – frustrating...client has to ask for repeat a lot and gets frustrated - family gets frustrated...daughter said something and mother doesn't respond, very annoyed’ (F-M 10); ‘feels he doesn't want to give wrong answers so just avoids the conversation in general.’ (F-M 11). The frustration and conflict around communication difficulties at home seemed more in relation to family members’ feelings, rather than the clients. However, family members also expressed empathy and sadness about the client’s situation: ‘family feels she needs help.’ (F-M 01); ‘Feels X is cut off from others.’ (F-M 05); ‘feels sad for mum...feels takes mum’s enjoyment away.’ (F-M 07); ‘aware he is missing out and feels for [him].’ (F-M 09); ‘church is important for mother, would like her to enjoy.’ (F-M 12). It would have been interesting to see the perspective of the family members in regard to the communication difficulties expressed by the HAD clients, in order to examine whether there were similar tendencies.

Both datasets also showed incongruent viewpoints between clients and family members, in relation to the extent and impact of the client's hearing impairment. This occurred more often in the F-M dataset, possibly because family members were present for all the appointments except one (F-M 08). These examples seemed mostly related to conflict relating to feeling “ignored”, or so-called “selective hearing”. However in F-M 01, the client stated they ‘talk too loud for the family and need a lot of repeats...feel isolated’, while their family member seemed to think it was the client's personality, rather than the hearing loss, that was the cause of the isolation: ‘feels not communicating with others and isolated but feels this is her personality.’ The HAD dataset had one instance of incongruence in which the client related his wife's opinion regarding his poor hearing, including issues with TV volume, yet he stated that he did not feel he was struggling with his hearing, and was unsure about trialling HAs. While these issues may be addressed to some extent through counselling with the client in a one-on-one appointment, they would be more effectively addressed if the family members were present (Armero, 2001; Hallberg & Barrenäs, 1994; Heine & Browning, 2002; Heine et al., 2002; Scarinci et al., 2008). Additionally, without family member presence, incongruences may be less likely to be uncovered (Meyer et al., 2015).

Both datasets shared the theme of Third-party Disability (Figures 13 and 14). Two examples from the HAD dataset described actions in relation to the television volume, which could be indicative of third-party disability (Hétu et al., 1987): ‘TV: Has it up more than wife would like.’ (HAD-15) and ‘TV: Has it up louder than wife and daughter would like.’ (HAD-18). There was potential third-party disability in the case of HAD 16, in which the family member/s may be being burdened with the role of interpreter (Armero, 2001; Scarinci et al., 2008, 2012): ‘Restaurant – needs family to accompany him if he goes because he can't hear.’ Without the family member present to provide their perspective on the impact these events were having on them, possible third-party disability can only be assumed rather than confirmed. Third-party disability seemed to be more clearly demonstrated in the case of HAD-10, where an emotional aspect was expressed (Anderson & Noble, 2005; Scarinci et al., 2008): ‘Her partner gets frustrated having to repeat things, ok 1:1 but only if he faces her.’ However, this comment is again presumed to have come from the client.

The F-M dataset had many instances reporting negative emotional impact on family members, including the unwelcome shouldering of extra communication burdens, an indication of third-party disability (Anderson & Noble, 2005; Armero, 2001; Scarinci et al., 2008, 2012): ‘Gets frustrated with high volumes that [client] needs.’ (F-M 05); ‘distressing for family...’ (F-M

07); ‘social gatherings, client avoids conversation so leaves all communication to wife - tired of having to speak for husband.’ (F-M 11); ‘avoid taking her into noisy situations as they have to translate constantly.’ (F-M 12). The fact that statements arose from family members indicating third-party disability provides opportunities for this to be addressed in clinic, which is an important part of family-centred-care (Backenroth & Ahlner, 2000; Scarinci et al., 2008). Additionally, the emotional impacts communicated can simultaneously be addressed (Singh et al., 2017). This is important as hearing loss can be associated with depression not only in the hearing-impaired, but their family members (Brewster et al., 2018; Brink & Stones, 2007; Chen, 1994; Kramer et al., 2002; Wallhagen et al., 2004).

There were also themes between the datasets which were different yet related. For example, avoidance (HAD dataset) and isolation (F-M dataset). This representation also illustrates the distinction between the ideas of “action” (avoidance) and “feelings” (isolation) behind the main themes (Figure 15). Recent research shows that exploring emotions during clinical appointments may have a positive influence on behaviour and motivation (Singh et al., 2017). The fact that emotion was prominent in the F-M dataset indicates that the clinicians using the tool were able to successfully utilise this aspect. It further demonstrates that clients and family members were willing to express emotions when asked, or volunteer the information without having been asked, as was possible in the HAD cases containing recorded statements from clients regarding emotional impact.

How clinicians respond to expression of emotions will be a matter of training and experience, especially if coming from a background where emotions have not been explored in typical appointments. This will require an adjustment in some cases, such as moving away from a site-of-lesion, audiologist-driven dialogue, to one in which clients and family members are allocated more speaking time (Ekberg et al., 2015; Meyer et al., 2015, Hickson et al., 2016). An advantage that audiologists in NZ have is the ability to make referrals to the free hearing therapy service provided by Life Unlimited (Life Unlimited, 2015). Hearing therapists provide a wide range of counselling services, including advice for clients and family members on bettering their communication skills in the face of hearing loss, and are able to dedicate more time to addressing the feelings and conflicts that may have arisen during an audiology appointment (Life Unlimited, 2015).

In UoA HATC HADs, it is normal practice to make use of COSI goals (Figure 8). The entire COSI tool is not incorporated, for example it does not include the outcomes section (Figure 8),

although outcomes can be discussed at follow-up appointments and captured as case notes. As noted previously, COSI was the favoured tool among the clinicians surveyed by Crowhen & Turnbull (2018a). Even though the COSI goals aren't specifically family-centred, clients in the HAD cases often set COSI goals that involved communication with their family members, suggesting this was important to them. Audiologists have also reported soliciting family member input when setting COSI goals with their clients (Meyer et al., 2015). Of course, this would require the family member/s to be present. Many goals from the HAD dataset also consisted of being able to lower the TV volume, which is often something that impacts on family members, which was apparent in the needs assessment for some of these cases.

The standard HAD format used by most of the sampled HAD appointments provides opportunities for the exploration of two key FOCAS-ME elements identified as themes (Figure 11). These were far-field hearing needs, and previous experience with HAs (Figure 8). The use of some of these elements during the appointments were at the discretion of the audiologist, for example the suggestion of ALDs when far-field hearing needs were discussed. The clinicians also have at their disposal the Your Hearing Needs diagram (Figure 9). This illustrates listening situations and corresponding HA technology in a way that is similar to the FOCAS-ME diagram (Figure 5).

The idea behind the near- vs far-field aspect of FOCAS is educational in one respect, in that it allows the clinician to inform the client that a specific need falls into whichever category, and the significance of that categorisation with regard to hearing technology solutions and projected outcomes (Crowhen & Turnbull, 2018a). This is with the aim of clearly setting realistic expectations in terms of the technology the client opts for, especially in relation to far-field need results that may be compromised if the client opts for HAs alone (Crowhen & Turnbull, 2018a). The same opportunity is clearly there within the HAD template, or the Your Hearing Needs diagram, but the key factor with the FOCAS and FOCAS-ME tools is that they include these distinctions as an integral component of goal setting (Figures 4 and 5). However, neither diagram was used in the majority of sampled cases. Additionally, the completed FOCAS-ME tools uniformly showed television as a near-field need when it was outlined as a goal, despite the suggestion of ALDs as a solution in more than half of these cases. The reasons for the above circumstances were unable to be determined, although they may reflect issues regarding audiologists' understanding of far-field hearing needs that were identified in the survey conducted by Crowhen & Turnbull (2018a).

The FOCAS and FOCAS-ME tools incorporate aspects of the Goal Sharing for Partners Strategy (GPS) by Preminger and Lind, which includes shared responsibility between clients and family members in dealing with the impact of hearing loss (Crowhen & Turnbull, 2018a; Preminger & Lind, 2012). Shared goals are an important part of this strategy (Crowhen & Turnbull, 2018a; Preminger & Lind, 2012). This does not preclude the inclusion of individual goals, for example if the client is having issues at work that they wish to address. Additionally, lack of family member attendance to the appointment does not preclude the use of the tools, as in the case of F-M 7. This would mean that the second part of section 2: Hearing and communication challenges (Figures 4 and 5) would be left blank, and goals would not have the direct input of a family member, unless they had discussed this with the client prior to the appointment.

The tools also include exploration of near- versus far-field hearing needs in relation to the goals, classifying the identified listening situations accordingly (Crowhen & Turnbull, 2018a). As mentioned previously, all seven cases that had TV as one of the goals classified it as a near-field need. Nevertheless, in three of these cases, TV streamers were suggested as the optimal solution. In the fourth case, the notes stated the client had essentially normal hearing, yet had issues with TV clarity. In this case, there was no optimal solution stated however in questions 3 and 5 of section 4: Motivation and experience (Figure 5), it was noted that the client had been researching generic TV headphones as a possible solution and was only interested in technology for the TV.

Goals can be assigned a level of importance between 0 and 10, in four stages from “occasional” to “critical” (Figure 6). Unlike the COSI, any number of goals can be assigned the same level of importance, rather than scaled from most important to least (Crowhen & Turnbull, 2018a). Most of the completed FOCAS-ME forms showed goals which shared the same level of importance with each other, reflecting that these were issues that clients and family members felt were equally crucial. For example, in the case of F-M 1, there were three goals designated, and all three were assigned “critical” importance. As with the COSI, the FOCAS and FOCAS-ME tools provide a method for recording outcomes, which would occur during follow-up appointments. This is rated as a percentage out of one hundred, in a five-step ratio (Figure 7). Four of the twelve FOCAS-ME forms had recorded goal outcomes, all of which were either 60-80% or 80-100%. It is not known what time period this signified.

The information provided by the data from either of the datasets in this study did not include the measure of which technology the clients ended up trialling, nor any further information. Therefore, with respect to HA uptake, the choice to use ALDs, satisfaction with chosen technology, or adherence to treatment plans, the information provided by the limited data in this study cannot demonstrate success or failure of the different approaches on these outcomes for the clients or their family members. Regarding the meeting of goals, there were only four FOCAS-ME cases in which outcomes were recorded, however, these were generally positive, ranging from 60-100%. This percentage can be used to either indicate the percentage of time that improvement was noted, or the percentage of improvement the client feels is applicable. It is not known how these outcome percentages were assigned in the four FOCAS-ME cases.

### **4.3 Future Directions**

Due to its nature as a communication disorder it would be beneficial for hearing loss to be treated as a family issue, including in the case of adult audiology (Danermark, 2005; Héту et al., 1993; Scarinci et al., 2012). Based on this observation, family-centred-care in adult audiology can be seen as a logical development (Backenroth & Ahlner, 2000; Hallberg & Barrenäs, 1994; Jennings, 2009; Preminger, 2003; Preminger & Lind, 2012; Scarinci et al., 2008). However, its successful implementation depends on whether the widespread structural and cultural changes necessary will come about (Ahmann & Johnson, 2001; Henneman & Cardin, 2002; Hostler, 1999; Johnson, 1999; Johnson, 2000; MacKean et al., 2005). The FOCAS and FOCAS-ME tools were developed with the aim of addressing gaps in adult audiology service provision identified in recent literature, including the implementation of family-centred-care in adult audiology.

Successful implementation of FCC is not limited to efforts by audiology clinic managers and clinicians, but also applies to clients and family members regarding their willingness to have family attendance at audiology appointments, and to overcome any logistical issues this may create for them, such as additional childcare needs, taking time off work, and coordinating schedules, etc. (Ahmann & Johnson, 2001; MacKean et al., 2005). Therefore, it may be considered an issue requiring a cultural change. In the case of this study, participants were unable to be recruited for the original study design, which proposed using the FOCAS tool in UoA HATC clinical appointments, and subsequently interviewing the clinicians, clients and family members regarding their experiences. Further efforts proposing the use of the FOCAS tool in pilot studies in NZ are still underway, with no pilot studies having begun to date.

In the end, a tool is as effective as the clinician who uses it, and rigorous training is recommended as an essential part of the implementation of any clinical tool, in order to cover intended aspects thoroughly, and reap maximum benefit from its use (Graham & Harrison, 2005, Hostler, 1999; Lawlor & Mattingly, 1998). For example, recent research shows that exploring emotions during clinical appointments may have a positive influence on behaviour and motivation, yet an important aspect of this is for the clinician to respond with empathy, as potentially negative effects may develop if the response is not appropriate (Singh et al., 2017). Therefore, having formatted questions may not necessarily guarantee achieving the desired results, as this will depend on how the clinician responds (Singh et al., 2017).

This research primarily involved people with acquired hearing loss, and findings do not necessarily address the issues faced by populations with congenital hearing loss and their family members. There is a gap in the literature regarding how audiology practice performs in regards to Maori and Pacifica populations, as well as other minority groups in NZ (Deloitte Access Economics Pty Ltd., 2017). There is a need to consider the cultural implications of clinical practice approaches in these groups as well as other ethnic minorities (Kreuter et al., 2003; Pasick et al., 1996). Groups with alternative sexual orientation are also under-represented in the literature (Kelly & Atcherson, 2011). Inclusion of these populations into future research of the FOCAS and FOCAS-ME tools is recommended.

It is also recommended that research into the use of FOCAS and FOCAS-ME involve audiovisual recordings of the audiology appointments. This will provide more insight into how the clinicians are using the tools, and how the clients and families are responding to them. Recordings would capture the entire interaction, and all of the verbal exchanges, which includes tone of voice. They could be in the form of audio alone, although audiovisual recordings are recommended, as not only will the verbal exchanges be captured in entirety, but also facial expressions and body language, which is information that can provide additionally insight into the transactions being observed.

The FOCAS and FOCAS-ME tools aim to be user-friendly and efficient, and the inclusion of family member involvement is not intended to cause any extension to clinical appointment times. Therefore, it is also recommended to conduct interviews with clinicians, to gather their opinions and perspectives on how the use of the tool benefited them and document any suggested improvements they might have. Interviews with family members and clients are also recommended for the same reasons, including investigating QoL outcomes. Questionnaires and

surveys are another way of gathering this information, all of which will contribute to research investigating the effectiveness and utility of the tools. For example, measuring QoL outcomes can be achieved using questionnaires such as the Hearing Handicap Inventory for Adults (HHIA), the Hearing Handicap Inventory for the Elderly (HHIE), and The Hearing Impairment Impact – Significant Other Profile (HII-SOP) (Ciorba et al., 2012; Cox et al., 2000; Newman et al., 1990; Preminger & Meeks, 2012; Weinstein et al., 1986)

The FOCAS and FOCAS-ME tools are potential alternatives to the COSI (Dillon et al., 1997), which is a very popular tool that has established use in adult audiology, and is not dependent on family involvement. The COSI was the preferred tool amongst clinicians who used a formal tool surveyed by the Crowhen & Turnbull (2018a). The COSI was preferred due to its ease, concise administration, and high validity (Crowhen & Turnbull, 2018a). FOCAS aims to expand on the COSI through incorporating FCC, while retaining crucial elements such as the exploration of challenging listening situations, goal setting, and tracking outcomes, as well as ease of use and efficiency of administration (Crowhen & Turnbull, 2018a). Additionally, the FOCAS tool expects to be globally accessible through translation into multiple languages (Crowhen & Turnbull, 2018). The COSI tool is popular due to its convenient and user-friendly nature and has experienced widespread use in audiology clinics around the world. Whether the FOCAS and FOCAS-ME tools will become alternatives to the COSI is outside the scope of this study.

#### **4.4 Limitations**

When conducting research retrospectively using data such as clinical case studies, rather than case studies conducted as part of a research project, there is a risk of missing information. This is because when planning research, variables can be accounted for in advance, and those partaking in the research can ensure that the data captured for the study contains all the relevant material. In this study, the data consisted of case notes and forms which originated from clinical audiology appointment records that were never intended to be part of a qualitative analysis. This rendered data that might have contributed to the research unobtainable, due to it never having been captured in the first place.

For example, knowledge of the presence or absence of family members in the HAD cases, as well as verbal interactions that occurred between the clients, family members and clinicians in all the cases studied, which might have added important nuances not apparent in the written

information. With regards to the FOCAS-ME cases the author did not have access to any other client records apart from the completed FOCAS-ME forms. Therefore, it is possible that other relevant information, such as that relating to tinnitus or noise sensitivity for example, may have been recorded by the clinicians as part of a separate appointment or record for that client.

The data in this study is third hand, in the form of notes written by clinicians from interactions they had with their clients and family members during audiology appointments. This means that the statements available are not exact, as they would be from audio or visual recordings, or verbatim transcripts of the same. This influences the nature of the information being reviewed, as each clinician has probably developed their own individual style of recording information and may even favour certain stock phrases that through experience they have found are useful shorthand for their case notes. Consequently, words recorded to describe a listening experience or situation may be paraphrasing by the audiologist, rather than words actually stated by the client.

Additionally, some of the content that formed the themes might be idiosyncratic to a certain clinic culture, or to a group of clinicians who were trained together, have worked together a long time, or belong to similar social groups with a certain language style. For example, “struggling” and “missing out” occurred more in the HAD cases, versus “minimise” and “clarity” in the FOCAS-ME cases. Furthermore, recorded statements may have been the results of prompting by the clinician. For example, an audiologist might ask a client “do you find that you are struggling?” or “is it the clarity?” etc. These kinds of cues might also reflect an individual audiologist’s favoured terminology to use in their clinical appointments and record-keeping. In other words, it would be conceivable that the content was almost entirely reflective of the clinician’s language, rather than of the client or family members. All these factors would inevitably impact upon the analysis.

The small study size is another limitation, as is the disparity in numbers between the two datasets. In addition, while it is not standard to record ethnicities in the UoA HATC database, it is observed that the main demographic of patients at the UoA HATC clinic tend to be Europeans who generally fall into the older age group. This portends a potential lack of diversity of cultural representation in the HAD dataset. The demographic of the clients from the completed FOCAS-ME appointments is also not known, however a similar concern would pertain to this dataset if the same trend were applicable. All of the cases studied also consisted mostly of married, cis-gendered couples, and did not represent a diversity of relationships.

Finally, the original study design involved use of the FOCAS tool in clinical appointments in NZ. However, participants were unable to be recruited to complete the study, and further pilot studies are not yet underway. The study was therefore limited to data which came from use of the FOCAS-ME tool in audiology clinics in Australia. While the FOCAS-ME incorporates the elements of the FOCAS tool in entirety, examining how information was managed through use of the shorter version may have had the potential to provide useful material for those proposing to trial the FOCAS tool in NZ. In addition, subtle differences in audiological practice between the two countries may have impacted on the research. For example, how clinical appointments are organised, or the order in which diagnostics and needs assessment discussions occur. Comparing practice from clinicians from the same country, and clinic type, with the same scope of practice, could limit any differences.

## **Chapter 5: Conclusion**

The preliminary results of this study showed that the FOCAS and FOCAS-ME tools have the potential to elicit the information intended towards achieving their aims, especially with regards to the emotional impact of hearing loss, and the impact of third-party disability through incorporating family-centred-care. The FOCAS-ME data showed evidence of the negative emotional impact that hearing loss can have on family members as well as clients, and exhibited the empathy family members can feel for the hearing-impaired person. By targeting this information with specific questions, the FOCAS and FOCAS-ME tools are able to ensure the dialogue will occur, rather than it being incidental or ancillary. Family members are intended to be involved by default in FOCAS and FOCAS-ME appointments, and are invited to contribute their perspectives, and participate in goal sharing, as an integral part of the tools' design. Family members expressed desire that the hearing-impaired person receive help, which may indicate a potential willingness to be an active participant in rehabilitation approaches.

The study also showed that similar information regarding emotions and third-party impact arose in the sampled UoA HATC HAD appointments. Additionally, the HAD dataset showed more examples of strategies that clients are using to cope with their hearing loss. This may reflect the awareness of these issues on the part of the clinicians, who could be encouraging this dialogue in clinical appointments without relying on it being part of the standard format of HAD discussions. It is also conceivable that the information was volunteered unprompted by clients and any family members in attendance. This would indicate that clients and/or family members were potentially eager to impart this information. Notwithstanding, the emotional aspect was much less evident in the HAD dialogues, which were more matter-of-fact observations. Further observations identified potential gaps in service provision in respect to tinnitus and sound sensitivity, as well as physical limitations of patients that could potentially impact their ability to manage hearing technology. These were consistently covered in the HAD appointments, but are not included in the design of FOCAS or FOCAS-ME.

In sum, the findings show that similar information was gathered in the appointments, independent of what clinical tool or format was used, and that the clients related experiencing essentially the same range of issues caused by their hearing impairment. The way the information was presented was different between the two datasets, and the evidence of emotional impact and third-party disability was more prevalent in the F-M dataset. Ultimately,

the benefit of using the FOCAS and FOCAS-ME as clinical tools to improve the quality of life of hearing-impaired persons and their families, and reduce the impact of third-party disability, can only be learned through longitudinal studies. Whether the projected benefits of targeting experience and motivation as part of the FOCAS-ME tool will be achieved, can also only be established through ongoing research that includes investigation into long-term outcomes of using the tool. Additionally, establishing if clinicians will find the tools user-friendly and efficient can be investigated through pilot studies such as the FOCAS-ME pilot study currently occurring in Australia. The qualitative nature and small sample size limit the findings of this study. Consequently, they cannot be applied to broader populations. Further investigation of a larger sample group, with a wider representation of diverse populations, is recommended.

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