

REACTIONS AND RESPONSES TO THE DIAGNOSIS OF A
PROGRESSIVE HEARING LOSS IN ADULTS

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ABSTRACT

Being given the diagnosis of a disability generally affects an individual's emotional state, however, this has not previously been investigated with respect to audiology and the diagnosis of hearing loss. The first aim of this study was to describe some of the common initial reactions to the diagnosis of hearing loss (HL). An awareness of these emotional reactions will aid audiologists in counselling their patients. Counselling occurs at the time of the diagnosis and throughout the aural rehabilitation process. However, counselling tuition is currently not provided for audiology students at New Zealand universities and there are few professional development courses for practicing audiologists. The second aim of this study was to evaluate current audiological counselling services and ascertain the impact on patients' decisions to get hearing aids (HAs). To accomplish these aims, 27 adults who had been newly-diagnosed with a HL completed an initial reaction questionnaire, partook in an interview which followed up on the questionnaire, and subsequently completed a second questionnaire at least three weeks later. There were two versions of the second questionnaire, depending on whether they had chosen to have HA(s) fitted. The results found that the common emotions reported were a sense of loss, sadness and resignation, as well as relief. Furthermore, an individual's level of optimism tended to decrease in response to the hearing test result. The ratings of the audiological counselling services were positive and seemed not to significantly influence the individual with respect to their decision to purchase HAs. The two areas of audiological counselling which could be improved related to how the audiologist explained the HL, particularly in relation to the individual's life, and also the provision of information to patients prior to the fitting of the HA. In addition to the data that was collected in relation to these aims, information was collected with respect to patients' perceptions of their HL prior to the hearing test, their interpretation of the hearing test results, and also how the patient's significant other responded to the diagnosis. The information from this study will be useful for equipping audiologists, both new graduates and those with more experience, to provide optimal audiological care for their patients.

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1. INTRODUCTION

Hearing is important for orientating oneself and interacting with the environment. Hearing background sounds makes us feel in contact with the environment. Through the sense of hearing we can identify things that are out of sight and ascertain their direction and location; for example, keys lost at the bottom of a bag, or children in another room. Hearing is important for communication, spatial orientation and our identity. Therefore, being diagnosed with a hearing impairment would be likely to provoke an emotive response. This study aims to identify the common reactions to a diagnosis of hearing loss and the role the audiologist plays in the individual's response.

This chapter provides the context to this study by firstly explaining hearing loss (HL) – its assessment and management - and then providing a review of the literature relating to initial reactions to a diagnosis, and audiological counselling. Based on this literature review, the rationale for the current study is presented at the end of this chapter. Before proceeding it is important to clarify that the term 'deaf' can be used to refer to any degree or type of HL. Furthermore, 'deaf' differs from 'Deaf', whereby the latter is used for individuals whose social identity is defined by their deafness. In this thesis the terms 'deafness', 'hearing loss' and 'hearing impairment' have been used interchangeably. The author acknowledges that 'hearing impairment' is a value-related term and some individuals may not perceive themselves as being impaired by their compromised hearing. Similarly, the terms 'patient' and 'client' are used interchangeably in this thesis; while 'patient' implies sickness, it is commonly used at audiology clinics and in the literature.

1.1 Hearing Loss

1.1.1 Overview

A hearing loss (HL) is defined as a hearing sensitivity worse than that of average normal hearing individuals (Harrell, 2002). When hearing is tested, the softest level (in dB HL) at which a frequency-specific sound stimulus is detected is defined as the person's threshold at that frequency and it is plotted on an audiogram (Harrell, 2002). Figure 1.1 provides an example of an audiogram for an individual with age-related HL. A person's HL is classified both in terms of the type and severity of the

loss. Impaired hearing may have a conductive, sensorineural or mixed aetiology. A conductive HL arises from impaired transmission of the sound through the outer and middle ear. This type of HL may be treated with surgery or antibiotics. A sensorineural loss arises from dysfunction of the cochlea or auditory nerve. Surgical repair and/or medical intervention for this type of HL is rare and instead hearing aids (HAs) are the most common treatment. HL which is the result of aging is known as presbycusis and is an example of a sensorineural HL which typically affects the high frequencies (as shown in Figure 1.1). A mixed HL involves a combination of conductive and sensorineural impairments.

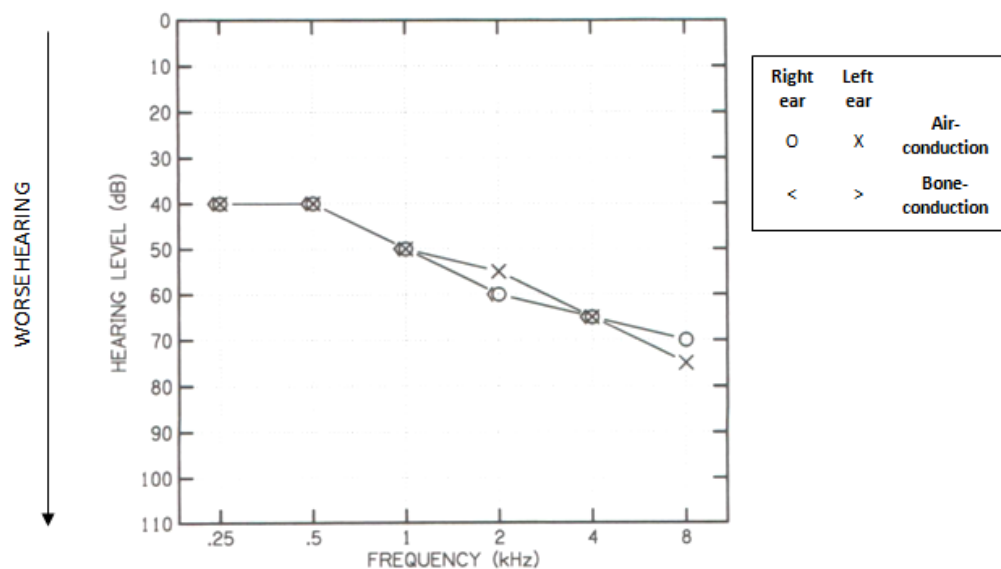


Figure 1.1 Example of an audiogram (adapted from Harrell (2002))

The severity of the HL is typically classified as mild, moderate, moderately-severe, severe or profound. For the clinics involved in this study, the classification system was as follows: Mild = 21 – 40 dB HL; Moderate = 41 – 55 dB HL; Moderately-severe = 56 – 70 dB HL; Severe = 71 – 90 dB HL; Profound > 91 dB HL. The degree of loss may differ across the frequencies; this is often referred to as the configuration of the HL. For example, if the loss is greater at the low frequencies than at the high frequencies, this is a rising loss, in contrast to a sloping loss, where the loss is greater at the high frequencies than the low frequencies. Given these different configurations, an objective measure is often used to describe the overall level of loss, called the pure tone average (PTA). This is the average of the individual’s thresholds (using pure tone

stimuli) at three or four frequencies on an audiogram. Often a HA is considered when the individual's PTA exceeds 30 dB HL (Karlsson Espmark & Scherman, 2003).

Typically the onset of a person's HL is described in relation to whether it occurred prior to the development of language (prelingual) or after the age at which an individual begins to develop language (> 3 years) (postlingual) (Mahshie, Moseley, Lee, & Scott, 2006). Given that prelingually deafened individuals have had a HL for the majority of their life, they are more likely to see themselves as part of a hearing impaired community. On the other hand, individuals who lose their hearing later in life will have regarded themselves originally as being part of the hearing world. Therefore, it is probable that prelingually and postlingually deafened individuals will differ with regards to how they perceive the HL.

The HL which is typically discussed in this thesis is a permanent HL, rather than a temporary HL that may result, for example, from an ear infection. Those individuals who have a permanent HL and are experiencing difficulties as a result of their HL are typically offered HAs. There are a number of HA manufacturers and each manufacturer produces HAs of varying style, size, price and with different technological capabilities. Each HA comprises of a microphone which transforms the acoustic signal into an electric signal; an amplifier which increases the level of the signal based on the user's HL and preference; a receiver which transforms the electric signal back into an acoustic signal and delivers the sound into the person's ear; and a battery to power the system (Figure 1.2) (Dillon, 2001). While the technology of HAs is constantly being researched and developed, some users are still frustrated by the limitations of their HA. For example, users complain that the HA does not always improve hearing acuity or enable them to hear when there are multiple noise sources. Some of this frustration could be reduced by more realistic expectations of the capabilities of the HA, which is one aim of audiological counselling. However even if an individual's expectations are addressed, HAs make an individual's HL more visible (Magilvy, 1985) and have an associated stigma, whereby individuals who have HAs may be perceived as less attractive and intellectually capable (English, 2008). Furthermore, for many patients HAs are an expensive purchase and as such they expect benefits for the expenditure.

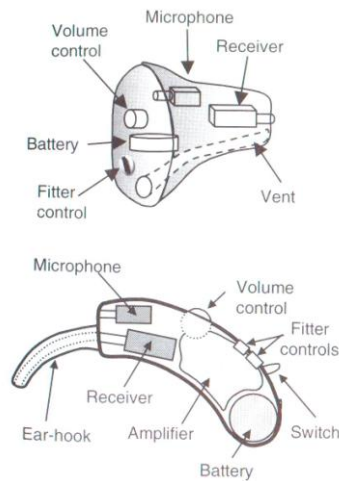


Figure 1.2 Components of a hearing aid, as shown for two styles of hearing aid: In-The-Ear (ITE) hearing aid and a Behind-The-Ear (BTE) hearing aid (Dillon, 2001)

1.1.2 Prevalence

No prevalence studies using objective measures of HL have been undertaken in New Zealand. Data from the United States suggests a prevalence rate of 16% amongst individuals aged 20 – 69 years (Agrawal, Platz, & Niparko, 2008). Using a definition of HL of a PTA of ≥ 25 dB HL across the frequencies 0.5, 1, 2 and 4 kHz, Agrawal et al. (2008) found a prevalence rate of 8.5% for individuals aged 20 – 29 years, and the rate increased with age. In New Zealand, surveys of self-reported HL have yielded prevalence estimates of 6.5% – 10.3% (Greville, 2005). Given that the New Zealand surveys relied on individuals' subjective reports, under-reporting may be an issue.

1.1.3 Impact of hearing loss

'Hearing disability' refers to the impact of a HL on a person's everyday life, including social, emotional and occupational considerations (Alpiner, 1997). Therefore, the 'disability' is due not only to the individual but also the society within which the individual exists. Previously a HL was ubiquitously defined as a disability. But since the development of the International Classification of Functioning Disability and Health (ICF), it has been recognised that the extent to which the HL is disabling differs depending on the individual and the context within which they live. The ICF is a classification system developed by the World Health Organisation which provides a framework as well as standardised language for describing health conditions and their

impact (World Health Organization, 2001). It classifies behaviour or traits rather than the individual, and can be used to describe the effect of a HL on an individual's everyday functioning (Smiley, Threats, Mowry, & Peterson, 2005). As shown in Figure 1.3, the ICF has two parts and each part comprises of two components (World Health Organization, 2001):

Part 1: Functioning and Disability

- (a) Body Structures and Function
- (b) Activities and Participation

Part 2: Contextual Factors

- (c) Environmental Factors
- (d) Personal Factors

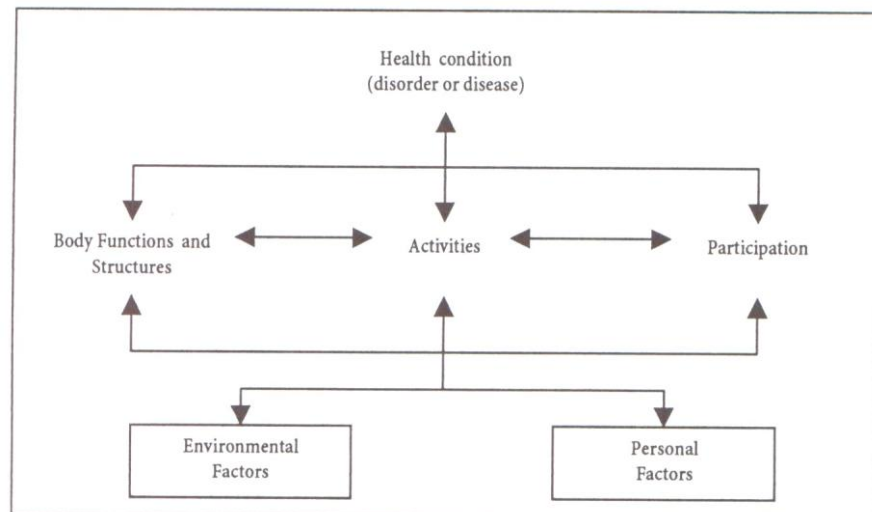


Figure 1.3: Interactions between components of the ICF (World Health Organization, 2001)

Figure 1.3 also illustrates how the components of the ICF interact and influence each other. The ICF defines 'Body Structures' as the anatomical parts of the body, and 'Body Functions' as the physiological functions of the body systems, including psychological functions. 'Activity' is defined as the execution of a task or action, while 'Participation' is defined as involvement in a life situation. 'Environmental Factors' constitute the physical, social and attitudinal environment in which the person lives and goes about their life (World Health Organization, 2001). 'Personal Factors' are internal factors which affect an individual's functioning but are

not part of a health condition, for example, gender, ethnicity, age, fitness, lifestyle, habits, upbringing, social background and education (Smiley et al., 2005; World Health Organization, 2001). Each of the four components ((a) – (d) above) can be considered from both a positive and negative perspective (World Health Organization, 2001). For example, with respect to ‘Activities and Participation’ ((b) above), the terms ‘Activity Limitations’ and ‘Participation Restrictions’ may be used to characterise a health condition which is hindering an individual’s involvement in his/her environment. An ‘activity limitation’ occurs when an individual has difficulty executing an activity, and a ‘participation restriction’ occurs when the individual has problems being involved in certain life situations (World Health Organization, 2001). Activity limitations and participation restrictions have been negatively correlated with wellbeing scores (Helvik, Jacobsen, & Hallberg, 2006). As such, the impact of a HL on an individual varies depending on a range of factors and can not be reliably predicted from the audiogram. It should be noted that the broad use of the terms ‘disability’ and ‘handicap’ was common place in the literature prior to 2001, and as such may occur in the following literature review.

1.1.3.1 Literature relating to the role of personal factors on the impact of HL

As stated in the ICF framework, the extent of the impact of a HL may be affected by personal factors. Several studies have found that age, gender, co-morbid health conditions and personality affect how HL impacts on the individual (de Graaf & Bijl, 2002; Erdman & Demorest, 1998; Helvik et al., 2006; Lupsakko, Mantyjarvi, & Kautiainen, 2002; Tambs, 2004). Tambs (2004) reported that age influenced the degree of association between HL and mental health, with the mental health of older (> 65 years) individuals being less affected by HL than for younger individuals. This may be because HL is expected to occur with age, and so an older individual with a HL is regarded to be ‘more normal’ than a younger individual with HL. Tambs (2004) also reported that gender influenced the effect of HL on mental health, with the effect being greater amongst males than females, possibly due to the greater vocational-related expectations placed on males. In contrast, some other studies have found that women place a greater importance on social communication than men and may consequently be more affected by HL (Erdman & Demorest, 1998). Lupsakko (2002) reported that a co-morbid health condition can heighten the level of disability perceived by the individual. Individuals who have both diminished vision as well as HL have been reported to have

a higher level of disability than those with just a single impairment, as measured by having fewer independent activities in their daily living (Lupsakko et al., 2002). Helvik et al. (2006) and de Graaf and Bijl (2002) showed that personality also affects the impact of a HL. In a sample of adults with hearing loss, sense of humour was positively associated with psychological well-being (Helvik et al., 2006), while lower levels of self esteem and a lack of acceptance of the HL were associated with higher levels of mental distress (de Graaf & Bijl, 2002). Finally, another personal factor which may affect the impact of a HL on an individual is their ability to communicate. For example, de Graaf and Bijl (2002) found that individuals who were less competent at speech-reading had higher levels of mental distress.

1.1.3.2 Literature relating to the role of environmental factors on the impact of HL

The impact of an individual's HL may also be affected by environmental factors, as recognised by the ICF. Such factors may include the individual's support network and their occupation, which can influence, for example, the level of demand placed on the individual to communicate and the quality of communicative exchanges. Knutson and Lansing (1990) found that poorer communication with family and friends was associated with feelings of loneliness and isolation. The impact of the HL may also be affected by the manner by which the HL occurred and how well the individual coped with the situation. For example, a gradual HL has been associated with a greater number of depression and anxiety symptoms than when the HL occurred suddenly (de Graaf & Bijl, 2002). Also there seems to be a greater effect on one's mental health when the hearing threshold deteriorates from normal to slightly impaired compared to when it declines from mild to profound (Tambs, 2004). This is possibly because with a slight hearing impairment there is the risk that the hearing could deteriorate further, whereas with a profound HL, the impact of further deterioration would be less substantial (i.e. there is little hearing left to lose).

As described in the preceding two paragraphs there are many factors that influence the impact of HL on an individual. In addition to these factors, there may be another factor which could partly explain why the impact of a HL is not predictable from an audiogram. The presence of a HL is clinically assessed in a sound-proof booth, whereas in the real world, speech usually occurs in the presence of background noise. Therefore, self-reported hearing impairment may be a better representation of the degree

to which an individual is affected by their HL in everyday environments. A self-report measure captures the individual's interpretation of their HL, which is important given that different individuals deal with HL in varying ways (Karlsson Espmark & Scherman, 2003). Some individuals are not affected by their mild HL, whereas others feel that their social functioning is significantly compromised and they feel left out, lonely and have difficulty paying attention (Wallhagen, Strawbridge, Shema, Kurata, & Kaplan, 2001).

Finally, the impact of a HL has been seen to differ between individuals who were prevocally deaf (i.e. their HL occurred prior to age 19) and those who had a later onset of HL. Magilvy (1985) found that while both groups experienced significant handicap due to their hearing difficulties, the latter group tended to have more emotional and situational problems, for example, they felt left out of groups and felt embarrassed and stupid. Meanwhile, the prevocally deaf individuals typically socialised with other deaf people, for example, they went to church services with interpreters in sign language, and as such did not report feeling left out. Instead, the difficulties they reported related to communication within the wider community (Magilvy, 1985).

1.2 A Personal Factor – The Individual's Initial Reaction To Their Hearing Loss

An example of a personal factor which interplays with an individual's perception of their HL is the individual's initial emotional reaction to being told by an audiologist that they have a HL. When an individual is given the diagnosis that they have a disability, such as a HL, there is likely to be a change in their emotional state. The individual's immediate response may affect their receptiveness to other information which the audiologist provides at this time and also their ongoing perception of the HL. There is a paucity of studies that have specifically investigated emotional reactions to the diagnosis of a HL. Knowing the common reactions that occur following the diagnosis of a HL would be useful for audiologists when counselling the patient (i.e. what are their support needs at this time) and for reassuring the patient that the recommendations made to them are beneficial and worthwhile.

There is just one published study that has reported on adults' immediate responses to the diagnosis of acquired HL (Martin, Krall, & O'Neal, 1989). In Martin et

al.'s (1989) study, a questionnaire was sent to 500 individuals (of which 276 responded) who were on a mailing list of a self-help group for hard-of-hearing people, inquiring about the initial impact of the diagnosis of acquired HL. The emotions the individuals reportedly experienced during their hearing test included sadness, worry, fear, disappointment, anger, surprise and shock (Martin et al., 1989). From Martin et al.'s (1989) article it is not clear how much time had elapsed from when the individual received the diagnosis to when they filled in the questionnaire. It is possible that a delay in time may have been associated with less accurate recall of their immediate emotional reaction.

While there are no other studies that have investigated initial emotional reactions to HL, there are a number of publications of a commentary nature which have discussed HL and the associated emotional impact. For example, Luterman (2006) described HL as being associated with feelings of loss, anger, anxiety, confusion, vulnerability and a loss of identity. When asked about the emotional impact of the diagnosis of HL, an individual with a severe-profound HL described it as "something similar to a bereavement" ((Barlow, Turner, Hammond, & Gailey, 2007), p. 444). In this same study by Barlow et al. (2007), which interviewed nine patients with a severe or profound HL, the common emotions which were retrospectively reported to have occurred during the initial and early stages of the diagnosis were anger, frustration, depression, loss of confidence, reduced self-worth, bewilderment, denial and lack of acceptance. These emotions are consistent with the stages of grief, which include denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). Many of the participants in Barlow et al.'s (2007) study reported that they felt they had lost their sense of self - they felt they no longer belonged to the hearing world but did not identify with prelingually deafened individuals. HL threatens one's self-concept (e.g. 'I am a person with normal hearing') and body image, with HAs being negatively associated with perceived attractiveness, intelligence and ability (English, 2008).

Studies that have examined the longer-term impact of the diagnosis have found some suggestion that symptoms of depression are more common amongst those with a HL than those with normal hearing (Cacciatore et al., 1999; Carabellese et al., 1993; Eriksson-Mangold & Carlsson, 1991; Gilholme-Herbst & Humphrey, 1980; Helvik et al., 2006; Stephens, 1980; Strawbridge, Wallhagen, Shema, & Kaplan, 2000; Tambs, 2004), and that there are fewer depressive symptoms amongst individuals who are HA wearers (Cacciatore et al., 1999; Mulrow, Tuley, & Aguilar, 1992). However, some of

the methodology of these studies has been drawn into question, for example, how individuals were defined as having a HL. Other emotions that have also been commonly reported, albeit anecdotally rather than empirically, amongst individuals with a HL include anxiety, guilt and feelings of isolation (Crowe, 1997b). There is however the possibility that an individual may have a positive reaction to the diagnosis. The majority of the individuals who attend the audiological assessment will do so because they suspect they have a HL and confirmation of this may actually be a comfort for some, providing a sense of relief. Therefore as a result of each individual's different social and lifestyle milieu, as well as their personality, it would be expected that a range of emotional reactions of differing intensities would be observed in a group of individuals who have just been diagnosed with a HL.

1.2.1 Reactions to the diagnosis of another chronic health condition

Due to a lack of research which has specifically investigated individuals' reactions at the time they were diagnosed with a HL, research from another health condition is reviewed here. There are relatively few studies which have been conducted regarding initial reactions to the diagnosis of a disability, and a number of the studies are in the area of dementia. Dementia has some similarities with HL with respect to its effect on the individual's physical health, its long term nature, lack of cure, and that the affected individual has some indication that they may have the condition prior to being diagnosed; however, there are also many differences between dementia and HL, such as the efficacy of the treatments. Studies of patients' reactions to the diagnosis of dementia have found some common responses to be shock, distress, anger, anxiety, fear, a sense of loss, an increased feeling of vulnerability, and reduced self-esteem (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Bamford et al., 2004; Husband, 1999; Wilkinson & Milne, 2003). Positive responses also occur, including relief, less uncertainty and a better understanding of the problems (Aminzadeh et al., 2007; Bamford et al., 2004). One individual, after being diagnosed with mild dementia, reported feeling less anxious – "At least I know what it is, I'm not imagining it" ((Husband, 1999), p.181). It is possible that some patients with a HL will have similar reactions to the diagnosis of their HL; although the multitude of losses associated with dementia and the lack of effective treatment may mean that a diagnosis of dementia produces stronger emotional reactions than a diagnosis of HL.

1.2.2 Measures for assessing emotional reaction to a diagnosis

Typically the measures that have been used to assess reaction to a diagnosis do so from a pathological perspective, suggesting that the individual is emotionally disturbed rather than just emotionally upset. For example, MacLeod and Hagan (1992) developed the Postdiagnostic Mood Assessment Questionnaire to assess how a diagnosis of cervical pathology affected patients emotionally in the week immediately following the diagnosis. The items in the questionnaire fell into two main categories – anxiety response items and depression response items – and assessed patients’ responses in relation to pathological symptomology. Similarly, to assess individual’s psychological reactions to receiving the diagnosis of dementia, Carpenter et al. (2008) used an anxiety measure and a depression scale. Bowman (2001) argued against this tendency to interpret an individual’s response from a psychopathological perspective and purported that emotional reactions to health-related conditions, such as coronary heart disease, are generally normal and the emotions an individual expresses may give some indication as to that person’s process of adaptation. Avoidance of the terms ‘anxiety’ and ‘depression’ and instead use of terms which more accurately define the emotions expressed by the patients (e.g. sadness, fear, hopelessness) may better guide the treatment (Bowman, 2001).

With respect to audiology, Vargo and McFarlane (1994) reported that the majority of audiology patients experience a relatively normal reaction to their HL; the emotions are not severe enough in magnitude and duration to meet psychiatric criteria and as such are subclinical. Therefore, the patient’s need for counselling to facilitate his/her recovery can usually be met by the audiologist (Vargo & McFarlane, 1994). This conclusion is supported by findings from a study of parents of a child with a hearing impairment. While it is not a direct comparison, because it is the parent rather than the individual themselves, this study found that the common initial reactions to the diagnosis are sorrow (encompassing sadness, grief and hurt), shock, disbelief and acceptance, none of which are extreme enough to be pathological (Martin, George, O’Neal, & Daly, 1987). Therefore, a measure which is used to assess an individual’s reaction to the diagnosis of HL should address normal emotions and avoid non-pathological terms.

1.3 Counselling

The practice guidelines of the largest governing body for audiologists, the American Speech-Language-Hearing Association (ASHA), specify that counselling is an integral component of audiological care (American Speech-Language-Hearing Association, 2006). The ASHA standards (2006) define counselling as “interactive and facilitative, wherein the communicative, psychosocial, and behavioral adjustment problems associated with auditory, vestibular, or other related disorders can be ameliorated” (p. 62). As defined by ASHA, the goals of counselling are to “enhance the patients’ and families’ understanding of, acceptance of and adjustment to auditory, vestibular, or related disorders, [as well as] HAs and hearing assistive technology” (p. 62). Furthermore, the counselling should engage the patient in the management of their communication problems and increase their awareness of the need for prevention to avoid further damage (American Speech-Language-Hearing Association, 2006). The specific goals and counselling approach are established based on the individual and their needs, motivation and willingness to be involved.

The ASHA standards for counselling emphasise the importance of engaging the patient in the management of their HL. This is reflective of the rehabilitation model of care, whereby the clinician aims to involve the patient in their care, as opposed to the medical model which typically involves the clinician dictating the course of treatment (Taylor, 1993). To engage the patient, a rapport needs to be established. A review of factors that are important to establishing a rapport identified the following: Empathy, genuineness and unconditional positive regard (Roberts & Bouchard, 1989). That is, an audiologist needs to accept a client regardless of their behaviour, demonstrate warmth, sincerity and an openness to share their experiences, and attempt to see the world through the eyes of the patient (Roberts & Bouchard, 1989). Roberts and Bouchard (1989) emphasised that the audiologist needs to listen attentively to the patient, evident by both their non-verbal (e.g. body posture) and verbal expressions (e.g. not interrupting the patient). When parents of a child with a HL were asked about what they appreciated in the audiologist’s approach, they mentioned the honest, direct and empathetic manner of the audiologist, as well as the willingness to help and spend time with them (Martin et al., 1987). More recently, English (2008) wrote a review on issues in audiological rehabilitation and presented evidence in support of a caring, trusting and supportive patient-clinician relationship. Such a relationship lends itself to effective counselling.

Counselling occurs with the diagnosis of the HL and throughout the process of the HA fitting. At the time of diagnosis, the counselling acknowledges the individual's initial reaction as well ascertains from the patient the degree to which they feel affected by the HL. Counselling during the process of HA fitting aims to address any impediments the patient is having in using their HAs and therefore hopefully improve compliance. Brooks (1979) investigated hours of use amongst 56 body-worn HA wearers to ascertain if counselling pre- and post-fitting of the HAs significantly affected the use of the HAs. The counselling given prior to the fitting of the HAs involved identifying difficulties the individual may have, while the post-fitting counselling involved giving advice and encouragement. It was found that individuals who received the counselling used their aids for a significantly greater number of hours and felt less handicapped by their HL than the non-counselled group (Brooks, 1979).

The counselling provided by audiologists has two main components: Informational counselling and affective (or personal-adjustment) counselling. Informational counselling relates to providing information regarding the HL, its consequences and alternative rehabilitative options (Laplante-Levesque, Pichora-Fuller, & Gagne, 2006; Taylor, 1993). Affective counselling relates to assisting the patient to accept their HL and cope with the difficulties (Taylor, 1993), or alternatively said, it is "the provision of support to facilitate adjustment to a potentially stressful situation" ((Laplante-Levesque et al., 2006), p. 698). Affective counselling may also entail altering the patient's perception so that they no longer view their HL as a 'hopeless handicap', but rather as a manageable condition (Crowe, 1997a).

A number of books have been written regarding audiological counselling (Crowe, 1997; Holland, 2007; Shames, 2006). Within this literature, several core skills and features have been emphasised as important for effective counselling. Webster (1966) stated that five prerequisites of an audiologist being a good counsellor were: Positive regard, respect for the patient, genuine listening skills, a wide knowledge of the field, and an ability to answer questions completely and accurately. More recently, with respect to informational counselling, English (2008) emphasised the need for the audiologist to regularly check that the patient has understood what has been said. This is important given that an individual's emotional response to the situation can affect the degree of information he/she retains (Martin et al., 1987). When parents of children with a HL were asked about the day that their child was diagnosed, they tended to recall trivial details (e.g. the weather, what the child was wearing), rather than factual

information that the audiologist gave them about the diagnosis (Martin et al., 1987). With respect to affective counselling, English et al. (1999) and Holland (2007) emphasised the importance of the audiologist talking less, listening more and listening actively, without the bias of their own subjective views. It was further said that audiologists need to demonstrate perceptiveness, respect and sensitivity (Holland, 2007), while they listen, empathise and provide emotional support (Vargo & McFarlane, 1994). These components of counselling represent person-centered therapy, which is not based on any particular technique but rather certain attitudes and beliefs of the clinician (Crowe, 1997). The therapy is based on the principle that by being genuine, caring and empathetic, the clinician can share the patient's internal framework of reference and, with the patient, gain insight into the barriers associated with their HL and audiological rehabilitation (Crowe, 1997). With person-centred therapy, the patient reaches his/her solutions with the non-directive assistance of the audiologist (Alpiner, 1997). There are other types of therapy but these are not discussed here because the current study does not evaluate the counselling model used.

1.3.1 Measures that are available for evaluating the audiologist's counselling

While a number of books have been written about audiological counselling, there appears to be only one study which has used an assessment tool to evaluate the efficacy of audiological counselling in a patient sample. The study used a measure called the Audiologist Counseling Effectiveness Scale (ACES) (Taylor, 1993), which requires the patient to evaluate and score their audiologist's counselling skills. This assessment tool is described in more detail below. Another measure has also been developed which assesses the competency of the audiologist with respect to counselling, but this tool is completed by a teacher or instructor of an audiological counselling course. This measure is called the Audiologic Counseling Evaluation (ACE) (English, Naeve-Velguth, Rall, Uyehara-Isono, & Pittman, 2007). The questions in these two assessment tools form the basis of the questionnaires used in this study, and are therefore discussed in more detail below.

Audiologist Counseling Effectiveness Scale (ACES)

Taylor (1993) developed an instrument – the Audiologist Counseling Effectiveness Scale – which can be administered to patients to ascertain the extent to which audiologists implement both emotional and informational counselling. This

instrument aims to elucidate whether the patient is satisfied with their care and if the audiologist is providing the appropriate support. The instrument was developed based on the rehabilitation model, which encourages patients to be actively involved in identifying and managing their condition (Taylor, 1993). It was also based on the author's experience of working with elderly patients. The ACES was psychometrically validated on a sample of patients with presbycusis who were being treated by an audiologist who knew the content of the instrument (Taylor, 1993). No other published study has used this measure.

Audiologic Counseling Evaluation (ACE)

The ACE was originally developed for training new audiologists at informing parents about their baby or child's HL (English, 2008). The parents are typically role-played by actors. The ACE is intended to guide a new audiologist through the steps required in an appointment, such as getting started, breaking the news, and assessing parents' understanding and reaction to the situation (English, 2008). The audiologist is rated by a supervisor, instructor or peer on 21 behaviours, using a 5-point scale. One example of an item in the ACE is 'Did the audiologist wait for the parents' response after giving the news?'.

Many of the questions in the ACES and ACE address skills that have been identified by studies investigating important aspects of a clinician's approach to delivering bad news (Baile et al., 1999; Girgis & Sanson-Fisher, 1998; Kumasaka & Dungan, 1993; Vaidya, Greenberg, Patel, Strauss, & Pollack, 1999; Wilkinson & Milne, 2003; Wolf, Woolliscroft, Calhoun, & Boxer, 1987). For example, Vaidya et al. (1999) and Baile et al. (1999) reported on workshops for medical students and professionals on communicating bad news to patients. The authors identified the important aspects of the clinician's approach as being: Establishing rapport, eliciting the patient's perception of the condition, providing understandable information to the patient, empathising with the patient, and giving a summary of the discussion and where to now. Girgis and Sanson-Fisher (1998) in their article advising clinicians how to break bad news to patients, emphasised the importance of simple language and allowing the patient to express their feelings. A review of studies which explored the patient's perspective of being diagnosed with dementia emphasised the importance of a person-centred approach in which time was available for the patient to discuss the diagnosis (Wilkinson & Milne,

2003). Furthermore, a study of nursing strategies to deal with patients' initial reactions to the diagnosis of cancer, found that it is important that the clinician ensures that the patient feels that they can ask questions and seek information (Kumasaka & Dungan, 1993). These behaviours are also expected amongst audiologists and are addressed by the ACES and ACE.

To conclude, there are two main components to audiological services – diagnosis and treatment. Counselling patients through both of these steps is critical to optimising the outcome for the patient. However, counselling tuition is not currently provided for audiology students at New Zealand universities or as a continuing education course for practicing audiologists. Prior to establishing a training workshop in counselling, it would be useful to ascertain what patients appreciate in the care they currently receive from experienced audiologists, what they would like to see improved, and how the counselling may affect an individual's choice to get HAs and their satisfaction with the aids.

1.4 Rationale for the Current Study

There is a lack of published studies which report on the emotional effect of being diagnosed with a HL and also the role that audiological counselling plays in an individual's response. This study aimed to go some way to filling this gap in the audiology literature. Experienced audiologists will most likely have an appreciation for the common responses that a patient has following a diagnosis of HL, however, some responses may be less overt. This study hopes to assist in increasing audiologists' awareness of such emotional reactions which they can then acknowledge in their counselling where necessary. Better counselling should result in better intervention outcomes, which will benefit both the patient and their significant others.

The first aim of this study was to identify some of the common emotional reactions that occur following a first-time diagnosis of HL in adults. As discussed above, many individuals' emotional reactions to a HL are subclinical. In other words, they are not severe enough to meet clinical criteria for a diagnosis of depression or an anxiety disorder. Measures are not available to assess these subclinical emotive reactions to the diagnosis of HL, and therefore one was developed for this study based on the emotions that have been associated with HL (Barlow et al., 2007; Luterman, 2006; Martin et al., 1989). The measure enquired regarding a range of emotions, given

that some individuals may be relieved to have their suspicions confirmed regarding a HL, while others may be saddened by the thought that they have permanently lost their hearing and see it as a sign of aging. Others may feel frustration and anger in response to the diagnosis because they despise the idea of wearing HAs which they see as an obvious indicator of a disability. Some of these emotional reactions may not be evident to the audiologist and/or may occur after the patient has left the audiologist's office. Identifying the common emotional reactions will better equip audiologists in supporting their patients when they give the diagnosis. This in turn may mean that the patient may better respect the advice given by the audiologist, which would lend itself to improved outcomes from aural rehabilitation.

The second aim of this study was to investigate current audiological counselling services and examine the impact on patients' decisions to get HAs. The skills and features which have been depicted to be important in effective counselling were discussed above. Many of these skills and features are addressed by the questions encompassed in the ACE and ACES. The current thesis will assess audiological counselling via two questionnaires and an interview which incorporate many of the questions from the ACE and ACES. A number of the questions in these measures corroborate what has been reported in the medical literature to be important when delivering a diagnosis. Audiological counselling has not previously been evaluated in New Zealand and no formal training has been, or is currently provided to audiology students/graduates. Findings from this study will be useful in representing the current standard of audiological counselling and how this may be improved (if applicable). The study was not intended to determine if the audiologists effectively sold the idea of HAs, but participants were asked if there was anything that the audiologist said that influenced their decision to have or not have HA(s). The participants who chose not to have HA(s) fitted were asked as to their reasons and what would need to change in order for them to re-consider.

The participants in this study were adults who had been diagnosed for the first time with a HL. Therefore, this study focused on postlingually-acquired HL, specifically amongst adults. There are children who suffer from postlingual HL, however it is expected that the psychological effects of HL amongst adults is likely to be different than for children, given differing vocational, social and family demands. These demands and expectations will not only affect one's reaction to the diagnosis, but also what is required in counselling by the audiologist. Furthermore, the current study

focused specifically on the responses of individuals who were diagnosed by an audiologist, as opposed to a medical practitioner, so that the role of counselling by an audiologist could be evaluated.

The specific aims of the study were:

1. To identify some of the common emotional reactions that occur following a first-time diagnosis of HL in adults; and

2. To investigate current audiological counselling services and examine the impact on patients' decisions to get HAs.

To accomplish these research aims, adults who had been newly-diagnosed with a HL completed an initial reaction questionnaire, partook in an interview which followed up on the questionnaire, and subsequently completed a second questionnaire at least three weeks later. There were two versions of the second questionnaire, depending on whether they had chosen to have HA(s) fitted. Questionnaires were implemented based on the finding that patients tend to answer more openly when using an anonymous questionnaire, which they can complete unhurried in the comfort of their own home (Stephens, 1980). The interview was done to provide a more complete picture (Stephens, 1980) and to develop a rapport with the participant which may lend itself to better response rates when asking them to complete a second questionnaire. Specific details regarding how these participants were recruited and the measures that were used to survey them are provided in the following chapter.

2. METHOD

This study received ethical approval from the University of Canterbury Ethics Committee and from the Health and Disability Upper South B Ethics Committee, and all procedures were in accordance with these approvals. All participants signed informed consent forms.

2.1 Recruitment Sites

Audiology companies with multiple clinics in Christchurch were approached and asked if they would consider being involved in the study. The manager at each clinic was emailed and sent a letter detailing the study. One clinic did not respond to any contact and was therefore assumed not to be interested in being involved. Two companies agreed to be involved, which included five clinics in Christchurch. Further to this, one independent clinic volunteered to be involved; this resulted in a total of six clinics from which participants were recruited. Based on discussion with the managers of these clinics regarding patient numbers, and taking into consideration that some eligible patients may decline to participate, the initial aim was to recruit 50 participants over three months.

Prior to commencing recruitment, a presentation was made at the monthly meetings of each of the clinics, where the study was explained and the questionnaires and interview schedule shown to all the audiologists and receptionists involved. Despite this, recruitment was considerably slower than anticipated. Within the first two months just five participants had been recruited, despite reminder notices being put up in each of the testing rooms at the clinics and weekly phone calls to the clinics. The researcher also emailed each of the clinicians weekly to ask if they were having any problems, if there was anything that she could do to make recruitment easier, and also as a friendly reminder of the ongoing study. It is unknown whether the slow recruitment was due to the clinicians forgetting or choosing not to mention the study to patients, clinicians having insufficient time to discuss the study, patients not being interested in being involved and/or patients not being eligible. The clinic managers were emailed weekly to ascertain if there were any particular reasons for the slow recruitment.

After three months of recruiting, just eight participants had been recruited. Initially the clinics involved were Christchurch-based so that the interviews could be

conducted face-to-face, but due to slow recruitment, other clinics nationwide were approached and asked to be involved in the study, with the plan of doing phone interviews. This brought the total number of clinics for the study to 16. Despite the additional clinics being involved, the rate of recruitment was still relatively slow and so it was decided that 30, rather than the original 50, participants would be recruited. These participants were recruited over a six month period.

2.2 Participants

Individuals were eligible to be involved in the study if they met all of the following criteria:

1. Aged 18 years or older;
2. Not had their hearing thresholds tested previously and subsequently diagnosed with a hearing loss (HL);
3. Has a progressive or gradual HL which has NOT arisen from one single incident in the last month (e.g. head trauma);
4. Has a four-frequency (0.5, 1, 2 and 4kHz) pure tone average (PTA) \geq 30 dB HL in either or both ears;
5. Uses spoken English as their main form of communication;
6. Has no other major impairment that may prevent them from completing a questionnaire (e.g. blindness or significant cognitive impairment).

The second criterion excluded individuals from the study who had been told of their HL by their General Practitioner (GP) as GPs typically do not elucidate the degree of the HL. GPs often test an individual's hearing using a tuning fork test, which can differentiate between a sensorineural or conductive HL greater than a mild level. However, GPs do not ascertain the individual's exact hearing thresholds. Therefore, when a patient is tested by an audiologist for the first time, it is typically the first time that they are informed as to the severity and nature of their HL.

The third criterion was included to minimise the degree of variability in the study sample. Individuals who experience a sudden drop in hearing may have a different emotional reaction to those whose HL has developed gradually. A sudden

sensorineural HL may be idiopathic and may recover spontaneously. Given the differences in aetiology and prognosis between sudden and progressive HL it was necessary to focus the study sample to just one of these categories of HL.

With respect to the fourth criterion, a four-frequency PTA was used based on the frequencies most important for speech perception (Agrawal et al., 2008). Specifically a PTA of greater than 30 dB HL was regarded as a HL in this study since audiologists usually begin to consider a hearing aid (HA) when an individual's hearing levels are above 30 dB HL (Karlsson Espmark & Scherman, 2003). Individuals with a unilateral HL were included in this study because some of these individuals choose to have a HA, for reasons such as 'balancing' their hearing.

The last two criteria ensured that the individual was capable of understanding and completing the two questionnaires and interview. Details regarding the participants which were recruited are presented later in the Results chapter.

2.3 Procedure

The protocol used in this study is described below. The protocol was discussed and agreed with the audiologists at the clinics involved. Further information regarding the development and content of the questionnaires and interview schedule is provided in Section 2.4.

2.3.1 Overall procedure

The same overall procedure was used for all 16 clinics. Potential participants made an appointment to see an audiologist and have their hearing tested. The hearing test could either be a screening test or a full diagnostic audiological assessment. A screening test is usually allocated a 20 – 30 minute appointment and involves fewer tests, and as such the audiologist can provide less information regarding the nature of the HL. A full diagnostic audiological assessment is typically allocated an hour appointment at a private audiology clinic, and during this time a number of tests are undertaken and the audiologist feeds back the results to the patient, as well as discusses HAs and the range of types thereof.

With respect to this study, if the hearing test found that the individual had a HL, the audiologist filled in an Eligibility Form (Appendix A) which checked that the

participant met all the criteria for the study, as listed above. If the individual was eligible for the study, the following protocol was undertaken:

1. The audiologist explained to the patient that there was a study which the clinic was currently involved in, and then gave the patient the Invitation Letter with the Information Sheet attached (Appendix B) which explained the study further.
2. Patients that agreed to participate then completed a consent form (Appendix C). There was the option for patients to take the Information Sheet home to read in their own time, but they were asked to complete the Contact Details Form (Appendix D) at the clinic so that the researcher could contact them.
3. All patients who were considering being involved or had consented to be involved were given the Initial Questionnaire (Appendix E) and asked to complete it as soon as possible, and within 24 hours of the appointment. The contact details of the researcher were included at the end of the questionnaire in case the patient had any questions whilst completing the questionnaire. The patient was told that the researcher would contact them within the next two days to organise a time to interview them within the week.
4. The audiologist stapled the Eligibility form to the Consent Form or Contact Details Form and then gave it to the receptionist to fax to the researcher, before filing it in a folder at the clinic. At the end of each week the researcher rung the clinics and double-checked the number of Consent Forms and Contact Details Forms received. At the end of the study, the originals of these forms were collected from the clinics.
5. The researcher contacted the patient within 48 hours of their appointment with regard to their participation and/or to organise an interview time. This interview could have been done at the patient's home, the university clinic or if the other options were not possible then via phone. If the interview was done face-to-face, the completed Initial Questionnaire was collected from the participant at the interview. If the interview was done via phone, the participant was provided with a stamped addressed envelope in which to return the completed Initial Questionnaire.
6. The interview (a copy of the interview schedule is provided in Appendix F) included a question about the patient's intentions to get HA(s) and if so, if they

had an appointment to have the HA(s) fitted. This date was recorded by the researcher so that the Hearing Aid Fitted Questionnaire (Appendix G) could be sent in the week that the patient was fitted with the aid(s). If the patient had decided not to have HA(s), this was also recorded so that the researcher could send the Non-Hearing Aid Fitted Questionnaire (Appendix H) three weeks after their initial hearing test. Alternatively, the researcher recorded that funding from ACC¹ or Enable¹ had been applied for and the patient was asked to contact the researcher when they were notified regarding the funding.

7. Individuals who decided to have a HA fitted were sent the Hearing Aid Fitted Questionnaire in the week following their HA fitting. They were asked to complete this within 24 hours to minimise any bias of HA efficacy on the individual's responses. The participants were provided with a stamped addressed envelope to return the questionnaire.
8. If at the time of the interview the patient had not yet made an appointment to have the HA(s) fitted, the researcher rung the participant approximately every two weeks to check about an appointment time.
9. Individuals who chose not to have a HA fitted were asked to fill in the Non-Hearing Aid Fitted Questionnaire with a time delay after the first questionnaire which was similar to that of the participants that were fitted with a HA - approximately three weeks. If the individual was denied ACC or Enable funding and chose not to get a HA, then they were also asked to complete the Non-Hearing Aid Fitted Questionnaire.

The consent form was the only form that contained the participant's name; all other documents were labelled with an identification number to ensure anonymity. Furthermore, the clinic that the participant attended and the name of the audiologist that they saw was not recorded on the forms, for confidentiality.

2.4 Materials

Three questionnaires were developed for this study. Two of these three questionnaires, along with an interview, were completed by each participant.

¹ ACC (Accident Compensation Corporation) provides funding towards HAs for individuals whose hearing loss is due to noise exposure. Enable provides funding from the Ministry of Health for adults working more than 30 hours a week, individuals aged 65 years or older, and children (< 21 years).

2.4.1 Initial questionnaire

There were two main parts to this questionnaire (a copy of the questionnaire is provided in Appendix E). The first section asked about the emotions the individual experienced when he/she was told they had a HL. The responses were in the form of a Likert-rating scale, and the list of emotions was based on research and commentary articles pertaining to the emotional impact of HL (Barlow et al., 2007; Luterman, 2006; Martin et al., 1989), as well as the clinical experience of this study's researchers.

The second section of the questionnaire asked about the audiologist's approach. The questions were largely derived from two previously published instruments - the ACES (Taylor, 1993) and the ACE (English et al., 2007). As described in the Introduction (Section 1.3.1), many of the questions in the ACES and ACE address attributes that have also been identified by studies investigating important aspects of a clinician's approach to delivering bad news (Baile et al., 1999; Girgis & Sanson-Fisher, 1998; Kumasaka & Dungan, 1993; Vaidya et al., 1999; Wilkinson & Milne, 2003; Wolf et al., 1987).

The majority of questions in this questionnaire required the participant to respond using a 5-point Likert-rating scale. For data entry and statistical analyses, the response categories were numerically coded, i.e. 0 = no change, +1 = increased slightly, +2 = increased greatly, -1 = reduced slightly, -2 = reduced greatly. Six of the questions within the section of the questionnaire which related to the audiologist's approach were negatively-phrased (e.g. "The audiologist seemed condescending") and were reversed scored for analysis, i.e. 0 = do not agree, -1 = slightly agree, -2 = moderately agree, -3 = considerably agree, -4 = extremely agree (Questions 23, 29, 32, 40 – 42 in Appendix E).

This initial questionnaire was kept relatively brief in order to maximise participation, with space provided for additional comments at the end of the questionnaire.

2.4.2 Interview

The aim of the interview was to corroborate the responses on the first questionnaire and to obtain more detailed information. The interview schedule (Appendix F) was divided into five sections incorporating a combination of response modes including closed-set answers, open-set comments and Likert-rating scales. The first section asked about the participant's perception of their hearing abilities prior to the

hearing test. The second section asked about the hearing test, including the emotions they felt immediately after they had been told their hearing test results; how/if their emotions had changed since then; what could have been improved in the appointment; if the patient became distressed, what was the audiologist's reaction and/or if it could have been improved; the patient's perception of the accuracy of the results; whether they had told others about their HL and if so, their reaction. The third section asked about their initial reasons for having a hearing test and choosing this clinic, and what would have encouraged them to have had their hearing tested earlier. The fourth section related to their future plans with respect to whether they would get a HA and if the audiologist or others had said anything to influence their decision. The final section covered demographic details, such as age, ethnicity, marital status, employment status, general health and approximate annual income. The last question was intended to give some indication as to the affordability of the aids for the individual. The interview was done within 5 – 7 days of the appointment and took approximately 30 minutes.

2.4.3 Hearing aid fitted questionnaire

The first part of this questionnaire (Appendix G) contained questions that were similar to those in the Initial Questionnaire regarding the audiologist's approach. There were a few questions that were added which were relevant to the HA fitting process (Questions 2, 6, 10, 13 - 16, 19 - 21), e.g. "The audiologist clearly described the process of follow-up appointments". As for the Initial Questionnaire, the responses which were based on a Likert-rating scale were numerically coded, and the questions which were negatively-phrased were reverse scored.

The remainder of the questionnaire asked about what they appreciated and what they thought could have been improved in the service they received, and whether they felt that they had enough knowledge about their HL and HA(s). This questionnaire took 15 – 30 minutes to complete.

2.4.4 Non-hearing aid fitted questionnaire

For those who decided not to obtain HA(s), this questionnaire (Appendix H) was completed instead of the one described in Section 2.4.3. It asked if their response to the diagnosis and proposition of HA(s) had changed and what would need to occur, or what had occurred, for them to re-consider. If the person still did not have a HA, they were asked about the use of other means of aural rehabilitation, who they had told about

their HL and these other peoples' responses, what their own expectations were for their hearing in the future, and what their intentions were with regards to monitoring it. If the person had reconsidered their decision to have a HA, they were asked the same questions as in the latter part of the Hearing Aid Fitted Questionnaire (described above in Section 2.4.3). The questionnaire took approximately 30 minutes.

2.5 Statistical Methods

All data were entered and analysed using The Statistical Package for the Social Sciences (SPSS). The responses for open-ended questions were coded with respect to their theme.

The primary method of analysis was calculation of frequencies of responses to the questions. T-test and chi-square tests of significance were undertaken to ascertain if there were differences between the 'Hearing Aid' and 'Non-Hearing Aid' group, as well as between those individuals who did not experience the emotion and those who experienced some degree of the emotion. This latter comparison was undertaken with respect to gender, age group and level of HL. Age was grouped as ≤ 65 years, 66 – 80 years and > 80 years based on publications which report percentage of individuals with a HL at 65 years and 80 years old (Greville, 2005). Level of HL was calculated as the average PTA of the individual's two ears (i.e. the PTA of the left ear was added to the PTA of the right ear and the total was divided by two). Level of HL was coded as 0 – 20 dB HL = normal, 21 – 40 dB HL = mild, 41 – 55 dB HL = moderate, 56 – 70 = moderately-severe, 71 – 90 = severe, > 90 = profound. Correlations were calculated between the level of emotion reported on the Initial Questionnaire and presence/absence of the emotion reported at the interview. Given the variables are ordinal, rather than interval measures, Spearman's rho was calculated. Two-tailed statistical tests with a significance value of $p \leq .05$ were used.

Chi-squared, or Fisher's exact tests where appropriate, were undertaken to compare the number of individuals who did not agree with the statement regarding the audiologist's counselling and the number who did agree to some extent. The Fisher's exact test was used when some cells in the crosstabs table had an expected count less than five. Given the differences between a screening hearing test and a full diagnostic assessment (described in Section 2.3.1), these analyses were repeated with individuals who had a screening test excluded.

To examine the impact of the audiologist's counselling on the patient's decision to get HAs, a logistic regression analysis was undertaken with total score for audiological counselling as a potential predictor, and the decision to get or not get HAs as the dependent variable. Each participant's total score for audiological counselling was computed by summing their responses to Questions 21 – 44 on the Initial Questionnaire (Appendix E), including the negatively-phrased questions which were reverse coded.

3. RESULTS

Sixteen audiology clinics from around New Zealand agreed to recruit participants for this study from April 1st to October 3rd 2009. In the end, 29 patients were recruited from 8 clinics, all in the South Island. The audiologists recruited these individuals on the basis that they met the eligibility criteria for the study, as detailed in the previous chapter (Section 2.2). After recruitment had ceased, the audiograms for the participants were obtained from each clinic to calculate the individual's pure tone average (PTA) and compare their audiogram with the degree of HL they recalled the audiologist saying they had. When the PTA was calculated for each individual, it was found that two individuals had PTAs that did not exceed 30 dB HL in either ear and thus these two participants were excluded from the data analyses. The following results are for the remaining 27 participants. It was possible that individuals who had a HL in just one ear (otherwise known as a unilateral loss) may have a different reaction to those with a bilateral loss. However there was only one individual within this sample who had a unilateral loss and so it was deemed unlikely that different results would be found if this individual was excluded from the analyses.

The data is presented in the order it was given to the participant in the Initial Questionnaire, Interview and Follow-up Questionnaires. Some questions were not answered by all individuals, and for these questions the percentage of responses is based on the number of respondents for that question rather than the total sample. Copies of the questionnaires and interview schedule are provided in Appendices E – H. The qualitative comments which the participants provided in the questionnaires and interview are presented in Appendix I.

3.1 Sample Characteristics

Table 3.1 presents a summary of the demographic information for the total sample ($n = 27$), as well as separately for those that requested hearing aids (HA group) and those that did not (NHA group).

Table 3.1 Demographic information for the whole sample, as well as for the HA and NHA groups separately

	% of Total sample (N = 27)	% of HA group (N = 17)*	% of NHA group (N = 10)
<i>Gender</i>			
Male	40.7	41.2	40
Female	59.3	58.8	60
<i>Ethnicity</i>			
NZ European	88.9	88.2	90
Maori	3.7	5.9	-
Asian	3.7	-	10
Other	3.7	5.9	-
<i>Marital status</i>			
Married/co-habiting	59.3	47.1	80
Divorced	14.8	11.8	20
Widow/widower	25.9	41.2	-
<i>Employment</i>			
Fulltime	14.8	11.8	20
Part-time	22.2	17.6	30
Retired	59.3	70.6	40
Student	3.7	-	10
<i>Health</i>			
Poor	11.1	17.6	-
Satisfactory	18.5	29.4	-
Good	25.9	29.4	20
Very good	44.4	23.5	80
<i>Approximate annual income</i>			
<\$40,000	63	70.6	50
\$40,000-60,000	22.2	23.5	20
\$60,000-80,000	3.7	5.9	-
\$80,000-100,000	7.4	-	20
\$100,000+	3.7	-	10

* At the time of data analyses, there were still 10 individuals who had requested HAs but had not yet received them because they were applying for third party funding to subsidise the cost of the aids. These individuals are included in the HA group because while they have not yet received the aids, they are in the process of getting them.

The mean age of the total sample was 71.0 years (SD 9.6). A t-test showed that the NHA group was significantly younger ($65.7 \text{ years} \pm 9.6$) than the HA group ($74.2 \text{ years} \pm 8.4$) ($t(25) = 2.4, p = .024$). A chi-squared test also showed that the NHA group had significantly fewer individuals than the HA group who rated their general health as poor or satisfactory ($\chi^2(3) = 9.44, p = .024$). There was no significant difference between the HA group and the NHA group with respect to gender ($\chi^2(1) = 0.004, p = .952$), ethnicity ($\chi^2(3) = 2.88, p = .411$), marital status ($\chi^2(2) = 5.56, p = .062$), employment ($\chi^2(3) = 3.42, p = .332$) or annual income ($\chi^2(4) = 6.15, p = .188$).

The average PTA for both ears was calculated for each individual. The mean PTA of the total sample was 39.6 dB HL (SD 10.8). A t-test showed that the NHA group had significantly lower PTAs ($32.8 \text{ dB HL} \pm 6.6$) (i.e. better hearing) than the HA group ($43.6 \text{ dB HL} \pm 10.9$) ($t(25) = 2.8, p = .009$). Table 3.2 provides details on each participant.

Table 3.2 Demographic information for each of the 27 participants

Participant	Age (years)	Gender	Ethnicity	Puretone average (dB HL)*		Marital status	Employment	Health	Income	Interview **	HA / NHA
				Left ear	Right ear						
101	70	Female	NZ European	47.5	45.5	Married	Part-time	Very good	\$80-100,000	F	NHA
102	82	Male	NZ European	55	52.5	Married	Retired	Good	<\$40,000	F	HA
103	56	Female	NZ European	35	30	Divorced	Retired	Very good	\$80-100,000	F	NHA
105	76	Male	NZ European	41.25	51.25	Married	Retired	Good	<\$40,000	F	HA
106	72	Male	NZ European	31.25	32.5	Married	Part-time	Very good	<\$40,000	F	NHA
108	64	Male	NZ European	37.5	38.75	Married	Part-time	Poor	\$60-80,000	F	HA
109	74	Male	Maori	66.25	78.75	Widow(er)	Retired	Poor	<\$40,000	F	HA
110	47	Male	Asian	33.75	11.25	Married	Student	Good	<\$40,000	F	NHA
203	79	Female	NZ European	36.25	35	Widow(er)	Part-time	Poor	\$40-60,000	F	HA
301	70	Female	NZ European	46.25	25	Married	Part-time	Very good	\$40-60,000	F	NHA
302	72	Male	NZ European	31.25	20	Divorced	Fulltime	Very good	<\$40,000	F	NHA
317	77	Female	NZ European	46.25	48.75	Widow(er)	Retired	Good	<\$40,000	P	HA
318	81	Female	NZ European	46.25	50	Divorced	Retired	Very good	<\$40,000	P	HA
319	75	Female	Other	35	40	Married	Retired	Very good	<\$40,000	P	HA
320	61	Male	NZ European	38.75	38.75	Married	Fulltime	Good	\$40-60,000	P	HA
322	77	Female	NZ European	30	32.5	Married	Retired	Very good	<\$40,000	P	NHA
350	61	Female	NZ European	36.25	43.75	Married	Retired	Satisfactory	\$40-60,000	P	HA
351	76	Female	NZ European	31.25	48.75	Widow(er)	Retired	Very good	<\$40,000	P	HA
352	65	Female	NZ European	42.5	41.25	Married	Part-time	Very good	<\$40,000	P	HA
353	74	Male	NZ European	40	40	Married	Fulltime	Satisfactory	<\$40,000	P	HA
354	68	Male	NZ European	42.5	50	Divorced	Retired	Satisfactory	<\$40,000	P	HA
382	76	Female	NZ European	33.75	27.5	Widow(er)	Retired	Good	\$40-60,000	P	HA
383	74	Female	NZ European	45	31.25	Married	Retired	Good	<\$40,000	P	NHA
393	78	Female	NZ European	41.25	76.25	Widow(er)	Retired	Satisfactory	<\$40,000	P	HA
617	59	Female	NZ European	30	35	Married	Retired	Very good	\$100,00+	F	NHA
619	60	Male	NZ European	33.75	28.75	Married	Fulltime	Very good	\$40-60,000	F	NHA
719	94	Female	NZ European	31.25	20	Widow(er)	Retired	Satisfactory	<\$40,000	F	HA

* Four-frequency average (500, 1000, 2000 and 4000 Hz)

** F = Face-to-face, either at their home or at the university clinic; P = phone

3.2 Initial Questionnaire

Participants completed the Initial Questionnaire within 24 hours of their hearing test (refer to Appendix E for a copy of the questionnaire). The questionnaire was completed by the individual at home and then returned either by post (if the participant lived outside of Christchurch) or at the interview. As it was therefore not possible to enforce that all questions be answered, the column labelled ‘N’ in Tables 3.3 – 3.5 represents the number of individuals who responded to that question. The first half of the questionnaire enquired about the individual’s reaction to the diagnosis of HL (the results are discussed in Sections 3.2.1 – 3.2.5), and the second half of the questionnaire asked the individual to rate the audiologist’s informational and affective counselling (Section 3.2.6).

3.2.1 “Were the results from the audiologist what you expected?” (Question 1)

Fourteen participants (53.8%) reported that their results were what they expected, with a further 11 individuals reporting that the results were ‘partly’ what they had expected. The comments participants made often referred to the hearing test showing a HL greater than they were expecting (refer to Appendix I for the list of comments). One individual (ID = 351) was not expecting the result she received and another individual (ID = 354) did not respond to this question.

3.2.2 Emotions experienced as a result of being diagnosed with a HL (Questions 2 - 10)

Table 3.3 presents the results to the question “as a result of being told that you had a hearing loss, to what extent did you experience the following emotions?”. Participants were asked to respond on a five-point Likert scale. In the table the emotions are listed in order from most to least frequently reported. The last two columns of Table 3.3 show the number of individuals who experienced some level of the emotion (i.e. their response was something other than ‘not at all’) and the number who did not experience the emotion. A sense of loss, relief and sadness were experienced by $\geq 50\%$ of participants.

Figure 3.1 is a graphical illustration of the percentage of participants who responded ‘not at all’, ‘somewhat’ or ‘very much so’ for each of the emotions. The plot was intended to illustrate the main differences in the responses across the emotions and so

for ease of interpretation the participants who did not give a response which was one of the three categories - not at all, somewhat or very much so - were not included.

Table 3.3 Percentage of individuals who experienced each emotion as a result of being told that they had a HL

Emotion	N	% of participants that experienced this level of the emotion					Number of participants who did and did not experience the emotion	
		Not at all	Somewhat	Very much so	Emotion absent	Emotion present		
Sense of loss	25	28	8	40	8	16	7	18
Relief	24	45.8	16.7	29.2		8.3	11	13
Sadness	26	50	11.5	30.8	3.8	3.8	13	13
Surprise	25	68	12	12	4	4	17	8
Shock	25	72	4	24			18	7
Disbelief	25	80	8	12			20	5
Apathy	23	82.6		8.7		8.7	19	4
Hopelessness	25	88		4		8	22	3
Anger	25	100					25	0

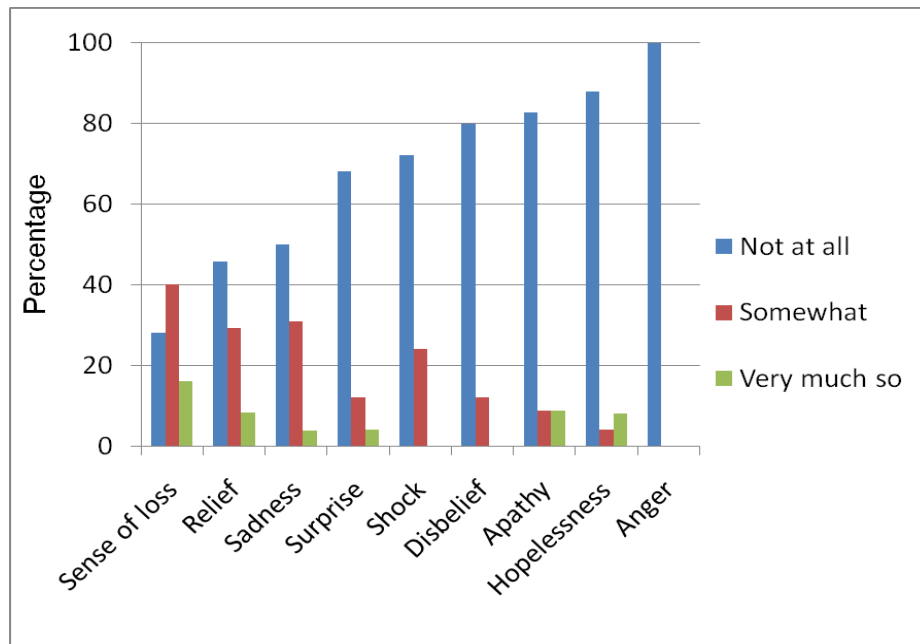


Figure 3.1 Comparison of the level of each emotion experienced after being given the hearing test result

A chi-square test was undertaken for each emotion comparing the number of individuals for whom the emotion was present and those for whom the emotion was absent. There were significantly more individuals who experienced some sense of loss ($n = 18$) than those who did not ($n = 7$) ($\chi^2(1) = 4.8, p = .028$). There were relatively equal proportions of individuals who did and did not experience some degree of sadness or relief. There were significantly more individuals who did not experience the following emotions than those who did: shock ($\chi^2(1) = 4.8, p = .028$); disbelief ($\chi^2(1) = 9.0, p = .003$); apathy ($\chi^2(1) = 9.7, p = .002$); hopelessness ($\chi^2(1) = 14.4, p < .001$).

Chi-square tests found no significant association between gender or age group (≤ 65 years, $66 - 80$ years, > 80 years) and the presence/absence of each of emotion. A significant relationship was found between level of HL and presence/absence of the emotions hopelessness and disbelief ($\chi^2(3) = 16.09, p = .001$ and $\chi^2(3) = 8.76, p = .033$, respectively), whereby the emotions occurred more often in patients with greater levels of HL.

3.2.3 Change in level of emotion as a result of being diagnosed with a HL (Questions 11 – 17)

As participants may have been experiencing a range of emotions prior to the appointment, they were asked “compared to how you felt prior to the audiologist appointment, how did your level of the following emotions change?”. Table 3.4 lists the emotions which were enquired of and how the level of emotion changed. The last two columns of Table 3.4 show the number of individuals who experienced some change in the level of emotion (i.e. their response was something other than ‘no change’) and the number who did not experience a change. The emotions are listed in order from most frequently changed to least often changed. Chi-square tests were undertaken to compare the number of individuals who reported some change in the level of the emotion with the number who did not experience any change. There were significantly more individuals who reported that their level of optimism had changed (either increased or decreased) than those who reported no change ($\chi^2(1) = 6.8, p = .009$). Meanwhile, there were significantly more individuals who reported that their level of embarrassment and guilt were unchanged compared to the number who reported a change in the level of these emotions (embarrassment: $\chi^2(1) = 4.2, p = .041$; guilt: $\chi^2(1) = 8.17, p = .004$).

Table 3.4 Percentage of individuals whose level of emotion changed as a result of being told their hearing test results

Emotion	N	% of participants that experienced this change in the level of their emotion					Number of participants who did and did not experience a change in the level of emotion	
		Reduced greatly	Reduced slightly	No change	Increased slightly	Increased greatly	Change	No change
Optimism	25	8	36	24	20	12	19	6
Anxiety	26	15.4	19.2	46.2	15.4	3.8	14	12
Vulnerability	24	12.5	8.3	45.8	29.2	4.2	13	11
Resignation	23	13	8.7	47.8	26.1	4.3	12	11
Fear	25	24		64	12		9	16
Embarrassment	24	8.3	8.3	70.8	12.5		7	17
Guilt	24	20.8		79.2			5	19

Figure 3.2 illustrates the percentage of participants who experienced some degree of increase in the emotion and the percentage who experienced some degree of reduction. Individuals tended to experience a decrease in their levels of optimism, anxiety and fear, whereas the levels of vulnerability and resignation tended to increase in response to the diagnosis of HL.

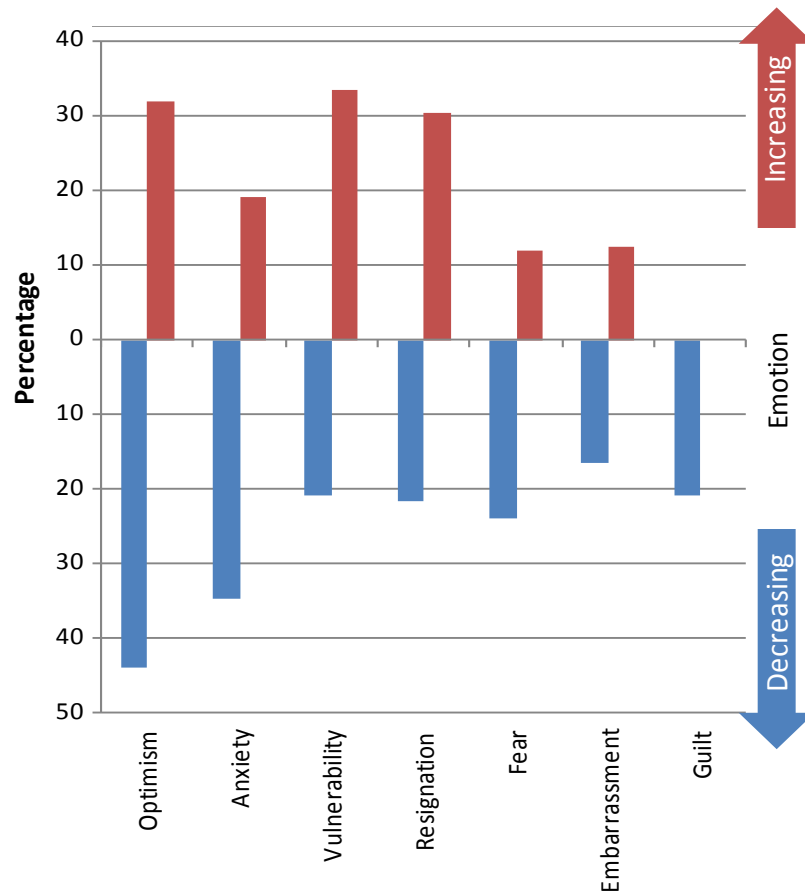


Figure 3.2 Comparison of the percentages of individuals who experienced an increase or decrease in the level of each emotion

3.2.4 “Did you have any other emotions that were not listed above?” (Question 18)

Seven participants responded affirmatively to this question. The other emotions which they reported experiencing were disappointment (n = 3), acceptance (n = 2), panic (n = 1) and worry (n = 1).

3.2.5 Appreciation of an official diagnosis and influence of emotional response on uptake of information (Questions 19 and 20)

When asked if they were glad to have an official diagnosis, 50% (n = 13) reported ‘very much so’ and 50% (n = 13) responded ‘somewhat’. Eighty-one percent of the participants (n = 21) did not feel that their emotional response to the test results hindered their uptake of the information the audiologist told them, whereas four individuals felt they

were somewhat affected and one individual (ID = 617) reported that she was very much affected.

3.2.6 Participants' rating of the audiologist (Questions 21 – 44)

The remaining questions of the Initial Questionnaire asked the participant to rate the audiologist, with respect to their counselling, on a five-point Likert scale. The questions and responses are presented in Table 3.5. Some of the questions have been paraphrased to fit in the table, but a copy of the original question is provided in Appendix E. For ease of interpretation, the questions have been grouped in the table with respect to theme, although they were not presented in this order in the questionnaire. Chi-square tests were conducted to determine if there were any significant differences between the number of individuals who agreed to some extent with the statement and the number that did not agree. Some of the chi-square tests could not be performed because all individuals reported that they agreed with the statement to some degree.

As shown in Table 3.5, the ratings of the audiologists were generally positive. For all positively-phrased questions, with the exception of one question (“the audiologist discussed how my HL would affect my life”), the majority of participants responded in agreement, and the chi-square test between the number of participants who agreed and did not agree was significant. Meanwhile for the negatively-phrased questions (which are indicated with an asterisks in Table 3.5), the majority of individuals typically responded that they did not agree. For one negatively-phrased question – “insufficient time was given to explaining the results and implications” – there was no significant difference between the number of participants who agreed with the statement and the number who did not, suggesting that this may be an area for improvement.

These analyses were repeated, excluding three individuals (ID = 203, 301 and 719) who had a hearing screening test (as described in Section 2.3.1). The results generally did not differ, although the chi-square test was no longer significant for “the amount of information was overwhelming” ($\chi^2(1) = 3.52, p = .061$), but was now just significant for “the audiologist discussed how my HL would affect my life” ($\chi^2(1) = 3.86, p = .050$).

Chi-square tests were also undertaken to ascertain if male ($n = 11$) and female ($n = 16$) participants differed in their rating of the audiologist. The only significant result was for the statement “the amount of information was overwhelming”, where females were more likely to agree than males ($\chi^2(1) = 4.21, p = .040$).

Table 3.5 The participants' ratings of the audiologist at the hearing test appointment

	N	% of participants who gave this rating					χ^2 (df = 1), p-value
		Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree	
<i>Provision of information</i>							
The audiologist used language I understood	27	0	3.7	11.1	33.3	51.9	-
The information provided was relevant to my situation	26	7.7	3.8	15.4	11.5	61.5	18.6, p <.001
I was satisfied with the information provided	27	3.7	3.7	14.8	22.2	55.6	23.1, p <.001
I feel better informed about how to cope with my HL	26	11.5	3.8	23.1	23.1	38.5	15.4, p <.001
Questions were answered clearly and completely	26	0	3.8	11.5	26.9	57.7	-
Insufficient time was given to explaining the results and implications*	27	59.3	14.8	7.4	3.7	14.8	0.9, NS
The amount of information was overwhelming*	26	69.2	15.4	11.5	0	3.8	3.8, p = .050
<i>Impact on individual's life</i>							
Audiologist discussed how my HL would affect my life	23	34.8	13	13	13	26.1	2.1, NS
Audiologist dealt with the fears and concerns I had about my condition	22	13.6	13.6	0	18.2	54.5	11.6, p = .001
Audiologist seemed to understand my experience	27	0	7.4	14.8	22.2	55.6	-
Audiologist seemed to trivialise the issue of my HL*	26	88.5	3.8	3.8	0	3.8	15.4, p <.001
<i>Patient's self-expression</i>							
I was able to express my feelings regarding the diagnosis	20	10	15	0	40	35	12.8, p <.001

Table 3.5 continued

	N	% of participants who gave this rating					$\chi^2(df = 1), p$ - value
		Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree	
I felt I could ask questions when I wanted to	27	0	11.1	7.4	37	44.4	-
Audiologist listened to me	27	0	3.7	7.4	37	51.9	-
I felt comfortable talking with my audiologist	26	0	0	15.4	15.4	69.2	-
<i>Audiologist's actions</i>							
Audiologist was supportive during the consultation	27	0	3.7	14.8	11.1	70.4	-
Audiologist was empathetic during the consultation	23	4.3	4.3	21.7	17.4	52.2	19.2, p <.001
Audiologist was patient with me	27	0	0	18.5	11.1	70.4	-
Audiologist went at a pace appropriate for me	26	3.8	0	15.4	19.2	61.5	22.2, p <.001
I felt I could trust the audiologist	27	7.4	11.1	3.7	22.2	55.6	19.6, p <.001
Would recommend this audiologist to a friend in a similar situation	26	0	3.8	7.7	15.4	73.1	-
Audiologist seemed condescending*	23	95.7	0	0	0	4.3	19.2, p <.001
Audiologist seemed aloof, detached or irritable with me*	25	92	0	4	0	4	17.6, p <.001
Audiologist made me feel embarrassed about my condition*	26	92.3	0	0	0	7.7	18.6, p <.001

NS = Non-significant ($p >.05$).

Bold indicates a significant difference between the number of individuals who agreed to some extent with the statement and the number who did not agree

* Negatively-phrased question

3.3 Interview

Each participant was interviewed, either face-to-face or by phone, 5 - 7 days after their hearing test (refer to Appendix F for a copy of the interview schedule). The interview comprised of four sections which addressed the participant's perception of their HL prior to the hearing test, their experience and emotions during the hearing test, other information (i.e. the patient's interpretation of the hearing test results and who they had told about the results), and the participant's future intentions. The responses to the questions in each of the sections of the interview are presented below.

3.3.1 Participant's perception of their HL prior to the hearing test (Questions 1 – 9)

Table 3.6 presents the responses to the questions in the interview which related to the participant's perception of their HL prior to the hearing test. The majority of participants felt that they had a HL, and regarded it as either mild or moderate in severity. Many of the participants reported some degree of problems from their HL, particularly within groups of people and when watching TV. The participants varied substantially with respect to how long they had been aware of their HL, but the median and mode for this sample was two years. Fifty-two percent of the participants had first noticed the HL themselves, and 44% of the sample reported that other people had also commented on their hearing. For 52% of participants the HL was not the result of noise exposure, whereas for 22% it was due to occupational noise exposure. The remaining 26% were unsure as to the role of noise exposure in the development of their HL. The final question in this section enquired about how many of their friends had a HL, as it was possible that this could affect the participant's awareness of HL, its effects and their acceptance of HAs. The majority of the participants (63%) had at least some friends who they thought had a HL.

Cross tabulation of participants' responses to Question 2 ("how severe did you feel the HL was?") with the level of HL found by the audiologist, found a non-significant association ($\chi^2(6) = 4.27, p = .641$). This indicates that an individual's subjective perception of their HL prior to a hearing test does not correlate with the actual HL found by a hearing test.

Table 3.6 Responses to questions pertaining to prior to the hearing assessment (N = 27)

Question	% who gave that response
1. Did you feel you had a hearing loss?	
a) Yes	92.6
b) No	3.7
c) Perhaps	3.7
2. If yes, how severe did you feel the hearing loss was?	
a) Mild	34.6
b) Mild-moderate	11.5
c) Moderate	53.8
d) Severe	-
e) Very severe	-
3. To what extent did your hearing loss cause problems?	
a) Not at all	3.7
b) A little	40.7
c) Moderately so	48.1
d) Very much so	7.4
4. Where did most of these problems occur?* ¹	
a) With groups of people	48.1
b) Watching TV	37
c) General conversations (including with one person, e.g. spouse at home)	18.5
d) In background noise	11.1
e) At the theatre	7.4
f) Listening to the radio	7.4
g) Hearing the grandchildren	7.4
h) In the car	7.4
5. When were you first aware of your hearing loss?	
a) < 1 year	7.7
b) 1 – 1.5 years	23.1
c) 2 – 3 years	26.9
d) 3.5 – 5 years	19.2
e) 5.5 – 10 years	15.4
f) > 10 years	7.7

Table 3.6 continued

Question	% who gave that response
6. <i>Who made you aware of your hearing loss?</i>	
a) Myself	51.9
b) Spouse	11.1
c) Children	11.1
d) Parent	3.7
e) Family	11.1
f) Others/everyone	7.4
g) Not applicable ²	3.7
7. <i>Have other people commented on your hearing?</i>	
a) Yes	44.4
b) No	51.9
c) Sort of	3.7
8. <i>Is your hearing loss due to noise exposure?</i>	
a) No	51.9
b) Occupational	22.2
c) Recreational	-
d) Both	-
e) Unsure	25.9
9. <i>What proportion of your friends do you think have a hearing loss?</i>	
a) None	37
b) Some	44.4
c) Approximately half	14.8
d) Majority	3.7
e) All	-

* The qualitative responses to this question were coded based on theme (refer to Appendix I)

¹ An open-ended question so participants could have provided more than one response

² This individual did not feel she had a HL until the audiologist told her

3.3.2 Participant's experience during the hearing test (Questions 10 - 14)

3.3.2.1 Emotions felt after the audiologist told them their hearing test results and how the level of emotion changed in the week following (Question 10)

Each participant was asked “which of the following emotions did you feel immediately after the audiologist told you your hearing test results?” and then “has this emotion increased or decreased since then, or has there been no change?”. Table 3.7 presents the responses to these two questions for the 16 emotions which were asked about. The emotions are listed in order from those which occurred most frequently to those which occurred least often. Almost three-quarters of the participants experienced resignation when they were told their hearing test results. Second to this was sadness, relief and optimism. Furthermore, a sense of loss and anxiety both each occurred within 26% of the sample. Table 3.7 shows that the level of emotion changed in a small proportion of individuals in the week after the hearing test; more often it was a decrease in the emotion, rather than an increase.

The emotions are the same emotions which were enquired of in the Initial Questionnaire, and the percentage of individuals who reported on the Initial Questionnaire that they had experienced the emotion or some change in the level of the emotion is presented in the last column of Table 3.7. For some emotions (marked with ** in the table) the question in the Initial Questionnaire asked “how did your level of the following emotions change?”. If an individual responded ‘no change’ to this question, it is not possible to know whether the emotion was absent or present. Therefore, for these emotions it is not possible to compare the responses on the Initial Questionnaire with the responses on the interview which asked about presence/absence of the emotion. For the other emotions (where the Initial Questionnaire asked “to what extent did you experience the emotion?”), correlation analyses were undertaken between the level of emotion reported on the Initial Questionnaire and presence/absence of the emotion as reported at the interview. The results of the correlation analyses are presented in Table 3.8. Table 3.8 shows that there were three emotions - shock, sadness and surprise - for which there was a significant correlation between the results on the Initial Questionnaire and the interview. This suggests that these emotions are more reliably reported between two time-points which occur a week apart.

Table 3.7 Emotions experienced in response to the hearing test results and how they changed in the week after the hearing test (N = 27)

Emotion	% who experienced the emotion	% of total sample who reported this change in emotion in the week post-hearing test			% who experienced the emotion or some change on the Initial Questionnaire*
		Decreased	No change	Increased	
Resignation**	70.4	7.4	88.9	3.7	52.2
Sadness	37	7.4	88.9	3.7	50
Relief	37	-	96.3	3.7	54.2
Optimism**	37	3.7	96.3	-	76
Sense of loss	25.9	-	96.3	3.7	72
Anxiety**	25.9	14.8	77.8	7.4	53.8
Surprise	22.2	7.4	92.6	-	32
Shock	11.1	11.1	85.2	3.7	28
Embarrassment**	7.4	-	100	-	29.2
Vulnerability**	5	3.7	96.3	-	54.2
Apathy	4	3.7	92.6	3.7	17.4
Disbelief	3	-	100	-	20
Fear**	1	-	100	-	36
Hopelessness	1	-	100	-	12
Anger	0	-	100	-	0
Guilt**	0	-	100	-	20.8

* Based on the individual's report that they experienced some degree of the emotion (i.e. a response other than 'not at all')

** The question in the Initial Questionnaire asked "compared to how you felt prior to the audiologist appointment, how did your level of the following emotions change?"

Table 3.8 Spearman’s rho correlation analyses between emotional response reported at the interview and on the Initial Questionnaire

Emotion	Correlation coefficient	Significance (2-tailed)
Shock	.621	.001
Sadness	.545	.004
Relief	.300	.154
Sense of loss	.369	.069
Surprise	.570	.003
Disbelief	.249	.230
Hopelessness	-.075	.721
Apathy	.133	.546

Bold indicates significant correlation. Correlation for ‘anger’ could not be computed because one of the variables (absence of emotion at interview) equalled zero.

Given that higher levels of anxiety have been associated with automatic selective processing of information in a sample of women diagnosed with cervical pathology (MacLeod & Hagan, 1992), a chi-square test was done to analyse the association between uptake of information (Question 20 on the Initial Questionnaire) and presence/absence of anxiety. The latter measure was from the interview since the corresponding question in the Initial Questionnaire did not provide the actual level of the individual’s anxiety (i.e. ‘no change’ could mean anxiety was present or absent). Individuals who reported no anxiety were significantly more likely to report that their uptake of information was not affected by their emotional response to the diagnosis ($\chi^2(2) = 9.12, p = .010$).

3.3.2.2 Suggestions for how the audiologist could have improved his/her approach (Questions 11 – 14)

Question 11 asked “is there anything the audiologist could have done better to improve how they...”. The first part of this question asked about how the audiologist explained the hearing test results, and 85.2% (n = 23) of the sample could not think of any suggestions. Four individuals suggested improvements; these related to explaining “the graph” (i.e. the audiogram), explaining what fricatives were, providing the

opportunity to ask questions, and explaining how the HL could be helped (refer to Appendix I for the original comments). The second part of this question asked about how the audiologist explained the consequences of the HL, and 77.8% (n = 21) reported that there was nothing that the audiologist could have improved, while the remaining 6 individuals reported that this was not addressed. The third part of this question asked about how the audiologist explained how to communicate better or cope with the HL, and 51.9% (n = 14) of participants reported that it had not been addressed or discussed, while the remainder reported that there was no way the audiologist could improve.

Participants were then asked if non-hearing alternative options were discussed with them (Question 12) and all participants responded no. While most participants said nothing could have been improved, it is interesting to note the large percentage of cases where topics were not addressed.

Question 13 asked participants if the audiologist asked them whether they understood before moving on to the next topic, and 63% (n = 17) reported that the audiologist did ask, whereas the remaining 37% of participants were not asked if they understood.

Question 14 asked “did you become distressed during the appointment?” and two participants reported that they did. For one participant it was due to the masking noise, used during testing, making him feel dizzy. He told the audiologist and she turned the noise down. The other participant’s distress was due to the audiologist’s cellphone ringing during the testing. She did not let the audiologist know she was distressed and she does not think he realised it. When asked “could the audiologist have done anything to improve his/her reaction?”, both participants responded no.

3.3.3 Participant’s interpretation of the hearing test result and sharing the test result with others (Questions 15 – 19)

3.3.3.1 “What degree of HL did the audiologist say you had?” (Question 15)

Participants were asked this question and then told that the audiologist would most likely have used the words: Mild, moderate, moderately-severe, severe or profound. Table 3.9 shows the responses to this interview question. Most commonly the participants did not know, but of the individuals who felt they remembered, ‘moderate’ and ‘moderately-severe’ was often reported. Table 3.9 compares the results from this interview question with the individual’s actual audiogram. No significant association

was found between the individual's perception of their HL and the hearing test result ($\chi^2(12) = 9.49, p = .661$). This suggests that the individual's recall of their hearing test results is limited. The comparison between the HL which the individual reported at the interview and their actual HL, for each individual, is illustrated in Figure 3.3. In Figure 3.3, there are eight individuals for whom only one bar is represented. These individuals reported at the interview that they did not remember what degree of HL the audiologist had said they had and so the one bar that is shown is the hearing test result. Figure 3.3 shows that there is a tendency for some participants to overestimate the degree of HL which they recall the audiologist saying they have, and there are a number of individuals who have no recollection of what degree of HL the audiologist said they had.

Table 3.9 Comparison of the interview question regarding level of HL and the audiogram

Level of HL	Number who reported this level of HL at the interview	Number who had this level of HL based on average PTA of both ears	Number with this level of HL in one ear	
			Left ear	Right ear
Mild	4	18	16	13
Mild-moderate	3	*	*	*
Moderate	7	7	10	9
Moderately-severe	5**	1	1	-
Severe	-	1	-	2
Profound	-	-	-	-
Don't know	8			

* 'mild-moderate' was reported by three individuals but is not a category typically used by audiologists and so the definition with respect to dB HL is not known

** This group of five individuals who recalled the audiologist saying that they had a moderately-severe HL did not include the two individuals whose actual HL based on their PTA was moderately-severe (ID = 393) or severe (ID = 109)

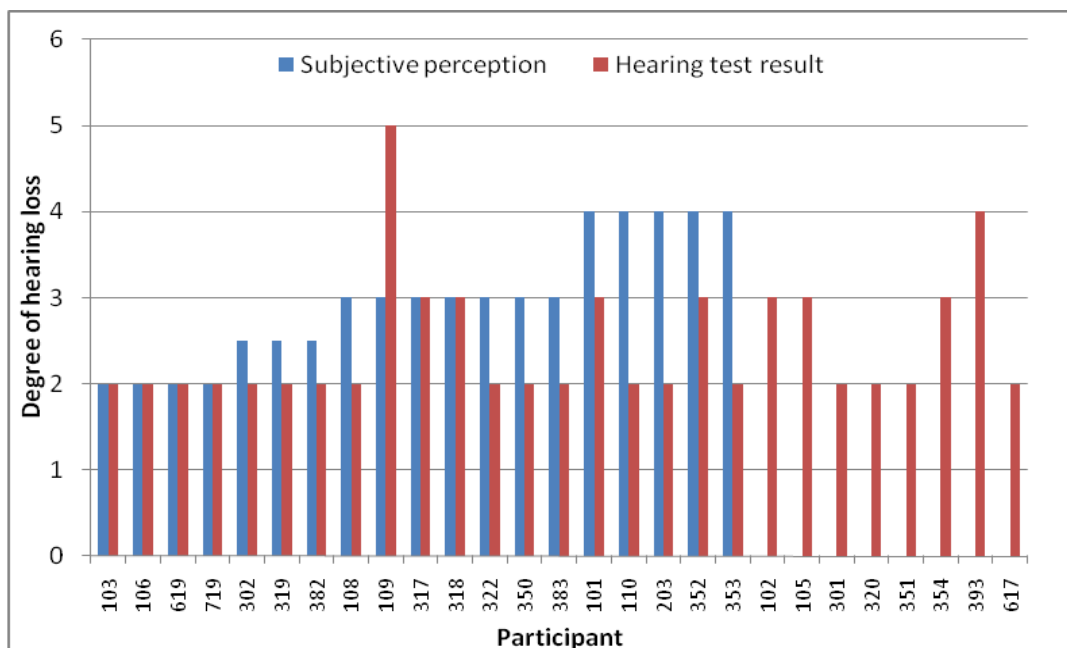


Figure 3.3 Comparison of patients’ perceptions of their HL and the actual hearing test result

Note: 0 = don’t know, 1 = normal hearing, 2 = mild HL, 3 = moderate HL, 4 = moderately-severe HL, 5 = severe HL

3.3.3.2 “Did you question the accuracy of the diagnosis?” (Question 16)

Only one participant reported that she questioned the accuracy of the diagnosis, as she “did not want to believe it”. This individual did get HAs.

3.3.3.3 “Have you done any research yourself into hearing loss and/or possible treatments?” (Question 17)

Three participants reported that they had done some research into HL and possible treatments. One participant had done some web searches, another had asked everyone who she saw with HAs about the aids that they were wearing, and the third person had done previous research as his daughter had a HL.

3.3.3.4 “How did your significant other react to the news?” (Question 18)

When asked how their significant other responded to the news of their HL, the participants’ replies suggested that the significant other, irrespective of whether it was the spouse or child of the participant, generally responded positively to the news of the HL (refer to Appendix I for their comments). Nearly half (48.1%, n = 13) of the comments specifically mentioned that the significant other agreed with the result and

was not surprised because it vindicated what they had been saying. The wife of one participant (ID = 110) was more sad about the news than her husband.

3.3.3.5 “Have you told any friends?”(Question 19)

The majority of participants (63%, n = 17) had told their friends about their hearing test results and the most common reaction was acceptance or lack of surprise. Other friends were supportive or matter-of-fact (refer to Appendix I for the full list of comments). Of the 10 participants who had not yet told their friends, 50% planned to tell them and they expected the reactions would be supportive. In contrast, one individual commented that she expected her friends would “probably say that I don’t need them [HAs]”.

3.3.4 Factors which led the participant to see this audiologist (Questions 20 – 22)

3.3.4.1 “What led you to see an audiologist?” (Question 20)

Participants were given a list of responses for this question and asked to give their primary reason. The most common reason was that they thought they had a HL (44.4%, n = 12). Meanwhile, 18.5% (n = 5) had a partner who told them that they had a HL, 7.4% (n = 2) had family that told them that they had a HL and 29.6% (n= 8) gave other reasons. These other reasons included a promotional offer for a free hearing test (n = 4), Ear, Nose and Throat (ENT) specialist referral (n = 2), recommendation by GP (n = 1), and musician’s earplugs (n = 1).

3.3.4.2 “Why did you choose this hearing clinic?” (Question 21)

This question was open-ended and the participants’ responses have been grouped according to theme (refer to Appendix I for their original comments). The main categories of responses and the proportion of participants who gave that response are presented in Figure 3.4. The most common reasons for choosing the hearing clinic that they attended were a promotional offer or advertising of that clinic and convenience of the clinic’s location to their home. Two participants gave reasons which related specifically to the university clinic - one participant thought it would be superior to other clinics because it is where the audiologists are trained, and another person was seen at this clinic as a result of being transferred from the hospital waiting list.

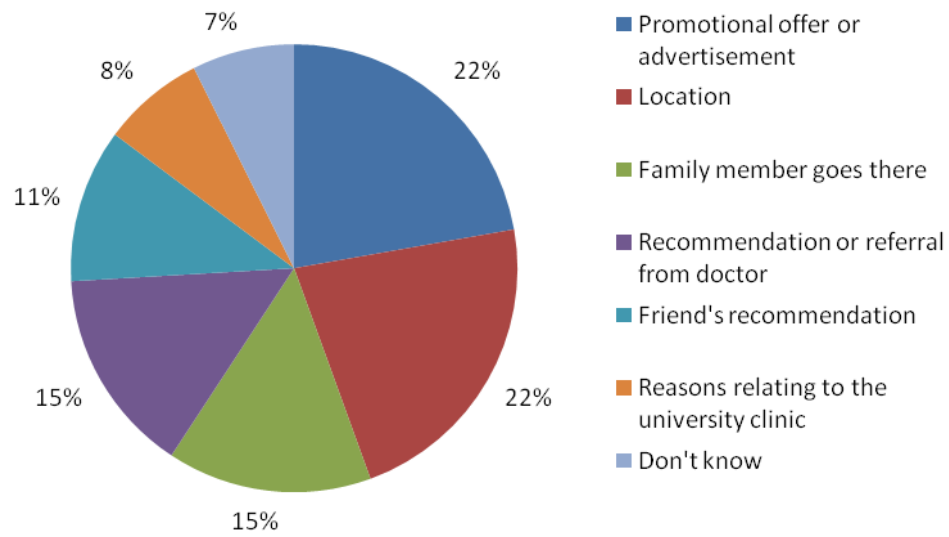


Figure 3.4 Responses to the question “Why did you choose this hearing clinic?” (N = 27)

3.3.4.3 “What would have encouraged you to have your hearing checked earlier?” (Question 22)

This question was also open-ended and the participants’ responses were grouped according to theme (refer to Appendix I for their original comments). The main categories of responses are presented in Figure 3.5. Most commonly participants cited earlier deterioration of their hearing (i.e. if HL had been worse or if other people had noticed and commented earlier) as a factor that would have caused them to have their hearing tested sooner, however 28% of the sample reported that nothing would have encouraged them to have had their hearing tested sooner. Two participants did not respond to this question because it was not applicable to them – one of the participants had attempted to have his hearing checked earlier but the clinic did not return his call, while another had had her hearing checked 6 - 7 years earlier but was found not to have a HL.

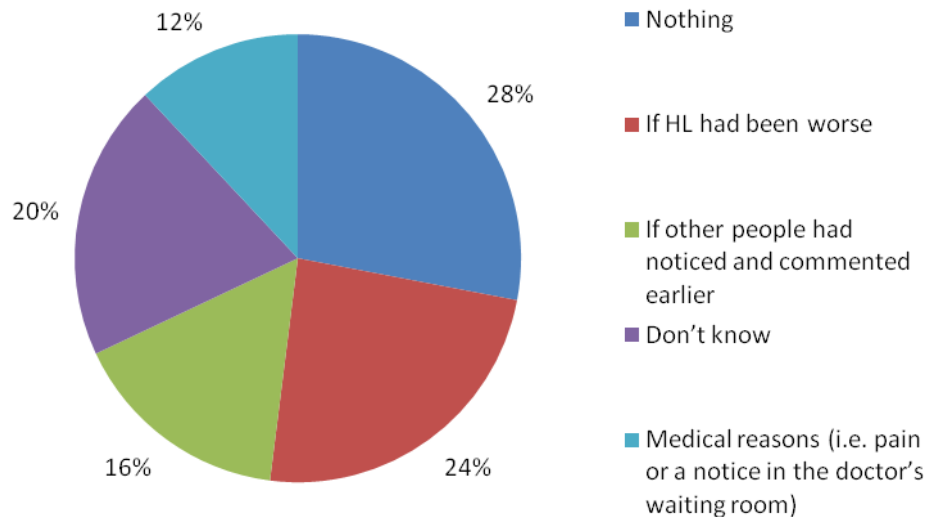


Figure 3.5 Responses to the question “What would have encouraged you to have had your hearing checked earlier?” (N = 25)

3.3.5 Participant’s intention regarding getting a HA (Questions 23 – 25)

Table 3.10 presents the results to the interview questions which enquired about the participants’ intentions to have a HA and what their main reasons were for their decision. At the interview, 63% of participants reported that they were intending to get a HA. The most common reasons that participants gave for doing so were to hear conversations and to generally hear better. On the other hand, the most common reason for not getting a HA was that the participant did not feel like he/she needed one. Many of the participants (63%) had decided prior to the hearing appointment whether they would or would not get a HA. Most of the participants (82%) reported that the audiologist did not say anything that influenced their decision, but five individuals felt that they were in some way influenced by what the audiologist said. They reported that the audiologist had said that “a hearing aid would help”, “that I would benefit from one”, “that I would benefit from it and that two would be better than one”, “[hearing aids] would assist me”, and one person said “[he] confirmed my feelings regarding the matter”. Figure 3.6 illustrates the number of individuals who ordered a HA.

Table 3.10 Responses to Questions 23 - 25 in the Interview (N = 27)

Question	% who gave a related response
23. Do you intend on getting a hearing aid?	
Yes	63
No	25.9
Undecided	11.1
cont 23. If yes, why?* ¹ (N = 19)	
To hear conversations	47.4
Generally hear things better	26.3
To avoid asking others to repeat themselves	15.8
Hear the TV	10.5
Hear grandchildren	10.5
Hear at work or meetings	10.5
Audiologist recommended it	5.3
cont 23. If no, why not?* (N = 8)	
Does not feel like need it	75
Cost	25
24. Prior to the appointment had you...	
Decided you would get an aid if needed	55.6
Decided would not get an aid	7.4
Undecided	37
25. Did the audiologist say anything to influence your decision?	
Yes	14.8
No	81.5
Partly	3.7

* The qualitative responses to these questions were coded based on theme (refer to Appendix I)

¹ An open-ended question so participants could have provided more than one response

3.3.6 Final decision to get a HA and the influence of the audiologist's counselling on this decision

At the end of the study, it was found that all seven individuals who did not intend to get HAs kept to this decision. Of the 17 individuals who intended to get HAs, 15 ordered HAs and 2 did not. Of the three individuals who were undecided, two got HAs and one did not. Figure 3.6 illustrates this.

A logistic regression analysis to identify the effect of an individual's rating of the audiologist on their final decision to get HAs was not statistically significant ($\beta(1) = 0.017$, Odds Ratio = 1.02, $p = .526$). As described in the Methods chapter, the audiologist's rating is the sum of the responses to Questions 21 - 44 on the Initial Questionnaire which relate to the audiologist's approach at the hearing test. Across the 27 participants, the total rating scores varied between 10 and 68 (out of a maximum score of 72), and the mean score was 51.5 (± 15.8). The majority of individuals (81.4%) gave a total score between 41 and 62, and just five individuals gave the audiologist a score less than 40.

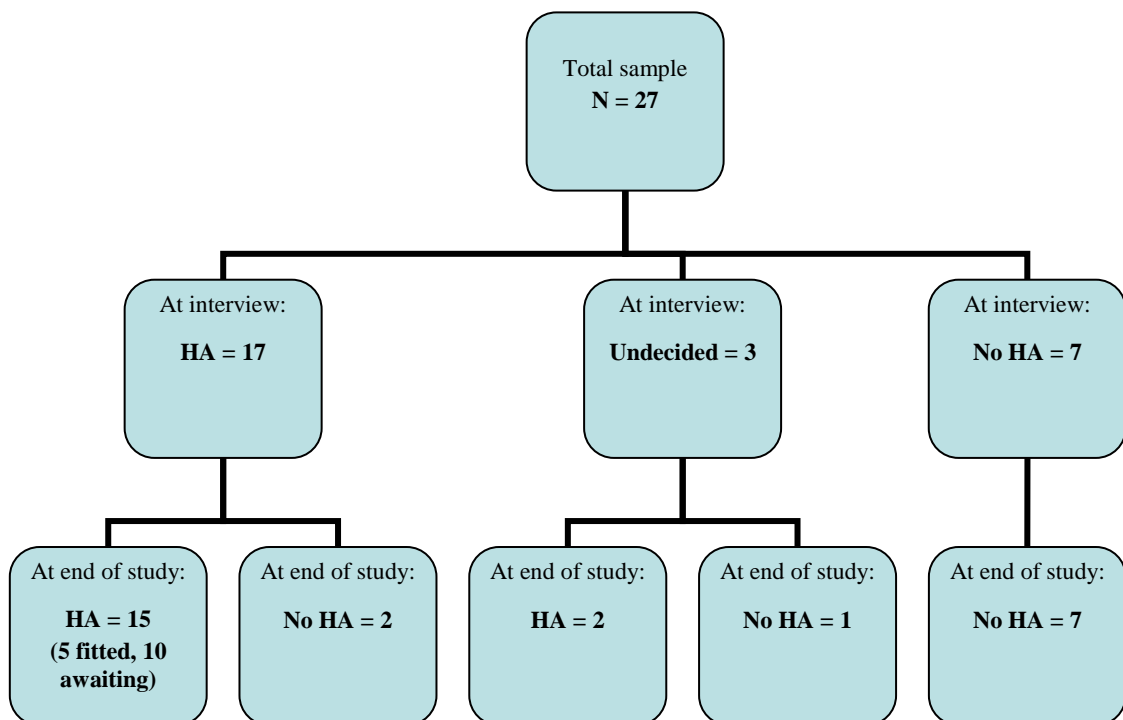


Figure 3.6 Flowchart illustrating the participants' decisions regarding HAs

3.4 Hearing Aid (HA) Follow-up Questionnaire

This questionnaire was completed by individuals who chose to have a HA fitted (refer to Appendix G for a copy of the questionnaire). At the time of analysis, 10 individuals were still awaiting notification regarding funding². Therefore, although 17 individuals chose to have HAs, only seven individuals had had the HAs fitted and completed this questionnaire by the time these analyses were undertaken. The questionnaire was completed by the participant at home so it was not possible to ensure that all questions were answered. Consequently, the column labelled ‘N’ in Tables 3.11 – 3.12 represents the number of individuals who responded to that question. The questionnaire was completed within two days of the fitting, with the exception of one individual who completed it 10 days later due to circumstances beyond the researcher’s control.

3.4.1 Participant’s rating of the audiologist’s approach (Questions 1 – 22)

The first section of the HA Follow-up Questionnaire asked the participant to rate the audiologist, with respect to their counselling, on a five-point Likert scale. The questions and responses are presented in Table 3.11. For ease of interpretation the questions have been grouped with respect to theme, although they were not presented in this order in the questionnaire. In the final column of Table 3.11 are the results of a chi-square test comparing those individuals who reported that they agreed to some degree with the statement and those that did not agree. The majority of the chi-square tests could not be performed because all individuals reported that they agreed with the statement to some degree, or disagreed if the statement was negatively-phrased, and as such the ratings of the audiologists were positive. For the questions where the analysis was possible, there were no significant differences found.

² Funding from ACC or Enable can take 9 – 12 months to be approved.

Table 3.11 The participants' rating of the audiologist at the HA fitting appointment

	N	% of participants who gave this rating					$\chi^2(df = 1)$, p-value
		Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree	
<i>Provision of information</i>							
Audiologist clearly indicated the purpose of the appointment	7	0	0	0	28.6	71.4	-
Audiologist clearly described the process of follow-up appointments	7	0	14.3	14.3	28.6	42.9	-
Audiologist made it clear when I should return for a follow-up appointment	7	0	0	0	28.6	71.4	-
Audiologist clearly explained the pros of hearing aid use	6	0	16.7	0	33.3	50	-
Audiologist clearly explained the cons of hearing aid use	5	0	20	40	20	20	-
I am satisfied with information I have about what kinds of improvements I can expect with my hearing aid(s)	7	0	14.3	14.3	42.9	28.6	-
Audiologist used language I understood	7	0	0	14.3	42.9	42.9	-
My questions were answered clearly and completely	7	0	0	14.3	14.3	71.4	-
There was insufficient time in the appointment to cover everything that I felt was necessary*	7	57.1	14.3	0	14.3	14.3	0.14, p = NS
Overwhelming amount of information*	7	28.6	42.9	0	14.3	14.3	1.29, p = NS

Table 3.11 continued

	N	% of participants who gave this rating					χ^2 (df = 1), p-value
		Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree	
<i>Impact on individual's life</i>							
Audiologist treated me as an individual	7	0	0	14.3	14.3	71.4	-
<i>Patient's self-expression</i>							
I felt I could ask questions when I wanted to	7	0	14.3	0	57.1	28.6	-
Audiologist listened to me	7	0	0	14.3	42.9	42.9	-
<i>Audiologist's actions</i>							
Audiologist was supportive during the consultation	7	0	0	14.3	28.6	57.2	-
Audiologist was empathetic during the consultation	6	0	16.7	0	50.0	33.3	-
Audiologist was sincere and gained my confidence	7	0	14.3	0	42.9	42.9	-
Audiologist was patient with me	7	0	14.3	0	28.6	57.1	-
Audiologist went at a pace appropriate for me	7	0	14.3	0	57.1	28.6	-
I felt I could trust the audiologist	7	0	14.3	0	42.9	42.9	-
I would go back to this audiologist	7	0	0	14.3	14.3	71.4	-
I would recommend this audiologist to a friend in a similar situation	7	0	0	14.3	14.3	71.4	-
Audiologist seemed aloof, detached or irritable with me*	7	85.7	0	14.3	0	0	3.57, p = NS

* Negatively-phrased. NS = Non-significant (p >.05)

3.4.2 Participant's satisfaction with the service provided by the audiologist and with the HAs (Questions 23 – 30)

The remainder of the HA Follow-up Questionnaire asked the participant to describe how the audiologist could have improved the service they provided. The questions were formatted so that a 'yes', 'no' or 'somewhat' response was required, followed by space for further comments. The closed-set responses are presented in Table 3.12 and the comments are discussed in Sections 3.4.2.1 – 3.4.2.8 (a copy of the original comments is provided in Appendix I). In addition to the questions presented in Table 3.12, there were two other questions (Questions 27 and 30) in this section of the questionnaire which were not prefixed with a closed-set response. These are also discussed below. In summary, the participants were generally satisfied with the amount of information they were given and could not identify anything that they would like to see improved or that did not occur which they were expecting.

Table 3.12 Responses to Questions 23 – 26, 28 and 29 in the HA Follow-up Questionnaire (Appendix G)

Question	% who gave this response
<i>23. Were you satisfied with the amount of information you received? (n = 7)</i>	
Yes	85.7
Somewhat	14.3
No	-
<i>24. Do you feel you have enough knowledge to use the hearing aids? (n = 7)</i>	
Yes	57.1
Somewhat	42.9
No	-
<i>25. Are you hesitant or unclear about any part of the whole process (e.g. HL or hearing aids)? (n = 6)</i>	
Yes	33.3
No	66.7

Table 3.12 continued

Question	% who gave this response
26. Are there any improvements that you would like to see in the service that you received? (n = 6)	
Yes	16.7
No	83.3
28. Was there anything that you were expecting from the audiologist that did not occur? (n = 7)	
Yes	14.3
No	85.7
29. How satisfied are you so far with your new hearing aid(s)? (n = 7)	
Very satisfied	28.6
Satisfied	28.6
Neutral	42.9
Dissatisfied	-
Very dissatisfied	-

**3.4.2.1 “Were you satisfied with the amount of information you received?”
(Question 23)**

Three people added comments to their response to this question, two of which were affirming of the information they were provided with. One individual commented that she “felt the information was clear but it was different when I was coping by myself”. The exact meaning of her comment is unclear – she may have felt the information, while clear at the fitting, was insufficient for her to cope on her own, or it may have been too much information for her to remember it at home.

**3.4.2.2 “Do you feel you have enough knowledge to use the hearing aids?”
(Question 24)**

The comments made by participants in response to this question corroborated the yes/somewhat responses which were given. Four of the comments indicated that the participants expected that there would be some period of adjustment, either to being

able to place the HAs in their ear, or to the discomfort, or the overall management of the HA(s).

***3.4.2.3 “Are you hesitant or unclear about any part of the whole process?”
(Question 25)***

Two individuals who responded ‘yes’ to this question made the following comments: “Hesitant. Apprehensive. A lot of information to take in at the one time” and “On when [to] wear the hearing aids to be honest. I enjoy the quiet of my home and with hearing aids in, the floorboards creak, eating becomes very loud – takes time to get used to”. It is unclear from the first comment what part of the HA fitting process the individual was unclear about, whereas the second comment reflects the part of the fitting process related to acclimatisation, which occurs at differing rates across first-time HA wearers.

3.4.2.4 “Are there any improvements that you would like to see in the service that you received?” (Question 26)

Just one recommendation was provided in response to this question. It was recommended that patients be provided with a procedures checklist prior to the HA fitting in order to prepare the patients (“Prior to this appointment I'd like to have received a procedures checklist to prepare me for what was going to happen, e.g. a brochure on hearing aids, how the hearing aid was being "tuned in", etc.”).

3.4.2.5 “Is there anything that you particularly appreciated in the service that you received?” (Question 27)

Two of the responses related to actually getting the HAs and having something to overcome their loss. Three other responses related to the manner of the audiologist, e.g. genuine, friendly, helpful, and one comment related to the proximity of the clinic to her home. The six responses which were provided are listed in Appendix I.

3.4.2.6 “Was there anything that you were expecting from the audiologist that did not occur?” (Question 28)

Two individuals commented on this question. One individual commented that he “couldn’t expect anything as I knew nothing about what was going to happen – other than receiving the aids”. Meanwhile, the other individual responded ‘yes’ to the

question but her comment suggests that she misinterpreted the question – “I don’t think so. She was most efficient”.

3.4.2.7 “How satisfied are you so far with your new hearing aid(s)?” (Question 29)

The three individuals who responded ‘neutral’ to Question 29 made comments which suggested that they were still getting used to the aids. This is not unexpected given the majority of participants completed this questionnaire within 48 hours of getting their HA(s).

3.4.2.8 “What would have led you to get a hearing aid sooner?” (Question 30)

Three individuals’ responses inferred that nothing would have led them to have HAs earlier, while two individuals mentioned that they had some difficulty adjusting to the reality that they needed to get a hearing test and may need HAs (refer to Appendix I for comments).

3.5 Non-Hearing Aid (NHA) Follow-up Questionnaire

This questionnaire was completed by individuals who chose not to be fitted with a HA (refer to Appendix H for a copy of the questionnaire). The questionnaire was sent to the individual three weeks after their hearing test, as this was reported by the clinic managers to be similar to the average time between a hearing test being done and a HA being fitted. As this questionnaire was completed by the participant in their own time, it was not possible to ensure that all questions were answered and therefore the number of individuals who answered each question varied. The questionnaire asked the participant about the decision process which led them to decide against a HA and how they were coping with the HL having made this decision.

At the interview, seven individuals reported that they intended not to get a HA. Three weeks after the hearing test, 10 individuals had decided not to get a HA and completed this questionnaire. Two of these individuals made comments which suggested that while they had decided not to get HAs at this time, they planned to get HA(s) in the near future.

3.5.1 Reasons for not getting a HA and what would need to change for them to reconsider (Questions 1 – 3)

For eight individuals it was for the same reasons that they gave at the interview that they still did not have HAs, which related to not feeling like they needed HAs and cost. The other two individuals did not respond to this question. All individuals cited deterioration of their hearing as the factor that would need to change for them to reconsider getting a HA (refer to Appendix I for comments). One individual also mentioned finances and removal of exostoses (abnormal bone growth).

3.5.2 “When did you decide that hearing aids were not an option for you?” (Question 4)

Two individuals decided before the hearing test and six decided after the hearing test. Of the six individuals who decided after the hearing test, five said they had decided in the time between the hearing test and the interview and one had decided after the interview. One individual initially decided to have HAs but changed her mind after the HAs had been ordered, and another individual did not respond to this question. The former individual said that after the interview she went to another audiologist who suggested “that I [she] was on the margin of needing a hearing aid”. The responses to this question are consistent with the responses the participants provided to the interview question “do you intend on getting a hearing aid?”, which was asked 5 – 7 days after the hearing test.

3.5.3 “Did the audiologist say anything that influenced your decision?” (Question 5)

The majority of participants (70%) did not feel that their decision to get HAs was influenced by the audiologist. However, there were three individuals who did feel that they were influenced by the audiologist. The three individuals who responded ‘yes’ (ID = 101, 103, 617) are not among the five individuals who responded ‘yes’ to the interview question “Did the audiologist say anything to influence your decision?” (ID = 106, 108, 109, 318, 350) (as reported in Section 3.3.5).

3.5.4 Living with the HL, who they have told about their HL and their plans for monitoring the HL (Questions 6 – 15)

The remainder of the NHA Follow-up Questionnaire addressed topics related to how the participant was coping with their HL, if they were utilising any other methods of aural rehabilitation, who they had told regarding their HL and their response to the decision, and the participant’s intentions regarding future hearing tests. The responses to these questions are presented in Table 3.13. The majority of participants felt that they were having no difficulties coping with their HL, and did not use assistive listening devices or listening tactics, nor had they accessed an aural rehabilitation program or other service for people with HL. Most people had told their partner and some friends that they had a HL, and most of these friends/family were supportive of the participant’s decision not to get HAs (refer to Appendix I for a copy of their comments). Unless the speaker was softly spoken, these individuals with a HL tended not to tell their communication partner(s) that they had a HL. Ninety percent of the NHA group planned to have regular hearing tests, typically annually.

Table 3.13 Responses to Questions 5 - 16 in the Non-Hearing Aid Follow-up Questionnaire (Appendix H)

Question	% who gave this response
5. Did the audiologist say anything that influenced your decision? (n = 10)	
Yes	30
No	70
6. How are you coping with your HL? (n = 10)	
With no difficulty	60
With some difficulty	40
With quite a bit of difficulty	-
7. Do you use any assistive listening devices or other methods of assistance for listening? (n = 10)	
Yes	10
No	90

Table 3.13 continued

Question	% who gave this response
8. Have you participated in any aural rehabilitation programs? (n = 10)	-
Yes	100
No	
9. Have you adopted any new listening tactics? (n = 10)	
Yes	30
No	70
10. Have you contacted or used any service(s) related to helping individuals with a HL? (n = 10)	
Yes	-
No	100
11. Who have you told about your HL?¹ (n = 10)	
Partner ²	80
Close family	60
Extended family	20
Some of my friends	80
Majority of my friends	20
Boss/supervisor/employer	10
Work colleagues	30
12. Do you generally tell people when communicating with them that you have a HL? (n = 10)	
Yes	-
No	70
Sometimes ³	30
13. What do your partner, family and/or friends think about your decision not to get a hearing aid?*(n = 9)	
Accepted it/Agree/Supportive	55.6
Not concerned or made no comment	22.2
Unsure	22.2

Table 3.13 continued

Question	% who gave this response
<i>14. Do you think your hearing levels have changed since your hearing test? (n = 10)</i>	
Yes	100
No	-
<i>15. Do you plan to get regular hearing tests in the future? (n = 10)</i>	
Yes	90
No	-
Unsure	10
<i>cont. Q15. If yes, when do you expect you will go for your next hearing test? (n = 8)</i>	
In one year	62.5
In a couple of years (1 – 2 years)	25
5 years or when deteriorate	12.5

* The qualitative responses to this question were coded based on theme (refer to Appendix I)

¹ Participants could provide more than one response

² Of the two individuals who had not told their partner, one was divorced and the other was married/co-habiting

³ They mentioned their HL when necessary – typically when the person had a soft voice or was whispering

3.5.4.1 Assistive listening techniques (Questions 7 and 9)

One individual, in response to Question 7, reported that she used a method of assistive listening which involved cupping her hand behind her ear, which she found helped. Three individuals reported in response to Question 9 that they used the following listening tactics, which they found worked: Approaching the person and asking the question face-to-face; using musician’s earplugs to prevent further damage; using a transistor radio which the individual could carry with her, rather than the radio in the main living room.

3.5.4.2 Association between the difficulty caused by the HL and whether regular hearing tests were planned (Questions 6 and 15)

The four individuals who reported that they were having some difficulties coping with their HL (ID = 101, 106, 302, 383) (Question 6) varied in their responses to Question 15 regarding when they expected they would next go for a hearing test. Two of these individuals (ID = 101 and 383) predicted that they would have another hearing test in a year, another said that he would go for a re-test in a couple of years (ID = 106) and the other individual did not complete Question 15. A chi-square test found that there was no association between the individual's response to the second part of Question 15 ("when do you expect you will go for your next hearing test?") and the degree of HL (based on the category of HL according to their average PTA) ($\chi^2(2) = 0.686, p = .710$).

3.5.4.3 Telling friends: Comparison of responses on the NHA Follow-up Questionnaire with interview responses (Question 11)

Six of the individuals who completed the NHA Follow-up Questionnaire reported at the interview that they had told their friends, and of these six individuals, five reported on the follow-up questionnaire that they had told some or a majority of their friends (Question 11). Therefore, there was general concordance between the interview and this questionnaire with respect to the matter of having told friends about their HL. However, there was one individual (ID = 101) who reported at the interview that she had told a few of her friends but reported on the questionnaire (three weeks later) that she had not told her friends.

3.5.5 "Do you have any expectations regarding your hearing in the future?" (Question 16)

Five individuals (55.6%) expected that their hearing would worsen (refer to Appendix I for the comments). Two individuals (22.2%) referred to using HAs in the future. One individual had no expectations, while another person responded "I would like to see a specialist to get more information" (ID = 110).

There was a further section to this questionnaire which was to be completed by individuals who had initially reported that they would not get a HA but had subsequently changed their mind and had been fitted with HAs by the time they were

sent the questionnaire. There were no individuals for whom this occurred and so there is no data for this part of the questionnaire.

4. DISCUSSION

This study surveyed 27 adults who had been told for the first time by an audiologist that they had a hearing loss (HL). The aims of this study were:

1. To identify some of the common emotional reactions that occur following a first-time diagnosis of HL in adults; and

2. To investigate current audiological counselling services and examine the impact on patients' decisions to get HAs.

Each participant completed a questionnaire within 24 hours of their hearing test regarding their emotional response(s) to the diagnosis and the audiologist's approach. A week after the hearing test the participant was interviewed, either face-to-face or on the phone, to ascertain if their response(s) to the HL had changed, what their initial reasons were for having the hearing test, and their intentions for the future. The researcher then stayed in contact with each of the participants and if they chose to have HAs the participant was asked to complete a questionnaire soon after the fitting to ascertain their satisfaction with the audiologist's approach. If the person chose not to have a HA, they completed a different questionnaire three weeks after the hearing test regarding their reasons for not getting an aid and what their plans were with respect to monitoring their hearing. Qualitative and quantitative data were collected from the questionnaires and interview, and these were analysed in the preceding chapter. A summary of the findings is provided in Sections 4.1 – 4.3 and is discussed in relation to the few studies which have investigated emotional reactions to the diagnosis of HL and audiological counselling. After this, the strengths and limitations of the current study are addressed, as well as the clinical implications and future directions of the research.

4.1 Aim 1: Common Emotional Reactions Following Diagnosis of a HL

The majority of individuals in this study were expecting the diagnosis of a HL, but to a lesser extent than the hearing test revealed. The most common emotional reaction post-diagnosis was a sense of loss. This was followed by relief and sadness. All of the participants in this study had a HL which was permanent and not amenable to surgery. Whilst HAs, as the name suggests, aid HL by amplifying sound, they do not

restore normal hearing and as such audiology patients may grieve the loss of their hearing. HL is typically a hidden disability, whereby affected individuals usually prefer to keep the disability concealed (Robertson, 1999). The sadness and sense of loss experienced by these individuals may be due to the inability to hide their disability any longer, as well as the loss of a skill often taken for granted. These emotions have also been reported by patients with dementia and their families (Aminzadeh et al., 2007; Bamford et al., 2004; Connell, Boise, Stuckey, Holmes, & Hudson, 2004). Dementia and HL share some similarities with respect to the effect of the condition on the individual's physical health, the long term nature of the condition, lack of cure and that the affected individual has some indication that they may have the condition prior to being diagnosed. The other emotion which was experienced by approximately half of the current sample was relief. While some of the comments indicated that they were not expecting as bad a HL, the comments that were made as an aside during the interview suggested that participants were glad that they now had someone who could help them.

The current study found no significant association between gender or age and emotional response. In contrast, Martin et al. (1989) found that females tended to experience greater levels of shock, anger, sadness, fear and worry than males. In their study, Martin et al. (1989) surveyed 276 members of a HL self-help group regarding their emotions following the diagnosis of their HL. The study was somewhat similar to the current study, although the participants in Martin et al.'s (1989) study completed the questionnaire some time after their hearing test (it is not clear from the article how long after, but the authors refer to age differences in years), and the effect of time on the accuracy of recall is unknown. In contrast, in the current study participants completed the questionnaire within 24 hours of the hearing test. Martin et al. (1989) found that younger patients (16 – 39 years) experienced significantly more shock, fear and surprise than older patients (40 – 89 years). In the current study no association with age was found but all participants in this study would have fallen within the older age group defined by Martin and colleagues. While no association with gender or age was found in the current study, the level of HL was seen to have an effect on an individual's emotional reaction post-diagnosis. Individuals with a greater level of HL (i.e. moderately-severe to severe) were significantly more likely to experience disbelief and hopelessness than those with less HL. In Martin et al.'s (1989) study individuals with a mild-to-moderate HL were significantly less likely to be fearful than those with a more severe HL.

The current study also found that the level of optimism an individual felt was commonly altered, often experienced as a reduction in the level of optimism, as a result of the hearing test results. As some emotions may have been present prior to the hearing test, participants were asked “compared to how you felt prior to the audiologist appointment, how did your level of the following emotions change?”. There were relatively equal proportions of individuals who did and did not experience a change in their level of anxiety, vulnerability or resignation. Meanwhile, the majority of individuals experienced no change in their level of embarrassment, guilt or fear. No such findings have previously been published with respect to audiology, but within the dementia literature it has been found that following the diagnosis of dementia, levels of anxiety typically decline (Carpenter et al., 2008).

The majority of participants in the current study did not feel that their emotional response to the hearing test results hindered their uptake of the information given by the audiologist, however, there were five individuals who reported that their retention was affected. Aminzadeh et al. (2007) reported that sometimes the emotional reaction to a diagnosis of dementia is so overwhelming that it precludes the reception of other information provided by the clinician. MacLeod (1992) found in a sample of 15 women diagnosed with cervical pathology, that higher levels of anxiety were associated with automatic selective processing of information, as measured with a modified emotional Stroop task. In accordance, our study found that individuals who reported no anxiety were more likely to report that their uptake of information was not hindered by their emotional response.

Participants were also asked during the interview as to what emotions they had experienced immediately after the audiologist told them their hearing test result. These responses, provided 5 - 7 days post-hearing test, were compared to the responses on the Initial Questionnaire. Generally at the interview fewer participants than on the Initial Questionnaire reported that they had experienced any emotion, possibly as a result of forgetting. There were two emotions however that were reported more often at the interview than on the Initial Questionnaire: Resignation and vulnerability. These emotions may have arisen in the week between the hearing test and the interview and these patients presumed that they had experienced these emotions from when they were told their hearing test results. Correlation analyses were undertaken to compare the interview and Initial Questionnaire responses. Significant correlations were found for three of the emotions - shock, sadness and surprise – indicating that the reporting of

these emotions (as either present or absent) at the interview corroborated the responses on the Initial Questionnaire. For the other emotions, there was no significant correlation between the responses given at these two instances. Participants were also asked if the level of emotion had changed in the week after the hearing test. For the majority of participants there was no change. When the level of the emotion had changed, it was more often a decrease, than an increase. There are no other published studies which have investigated changes in emotion in the week post-diagnosis within the field of audiology or dementia.

In conclusion, the main emotions associated with the diagnosis of HL for the participants in this study were sense of loss, sadness and resignation, as well as relief. Furthermore, there was commonly a reduction in the level of an individual's optimism. Many participants reported no change in the level of the emotion in the week following the hearing test; however, the responses that participants gave to the same question asked less than 24 hours after the hearing test and 5 – 7 days later were generally not consistent.

4.2 Aim 2: Evaluation of Audiological Counselling Services

Participants were asked to rate the audiologist's approach at the hearing test appointment and at the HA fitting appointment. The ratings of the audiologists were generally positive. On the Initial Questionnaire, all positively-phrased questions, with the exception of one ("the audiologist discussed how my HL would affect my life"), had significantly more individuals who supported the statement than those who did not. For the majority of negatively-phrased questions on the Initial Questionnaire there were significantly more individuals who did not agree with the statement than those who did. The two aspects which arose as possible weaknesses in the audiologist's approach related to the amount of time given to explaining the hearing test results and their implications, and whether the audiologist discussed how the HL would affect the individual's life. These aspects are both related to how the audiologist explains the results of the hearing test within the context of the individual's life from both an informational and affective counselling standpoint. The findings suggest that patients want more time given to discussing the impact of their HL on their individual lives at the initial hearing assessment.

On the follow-up questionnaire which was given to individuals who were fitted with a HA, all individuals agreed to some degree with the positively-phrased statements and the majority of individuals responded that they did not agree with the negatively-phrased questions. Caution is required when interpreting these findings from the follow-up questionnaire given that just seven individuals completed the questionnaire. Comments on the follow-up questionnaire about the aspects of the audiological service which the patients appreciated related to the friendly and helpful nature of the audiologist, as well as the availability of someone to help them overcome their HL. Male and female participants did not typically differ in their rating of the audiologist, with the exception that significantly more females than males found the amount of information overwhelming. Previously Martin et al. (1989) found that men were generally more satisfied with the counselling than women.

Comparing the results of the current study with other similar studies that have evaluated the audiologist's counselling skills, finds that the deficiencies previously reported in the audiologist's approach are not complaints of the current sample with respect to their audiologist. Martin et al. (1989) also analysed adults with acquired HL and found that of the participants diagnosed by an audiologist, only 39% felt that their audiologist considered their feelings. This was not specifically asked in the current study, but the ratings of the audiologist's empathy and supportiveness were generally positive in this sample. Martin et al. (1989) also found that half the audiologists did not describe the information in a manner understandable to the patient. Similarly, Sweetow and Barrager (1980) surveyed parents' perspectives of the audiologist's competency at counselling and found that while the parents were happy with the service, they found a weakness in the audiologist's ability to describe the HL in non-technical terms. In contrast, on both the initial and follow-up questionnaires of the current study, all participants agreed with the statement "the audiologist used language I could understand". Martin et al. (1987) surveyed parents and found that there was some need for improvement, specifically in being supportive listeners, in helping the parent work through their emotions and giving them realistic hope, and also in being willing to spend time with the parents after giving them the diagnosis. In the current study these matters did not arise as aspects needing improvement; although the current study comprised of adults who suspected that they had a HL and so these aspects may be less relevant. In a final comparison of the current study with the audiological counselling literature, it is worth noting that a number of audiological counselling texts mention the

significance of having the audiologist's response match the intent of the patient's comment so that the patient feels that their response was acknowledged and valued (Crowe, 1997a; English et al., 1999; Luterman, 2006; Tanner, 1980). In this study the patients were not specifically asked if they felt their emotions were acknowledged, instead they were asked if they agreed with the statement "the audiologist was empathetic" and a significant number of individuals agreed, which represents good affective counselling.

It is reasonable to consider that an audiologist's counselling at the hearing test appointment could impact on a patient's decision whether to pursue HAs. To investigate this, the participant's rating of the audiologist's approach was analysed as a possible predictor of whether the individual chose to have a HA or not. The analyses in the current study found no significant effect, which may in part be due to lack of variation in the sample. The ratings were based on the participants' responses to the Initial Questionnaire which related to the audiologist's approach at the initial hearing test. Unfortunately no other published studies have investigated the association between HA uptake and perception of the audiologist.

In the interview participants were invited to offer suggestions for how the audiologist could improve their informational counselling, specifically with respect to how they explained the hearing test results, the consequences of their HL, and/or how to better cope with the HL. A few suggestions were offered including explaining the audiogram, explaining what fricatives were, providing the opportunity to ask questions, and explaining how the HL could be helped. These issues seem to be more specific to the individual case, because they were not reiterated by other individuals despite the same audiologists testing other participants in this study. However, the issues of inadequate explanation of the audiogram and lack of opportunity to ask questions was also found by Sweetow and Barrager (1980) in a survey of parents of children with a HL. The majority of participants in the current study could not provide any suggestions for improvement. While this is seemingly an extremely affirmative response, there are two factors to consider. Firstly, the participants may have been selected by the audiologist to be involved in the study because they seemed satisfied with the service during the appointment. Secondly, the patients may have not known what to expect from the audiologist during the appointment. For some participants being involved in this study, and completing the questionnaires and interview, was possibly the first time that they had thought about what they would expect from the audiologist. It would have

been useful to have assessed pre-appointment expectation, because if an individual has no expectation regarding the service then any help that they receive for their difficulties would be appreciated.

Despite the few self-initiated suggestions for improvement, over half the participants in this study reported that the audiologist did not address or discuss how to communicate better and/or cope with the HL. It is not clear from the participants' comments whether this is something that they would have like addressed as part of the informational counselling. Similarly, non-HA alternatives were not discussed with any of the participants; although it was not ascertained in this study as to whether this is something that the patients would like to have been informed of. Martin et al. (1989) found that their participants wanted to receive information on support groups, FM systems and alerting devices. The participants in the current study were asked if the audiologist asked them if they understood what he/she was saying before moving onto the next topic, given that this is a recommended practice of audiological counselling (English, 2008). Thirty-seven percent of the participants reported that they were not asked. It would be useful to ascertain if these aspects of informational counselling are important for the patients at the initial hearing test given that there is a considerable amount of information for the audiologist to address in this appointment.

Individuals who were fitted with a HA were asked to complete a follow-up questionnaire which in addition to the audiological counselling questions reported above, enquired about the amount of information the participant was provided, suggested improvements to the audiological service and the participant's satisfaction with the HAs. The results from these questions are discussed in the following paragraphs. The majority of individuals were satisfied with the amount of information they received. This is a good result given that audiologists tend to give the patient all the information they may need at the HA fitting which can be overwhelming for some (English, 2008). English (2008) instead recommends that the information be given in doses with the key points provided at the appropriate times, as well as in written form for reflection by the patient in their own time. When asked if they had enough knowledge to use the HA, there were similar proportions of patients that felt they had enough knowledge to those who felt they had some knowledge. The comments from the latter group implied that they were expecting some period of adjustment to inserting, wearing and/or managing the HAs – “as long as I can actually master getting them in my ears”, “I suppose I will come to grips with it all – if other people can, I can”. When

asked if they were hesitant or unclear about any part of the whole process (e.g. HL and/or HAs), two individuals responded yes. Their comments referred to difficulties in their own adjustment process, i.e. the loudness of sounds when wearing the HAs and their hesitation and apprehensiveness. The audiologist may have counselled on these matters, but individuals adjust and learn at different rates.

In response to the question in the HA Follow-up Questionnaire which asked for suggestions for improving the audiological service, one participant suggested providing patients with information prior to the HA fitting appointment which informed them about the fitting process, such as the types of HAs and how the HA is tuned. Concordant with this comment, someone else responded to another question regarding expecting things from the audiologist which did not occur by saying “I couldn’t expect anything as I knew nothing about what was going to happen – other than receiving the aids”. These comments suggest that informational counselling should occur prior to the HA fitting appointment, whereby individuals who choose to order a HA are given written information describing HAs, how they are fitted and the adjustment process. Surveys of parents of children with HL have also found that the parents wanted more information in written form (Martin et al., 1987; Sweetow & Barrager, 1980). Such information enables the patient and family to be informed, active participants in the aural rehabilitation process, which favours compliance and successful management of the HL (Taylor, 1993). Providing the information in written form ensures that the appropriate person has the information and can refer to it in due course.

Finally, the majority of individuals who were fitted with HAs were satisfied with the HAs when they completed the HA Follow-up Questionnaire. The individuals were asked to complete the questionnaire within two days of being fitted, so as to minimise the individual forgetting the audiologist’s approach and their recall of the appointment being biased by the performance of the HA. Consequently though, it was too short a time for some individuals to adjust to their HAs and so when asked if they were satisfied with their new HAs, some responded that they were still getting used to them. When asked “what would have led you to get a HA sooner?”, three individuals felt that nothing would have led them to have HAs earlier, while two individuals mentioned that they had some difficulty adjusting to the reality that they needed to get a hearing test and may need HAs. The stigma associated with HL and HAs causes individuals to be reticent in addressing the condition. In New Zealand some audiology clinics and HA manufacturers have recently begun marketing in the public domain in

the hope that increased awareness and better understanding of HL will improve acceptance and reduce negative perceptions of HL.

In summary, the audiology patients surveyed in this study were generally satisfied with the audiological counselling provided at the initial hearing test and HA fitting appointment. Although, there is possibly room for improvement with regards to how the audiologist explains the results of the hearing test within the context of the individual's life. Furthermore, while few participants offered suggestions for improving the audiological counselling services, there were some matters which are considered to be integral to audiological counselling that were not provided, such as checking that the patient has understood what the audiologist has said before proceeding on to discuss the next topic. Finally, the patient's satisfaction with the audiologist's counselling seemed not to influence the patient's decision whether or not to get HAs.

4.3 Other Findings

4.3.1 Preceding the hearing test

Although not directly related to the two aims of this study, data was collected from each participant regarding their awareness of their HL prior to the hearing test. There are no published studies which have reported such data. The majority of participants reported at the interview that prior to the hearing test they felt they had a HL. Over half of the participants reported that they thought they may have had a moderate HL, however, the individuals' expectations of their HL did not correspond well with the actual hearing test result. The common situations where the HL caused problems included group situations and when watching television. There was large variation in how long the participants had been aware of their HL, from zero days for one individual to 30 years for another, but the most common response was two years. Commonly it was the individual themselves who had first noticed the HL, although almost half the participants had also had other individuals comment on their HL. When asked if their HL was due to noise exposure, half the sample responded no, a quarter of the sample implicated occupational noise exposure and the remaining quarter were unsure. In summary, most of the participants in this sample were well aware of their HL prior to seeing the audiologist, although the origin and duration of the HL varied across the sample.

When asked what led them to see an audiologist, most participants reported that it was because they thought they had a HL. Second to this was their partner told them that they had a HL. Thirdly, there was a promotional offer for a free hearing test. Martin et al. (1989), in their sample of adults with acquired HL, similarly found that the two main motivating reasons for getting a hearing test were personal concern and concern of spouse or family. Participants in the current sample were also asked why they chose the clinic they went to. Concordant with the third motivating factor in the current sample, the hearing clinic was most commonly chosen based on a promotional offer or advertisement. The other common reasons were location, e.g. “nearest to where I live”, and recommendations of a family member, doctor or friend. There is no other audiological study which has addressed this matter.

When asked “what would have encouraged you to have had your hearing checked earlier?”, the most common response referred to the HL being worse and having other people notice. Three individuals hypothesised that health reasons, such as pain or an advertisement in the doctor’s waiting room, would have encouraged them to have seen an audiologist earlier. However, a quarter of the participants thought that nothing would have encouraged them or rather they would not have bothered. These responses emphasise the stigmatised nature of HL, and that unless others pass comment, many individuals with a HL prefer to keep the condition hidden. In part, there may also be some apathy towards seeking treatment for non-life threatening medical conditions.

4.3.2 Patients’ interpretation of hearing test results

In the interview participants were asked to recall what degree of HL the audiologist said they had. The level of loss which they recalled was compared to their actual audiogram and it was found that there was a lack of correspondence. There were more individuals who recalled their HL as moderately-severe than there were based on the pure tone average (PTA) calculated from the audiogram. The majority of individuals who recalled having a moderately-severe HL actually had a moderate HL based on their audiogram. The lack of association could be in part due to the PTA poorly representing the configuration of the HL. It is difficult to use one value to depict an individual’s HL given that the hearing test results may have different configurations, for example, sloping, rising, flat or u-shaped (as described in Section 1.1.1). Different configurations of HL result in different auditory stimuli being audible, and so the impact is different for alternative configurations despite the same PTA. Also, the lack of association

between what the patient recalled and their actual HL, may be in part due to the patient remembering only part of what the audiologist said. The audiologist may use more than one term to describe an individual's HL, for example, the HL may be mild sloping to moderately-severe. Therefore, a patient may remember just one of these words, i.e. 'mild', 'moderate' or 'severe'. The degree of HL would be described in the report which the patient receives approximately a week after their hearing test, which reports the results of the audiological assessment and the recommended follow-up. However, participants may not have received their report by the time the interview was done (5 - 7 days after the hearing test) or alternatively the patient could only recall part of what was written.

The frequency by which audiology patients question the accuracy of their diagnosis and/or undertake research into their diagnosis has not previously been reported. All but one participant in this study did not question the accuracy of the diagnosis, and the individual who did said it was because she "did not want to believe it", although she consequently chose to get HAs. In the current study there were a few individuals who did independent research after the hearing test into HL and/or possible treatments. One person searched the internet, and the other person approached people who she saw wearing HAs to ask what they thought of them. Both individuals reported at the interview (a week after the hearing test) that they were going to purchase HAs and did so; it is unclear as to the influence of their research on their decision.

4.3.3 Significant others' responses

When asked how their significant other reacted to the hearing test results, all participants, with the exception of one, made comments that suggested the other person was supportive or in agreement with the results. The wife of one participant was saddened by the news, more so than the participant himself. He said that he tried to explain it to her as it just being a part of getting older. Participants were also asked if they had told their friends yet and what the common reaction was, and if they had not told them, were they intending to and what reaction they expected. The reactions, either reported to have occurred or expected by the patient, were all generally supportive in nature. The positivity of these comments is good for these patients, given that dementia research has shown that the reactions of other people can significantly affect the patient's response to the diagnosis (Bond & Corner, 2001). One individual, who had yet to tell her friends, hypothesised that her friends would suggest that she did not need

HAs; however, she ended up purchasing them. This is just one individual case, although it would be useful to investigate the role of friends' perceptions in the decision to get HAs in a larger sample. As described by the ICF framework (World Health Organization, 2001), the perceptions of a patient's family and friends are environmental factors which influence the impact of a HL on an individual. It may be useful for the audiologist to discuss with the patient their family and friends' perceptions of the HL and HAs if the audiologist is advocating that the individual gets HAs.

Participants who chose not to get a HA were also asked who they had told about their HL. The majority of individuals had told their partner and some of their friends. Sixty percent had told close family, 30% had told work colleagues and 10% had told their boss/employer. Martin et al. (1989) found that individuals recently diagnosed with a HL had more difficulty telling their friends and co-workers than family. The current study is concordant with co-workers being infrequently told, however in this sample, friends were one of the most commonly told groups of people. Martin et al. (1989) found that some individuals feared pity and loss of employment so did not tell their boss or employer, but in the current sample the low rate of bosses or employers being told is probably attributable to the majority of individuals being retired. Our study suggests that the majority of individuals with a HL do not generally tell people who they are communicating with that they have a HL, unless the individual has a soft voice or is whispering. This further highlights that HL is a hidden disability (Robertson, 1999). A greater awareness within society of the number and different ages of individuals affected by HL may improve the willingness of individuals who suspect that they have a HL to have a hearing test and/or proactively take charge of a communication exchange.

The follow-up questionnaire which was completed by individuals who chose not to have a HA asked the participant what their partner, family and/or friends thought about their decision not to get a HA. The majority of comments were supportive; although two participants implied that their family/friends were not concerned with their decision, and another two participants were unsure of others' views – "Not sure. They didn't know whether I need a HA or not", "That is my decision". This latter comment was interpreted as suggesting that the participant was not interested in others' views, although, it could alternatively mean that others were not concerned with his decision or did not feel it was their place to comment. This is an example of how questionnaires can be misinterpreted by the person completing it and/or the person scoring it, as the author

is not there to clarify their intentions. The comments from the current study suggest that generally family and friends of the hearing impaired individual are supportive of them not getting a HA. It would be useful in future research to directly ask the patient's significant other, and ascertain the frequency by which individuals with a HL selectively recall the significant other's response so that it aligns with their preference regarding whether or not to get HAs.

4.3.4 Decision regarding HAs

A week after their hearing test, 63% of participants reported at the interview that they were intending on getting a HA. The most common reasons cited for doing so included to hear conversations, to generally hear things better, and to avoid asking others to repeat themselves. The other reasons included to hear the TV, to hear the grandchildren and to hear at meetings or work. Of the 17 individuals who intended to get HAs, 15 did so or are in the process of waiting for funding. Previously, Vesterager (1988) hypothesised that individuals in higher social classes live more active lives and may therefore become more aware of their hearing difficulties and seek treatment more often to minimise any disability that the HL may cause. The current study did not find a significant difference with respect to approximate annual income, employment, gender, ethnicity or marital status between the group who chose to have HAs and those who chose not to. However, the individuals in the non-HA group were significantly younger than those in the HA group, and concordantly the overall general health of the non-HA group rated better than the general health of the HA group. Furthermore, the average hearing level of the non-HA group was significantly better than the HA group.

Seven participants reported at the interview that they were not intending to get HAs, and the two reasons given were: Did not feel like they needed a HA and cost. Three weeks after the hearing test, 10 individuals had decided not to get a HA. This included the seven individuals who reported at the interview that they would not get HAs, as well as one individual who had been undecided and two individuals who had initially intended to get HAs. One of these individuals changed her mind after she got a second opinion from another audiologist, and the reasons for the other person changing his mind are unknown. Concordant with the reasons given at the interview for why they may not get a HA, the non-HA group cited deterioration in their hearing as the factor which would need to change for them to consider getting HAs. These individuals were sufficiently concerned regarding their hearing to have a hearing test and they were

found to have hearing thresholds that normally warrant a HA, yet these individuals still feel that their hearing is not bad enough to get a HA. It would seem that some of these individuals may be at stage two or three of the 'help-seeking' process described by English (2008). Individuals at stage two know they have a problem but do not feel they need help, while individuals at stage three know they need help but will not accept help (English, 2008). Two individuals made comments which suggested that while they had decided not to get HAs at this time, they planned to get a HA in the near future – “I will approach the clinic in the near future to arrange a fitting” and “I do intend to get one soon”.

The majority of patients decide prior to the hearing test whether they will have HAs; yet, there are some individuals whose decision to purchase HAs is based on the audiologist's comments. Participants were asked at the interview if they had pre-decided whether to get a HA or not before their initial appointment. Thirty-seven percent of participants were undecided, 56% had decided they would get a HA and 7% had decided they would not. The final decision appears to be minimally affected by what the audiologist says, as the majority of participants reported that the audiologist did not say anything to influence their decision. Five participants were influenced by the audiologist's comments that a HA would be of benefit to them. They reported that the audiologist made such comments as “a HA would help”, “that I would benefit from one”, “that I would benefit from it and that two would be better than one”, “would assist me”, and one person said “[he] confirmed my feelings regarding the matter”. Individuals who chose not to get a HA completed a questionnaire three weeks after their hearing test. A question in this questionnaire asked “did the audiologist say anything that influenced your decision?”. Three of the 10 individuals who chose not to get HAs responded ‘yes’ and made the following comments: “HA not appropriate”, “I was uncertain after my first appointment and I went to see another audiologist today”, and “the implications of the HL and hearing test were explained very well”. It is unclear from the first comment (which was a written response on the Non-HA Follow-up Questionnaire) whether it was what the audiologist said or if that is what the participant decided. Furthermore, the last comment suggests that the respondent may not have understood the aim of this question. The three individuals in the non-HA group who said that the audiologist had influenced their decision were different to the five individuals who stated the same thing at the interview. Therefore, the interpretation of the findings related to the audiologist's influence on the decision to get HAs may need

to be treated with caution given the lack of reliability in responses to the same question asked 5 – 7 days apart.

4.3.5 Approach of individuals who chose not to have HAs

Those individuals who chose not to have HAs were asked if they used any assistive listening devices. The majority of individuals did not, but one individual reported that she cupped her hand behind her ear, which she found to be useful. None of these individuals had participated in aural rehabilitation programs or had contacted services related to helping individuals with a HL (e.g. the Hearing Association). When asked if they had adopted any new listening tactics, three individuals reported that they had, which included: Approaching the person and asking the question face-to-face; using musician's earplugs to prevent further damage; and using a transistor radio which she could carry with her rather than listening to the radio in the main living room. These tactics were reported to have helped. There are no other studies which have reported the frequency by which such assistive listening techniques are implemented by individuals who decline to have HAs.

The 10 individuals who chose not to have HAs were asked how they were coping with their HL. Over half responded 'with no difficulty', but four individuals said 'with some difficulty'. When asked about their future plans to monitor their hearing, the majority planned to have regular hearing tests and expected that their next hearing test would be in a year. There were three individuals who were going to leave it a little longer before being re-tested - two individuals expected that their next test would be in a couple of years (i.e. two years) and one person was planning to leave it for five years or until she noticed further deterioration. The majority of these individuals anticipated that their hearing would worsen in the future, and two individuals specifically made comments about obtaining HAs in the future. Meanwhile, there was one individual who had no expectations regarding his hearing in the future and another person who wanted more information from a specialist. Previously Karlsson Espmark et al. (2002) found in a sample of elderly individuals with age-related HL that many were worried about the progression of their HL. However, based on the comments of participants in the current sample it would appear that this finding is not replicated in this study. It is unknown as to why the participants in this study typically intended to have an annual hearing check, although this timeframe is generally recommended by audiologists for individuals with pre-existing HL. Karlsson Espmark et al. (2002) found that women worry about hearing

deterioration more than men. Of the three individuals in the current study who were not planning to have their hearing tested in a year, there was one man and two women.

In summary, the majority of individuals who chose not to have HAs reported that they were not experiencing difficulties as a result of their HL, despite not using any assistive listening devices or techniques. Many of these individuals planned to have annual hearing tests and were expecting that their hearing would worsen over time.

4.4 Strengths and Limitations of this Research

The findings described above need to be considered in the context of the limitations in the methodology of this study and the sample of individuals being analysed. However, the strengths of the methodology also need to be acknowledged.

4.4.1 The questionnaires and interview used to survey participants

Participants in this study completed two questionnaires. The first questionnaire was completed after the individual had their initial hearing test. The strength of this initial questionnaire was that it was completed by all participants, with the exception of one, within 24 hours of being given their hearing test result, which minimised the effect of forgetting. However, there are limitations inherent in questionnaire-based research. Firstly, questionnaires entail subjective answers and it is not possible to determine if the participant interpreted the question in the manner it was intended. Secondly, it is assumed that the questions will be answered honestly. Thirdly, there is the risk that not all questions will be answered by all individuals, altering the number of responses for each question and possibly leading to a bias in the results. The significance of the first issue to the current study was hopefully minimised by making the questions simple and specific in their wording. The second issue was addressed in the current study by having the participant complete the questionnaire in the privacy of their home and with the reassurance that their clinician would not see their responses.

Participants in this study also completed an interview. If the individual lived in Christchurch then the interview was conducted in person and the participant was able to read the questions as the interviewer read aloud. For the participants who lived outside of Christchurch, the interview was done via phone. This is a limitation of the study given that verbally-administered measures which rely on the individual using just their hearing to interpret what the researcher is asking, have compromised validity amongst

samples of hearing-impaired individuals (Gilholme-Herbst & Humphrey, 1980). For this reason the majority of the assessment in this study was done by questionnaire, however in addition to obtaining more detailed information, the interview was also used to develop a rapport with the participant in the hope that it would facilitate their co-operation in answering the follow-up questionnaire. A phone-based interview was the only means by which to interview individuals who resided outside of Christchurch, and it was necessary to recruit further afield in order to increase the number of participants. A strength of the interview itself was that many of the questions were open-ended, which is better at eliciting the patient's true perspective rather than the answer from the closed-set options on the questionnaire which best approximates the truth. Furthermore, an interview enables both the interviewer and interviewee to clarify the meaning of the question and/or response, which as mentioned earlier, is an issue with questionnaires.

There is the risk that a Hawthorne effect may have occurred whereby the audiologists' behaviour was altered as a result of them being aware that they were being evaluated as part of the study. Initially it was proposed that the receptionist would inform the patient about the study and keep the audiologists "blind" to which patients agreed to be involved. However, when the researcher met with the audiologists, they preferred that they themselves would invite the patient to be involved in the study. Their justification was that this reduced the amount of work required by the receptionists who were already very busy. Furthermore, the ethics committee also required that the audiologists, and not the receptionists, approached the patients. This meant though that the audiologists were aware of which patients were likely involved in the study, raising the possibility of a Hawthorne effect. On the other hand it could be argued that an audiologist's behaviour is constantly being evaluated by their patients who are their customers, irrespective of the fact a research study is being conducted, and so there may not have been a significant Hawthorne effect. It is also possible that not all eligible patients were approached regarding the study; the audiologist may have selectively told patients about the study depending on how well they felt they conducted the appointment and/or if there was sufficient time in the appointment.

This method of having the audiologist approach the patient regarding the study may have also contributed to the emotional reactions which were found by this study. It was initially proposed that the receptionist would inform the patient of the study when he/she arrived for the hearing test and give them the Information Sheet to read while in the waiting room. At the completion of the appointment the audiologist would then

complete a form letting the receptionist know if the patient was eligible for the study and the receptionist would invite the patient to be involved. This was the preferred method for a number of reasons: The patient generally has more time before the appointment to read the information than at the end of the appointment; an individual's judgement regarding being involved in the study may be less clouded by emotion prior to the appointment than following it; the audiologist has enough information to give to the patient during the appointment and may not have the time to properly explain the study and/or answer the individual's questions; the audiologist would be more "blind" to who is involved in the study, and the patient may not feel sub-consciously persuaded by the audiologist to be involved in the study through fear that it would affect their treatment. Furthermore, there was the possibility that individuals who were more upset or in shock post-appointment would opt not to be involved in the study, causing a bias in the sample towards individuals less affected by the news. (The issue of participant self-selection is discussed further in Section 4.4.2 below). Lastly, there was the concern that if patients were informed of the study for the first time after they had been told that they had a HL, their level of stress could be heightened and they may decline to be involved because of the burden of extra information. It is not possible to know how much these factors influenced the results that were found. Ideally the Information Sheet would have been sent to the individual prior to the appointment so they had time to read it and consider it. Although this would not have been feasible for all patients, given that at some clinics a patient can be seen within a week of ringing to make an appointment.

4.4.2 Participants

Audiology patients are a very heterogeneous group of individuals, therefore large sample sizes are needed to draw valid and reliable conclusions, as well as to analyse the effect of moderating factors, such as gender, age and ethnicity. A limitation of the current study is the relatively small sample size. Prior to commencing recruitment, the managers of each of the audiology clinics involved in the study provided estimates of the number of new patients seen at their clinic each week. Based on these estimates, it was anticipated that 50 – 100 individuals could realistically be recruited within six months. It is unknown as to why this did not occur; the clinic managers were asked but they could not provide specific reasons. It is hypothesised that the slow rate of recruitment may be due to four reasons: Patients declining to be involved, patients not being eligible, clinicians forgetting about the study, and clinicians

choosing not to invite certain patients. To minimise the issue of clinicians forgetting, reminder notices were placed in the testing rooms in each of the clinics and each week the clinics were rung and the audiologists were emailed to remind them about the study. Also, mid-way through the study the researcher delivered chocolates to each of the clinics in appreciation of their efforts. The lack of participants could also be in part due to the type of hearing test which was done. Eleven of the 16 clinics offered free hearing screening tests, for which a 20 minute appointment was allocated. In this appointment there is insufficient time to do the hearing test, describe the results and describe the study. Consequently, the audiologists did not generally approach these patients to be involved in the study. This significantly reduced the number of individuals that could have been recruited, because although these patients typically returned for a full diagnostic audiological assessment later, they had already been told by an audiologist at the screening test that they had a HL and were therefore ineligible to be involved in this study.

Participant self-selection is a potential limitation of this study which may have biased the sample and results in some way. For example, individuals who were particularly upset by the results of the hearing test may have felt that being in a research study was another stress that they did not want at that time and may have opted not to be involved. As a result the sample may be biased towards individuals who had less extreme responses to the diagnosis and/or those who wanted their opinion heard as they were very happy or very unhappy with the audiology service. The study involved a fair amount of time (60 - 90 minutes) and effort from each participant, with no reimbursement provided. Furthermore, as mentioned above (Section 4.4.1), there may be some bias arising from the audiologists selecting, albeit consciously or subconsciously, who they invite to be involved in the study. The perceptions regarding the audiologist's approach were generally very positive. It is possible that these perceptions are not truly representative of all patients as a result of the audiologist selecting who should be involved.

Furthermore, the recruitment criteria for the study limited somewhat the representativeness of the sample group to the population of hard-of-hearing individuals. Specifically adults from private audiology clinics were recruited for this study. This was intended to minimise the variation within the sample which could possibly obscure associations. The sample was biased towards individuals whose HL could be managed with a HA, as opposed to HL which is amenable to surgery and is normally managed by

an Ear, Nose and Throat Specialist. The majority of participants in the current study were of European ethnicity. This composition of ethnicities is relatively representative of the population of the south island of New Zealand where the participants were recruited from, but the limited number of other ethnicities within the sample precludes any cultural factors from being analysed.

4.5 Clinical Implications

The results from this study demonstrate the uniqueness of each patient's journey - there were variable emotional responses, different reasons that brought participants to the audiologist and the clinic, and no consistent pattern for choosing for or against having a HA. For example, the decision to get HAs was not related to gender, ethnicity, marital status or employment. These results emphasise the importance of spending time getting to know the patient - their perception of HAs, motivation, needs, expectations and goals - despite the typically very limited time in an audiology appointment. Tools have recently been developed by the Ida Institute in Denmark, to efficiently elucidate this information from the patient. Further information regarding these tools can be found at the Ida Institute website - www.idainstitute.dk. Alternatively, the Attitudes Towards Loss of Hearing Questionnaire, developed by Saunders et al. (2005), could be used to elucidate the patient's perception of their HL as well as HAs. This questionnaire comprises of 22 questions on 5 scales: Denial of HL, Negative Associations, Negative Coping Strategies, Manual Dexterity and Vision, and Hearing-Related Esteem (Saunders et al., 2005). Otherwise, some audiology clinics use their own questionnaires that they have developed or use other existing measures, such as the Client Orientated Scale of Improvement (Dillon, James, & Ginis, 1997) which determines the patient's goals for the HA fitting.

With respect to the individual's immediate emotional reactions to the diagnosis of HL, it seems that sense of loss, sadness, relief and optimism are emotions significantly affected by the hearing test results. Other emotions do occur, but in fewer individuals. This variation in emotion may reflect the different phases of the grieving process which the individuals with the HL are in, e.g. denial, anger, bargaining, depression or acceptance (Kubler-Ross, 1969). For example, some may still be denying that they have a problem, but are at the hearing test because their spouse has told them to go. Meanwhile, others may have reached the stage of acceptance and been there for

some time, but not seen the audiologist because of circumstantial reasons, e.g. money or time. The different stages of the grief process will affect treatment outcomes (Crowe, 1997) and so intervention should account for which stage the individual is at (Aminzadeh et al., 2007). Asking the patient how they feel about the hearing test results and gauging the extent of their reaction will also be useful given that the emotional reaction of some patients precludes them from retaining any further information given by the audiologist. If the audiologist ascertains that the individual is feeling very emotional about the diagnosis then proceeding to discuss treatment options may not be appropriate at that time.

This study's evaluation of the audiological counselling - both informational and affective - currently provided by experienced audiologists, found that these New Zealand audiology patients were generally happy with the care they received from their audiologist, both when they were diagnosed with their HL and when they were fitted with their HAs. We can not however extrapolate these findings to conclude that patients continue to be happy with the care given by audiologists throughout the HA adjustment process and other follow-up appointments. While the participants in this study were generally happy with the care provided, they were less satisfied with the amount of time given to discussing the hearing test results and the effect of the HL on their life. Audiologists may need to remember that while they hear the same complaints regularly, this is this patient's first time and so they need to consider this patient as an individual rather than 'one of the same'. It is also possible that there are other things which patients would like to see from their audiologist, but because they were unsure as to whether this was common practice for an audiologist, the participants in this study did not mention it. Therefore, the general satisfaction amongst the patients may be due to not knowing what to expect and/or an appreciation for any assistance they can receive for their HL. Alternatively, the audiologists may be doing a good job, suggesting that formal training in audiological counselling may not be critical and adequate skills can be acquired through clinical practice. The current study did not record information regarding the audiologists, such as years of experience, so it is not possible to ascertain if the participant's rating differed with the audiologist's experience. Luterman (2001) however feels that counselling skills are too important to be left to chance or to assume that students will pick it up as they go along. A number of texts have been written encompassing guidelines and skills for audiological counselling (Alpiner, 1997; English, 2008; Holland, 2007; Luterman, 2006; Vargo & McFarlane, 1994). This

literature, along with the practical tools and practice examples developed by the Ida Institute and the other above-mentioned assessments, could form the foundation of a valuable workshop for training audiologists to increase their awareness and implementation of audiological counselling.

In addition to the implementation of a workshop, I have two further recommendations for improving clinical practice based on the findings of this study:

- Information should be sent to the patient when they make an appointment for a hearing test, explaining about the basis of HL, causes, means of prevention, the different types of HL and the methods of treatment/management. It should also include a slip of paper with two simple questions which the patient should complete and bring to the appointment: (1) What is your main reason for attending the appointment?; (2) Would you be interested in getting HAs if you need them? These recommendations are based on the comments of the participants in this study and on the finding that most participants have made the decision whether or not they will get HAs prior to their appointment. If the clinician was to know in advance, it would assist them in planning their time and discussion with the patient post-hearing test. This also provides the patient with time to consider the information and formulate questions so that they can be an ‘informed’ patient and play a more active role in their subsequent care.

- If a patient chooses to have HAs, the patient should be provided with information regarding HAs, how they are fitted and the adjustment process, prior to the fitting appointment so that the patient feels that they have the vocabulary and are informed and active participants in the fitting process. This pamphlet could be produced in consultation with community-based groups for people with HL, such as the Hearing Association. One participant in this study went to the Hearing Association and found it very useful - she said that she felt better prepared when attending the fitting appointment because she knew the questions to ask and did not feel like an uninformed participant. The audiologist-patient relationship is generally long term and relies on the patient accepting and actively participating in their rehabilitation (Taylor, 1993).

Both recommendations corroborate the ASHA guidelines (American Speech-Language-Hearing Association, 2006) which emphasise the importance of engaging the patient in the management of their HL and as such implementing a rehabilitation model of care, rather than a medical model of care. The recommendations relate to providing

the patient with information, which will hopefully serve to empower them and encourage them to be active participants in the rehabilitation process. This education of the patient would be regarded as a positive personal factor within the ICF framework (World Health Organization, 2001). As described in the Introduction of this thesis, the ICF describes how different factors, both internal and external to the individual, can positively and negatively influence the extent to which a HL affects an individual's daily functioning.

4.6 Future Directions

While the current study investigated the prevalence of emotions in response to the diagnosis of HL, it did so with a relatively small sample size. Future research should investigate emotional reactions in a larger sample, and concurrently investigate the role of a patient's view of society's perception of deafness on their reaction. It is likely that the participants' responses in the current study are in part due to societal factors, as described by the ICF framework (World Health Organization, 2001), such as the unwillingness to be associated with hearing impaired individuals.

With respect to the audiologist's counselling, there are some questions which remain as to what the patient is expecting from the audiologist. This study found that audiologists did not discuss listening tactics and non-HA alternatives with their patients at the hearing test appointment, but it remains unknown as to whether this is something the patients would appreciate in the care they receive. It would also be useful to assess patients' pre-appointment expectations regarding the hearing test appointment, HAs and what they expect from the audiologist. This will be informative for clinicians and can be taken into account when analysing the individual's perception of the audiologist's approach.

Another possible future study involves investigating the relationship between the individual's perception of their audiologist's counselling and the number of hours of HA use, i.e. if the patient regarded the audiologist more favourably, did they have higher levels of compliance with respect to wearing the HAs. It was initially proposed that the number of hours of use reported at the first HA follow-up appointment would be recorded and included in the analyses. However, the audiologists were hesitant to commit to recording this value and the researcher was reticent to ask the audiologists to do anything beyond what was already required of them.

A number of self-assessment tools have been developed which address the impact of the HL on the individual and the goals they have for their HA(s), such as the Client Orientated Scale of Improvement (Dillon et al., 1997), Glasgow Hearing Aid Benefit Profile (Gatehouse, 1999), Hearing Handicap Inventory for Adults (Newman, Weinstein, Jacobson, & Hug, 1990), and the Attitudes Towards Loss of Hearing Questionnaire (Saunders et al., 2005). These measures elucidate information which is important for the rehabilitation process and the counselling which occurs throughout. Furthermore they provide a way of demonstrating to the patient, and others, the benefit gained from the HA(s). This study did not enquire if such a measure was used, but it would be useful to ascertain the extent to which such measures are used and how they are used with respect to counselling, for example, does the patient value the use of these scales because their concerns are explicitly identified and acknowledged.

Finally, another area of potential future investigation relates to the role of the significant other. It would be useful for audiologists to know the influence the significant other's reaction to the HL can have on the individual's acceptance of the diagnosis and decision to get HAs. However, it is expected that these associations will vary considerably with individuals' different personalities and types of relationships. Also, an evaluation of significant others' perceptions of the audiologist's counselling would identify ways by which audiologists may need to improve the care they provide for the patient's significant other. The inclusion of the significant other in the counselling is important given the support that this person provides to the individual outside the clinic. A patient's support network is one environmental factor, as depicted by the ICF framework (World Health Organization, 2001), which can significantly influence the impact of a HL on an individual.

4.7 Conclusion

In conjunction to diagnosing and treating HL, an audiologist's job involves teaching and counselling the patient. The counselling encompasses both informational and affective counselling, the latter of which can be alternatively described as providing emotional support (Luterman, 2006). If the audiologist fails to recognise the emotions, it limits their ability to help the patients, because HL is associated with many emotions (Luterman, 2006). This study found that patients experience a range of emotions; although in this sample three emotions were more common – a sense of loss, sadness

and relief. Furthermore, in this study the audiologists were rated well by the participants suggesting that the audiologists evaluated through this study were generally providing the support that the patients needed. This however does not mean that all audiologists are providing appropriate counselling to their patients, and/or it is unclear how long it may take an audiologist to acquire these skills to a competent level. Hence I feel there is still the need for formal training in audiological counselling for both current and future audiologists. Such training would hopefully avoid audiologists feeling that they lack the knowledge and skills to provide audiological counselling, but would also educate them as to when to refer a patient on to a professional counsellor.

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APPENDICES

APPENDIX A
ELIGIBILITY FORM

Reactions and responses to the diagnosis of a progressive hearing loss in adults

Patient's name:.....

Is this patient eligible?

Tick if criteria met

- Aged > 18 years
- NOT had their hearing thresholds established previously
- Has a progressive or gradual hearing loss which has NOT arisen from one single incident in time
- Has a four-frequency (0.5, 1, 2 & 4kHz) PTA > 30 dB HL in either or both ears

Patient's four-frequency PTA for left ear =

Patient's four-frequency PTA for right ear =

- Uses English as their main form of communication
- Has no other major impairment that may prevent them from completing a questionnaire (e.g. blindness or significant cognitive impairment)

If all boxes are ticked, please inform the patient of the study.

Please staple this form to the signed Contact Details form or Consent Form.

Thank you very much for your help

APPENDIX B

INVITATION LETTER AND INFORMATION SHEET

April 1 2009

Dear Sir / Madam,

Welcome to (*clinic name inserted here*)

This clinic is currently involved in a study that I am undertaking as part of my Masters of Audiology at the University of Canterbury. The study is investigating reactions to the diagnosis of a hearing loss in adults. This has not previously been investigated in New Zealand and will be useful in providing audiologists with the information to provide optimal care.

Attached to this letter is an information sheet which will provide you with more information regarding the study. Your eligibility to be involved in the study will depend on the results of your hearing test. If you are eligible and would like to be involved, the audiologist will ask you to sign a consent form after reading the information sheet. If you have insufficient time to read the information sheet you may take it home, however we would appreciate it if you could leave your contact details with the audiologist so that I can contact you to see if you are interested in participating, once you have had time to read the information.

If you are able to be in the study, you will be asked to complete a questionnaire, which should not take longer than 30 minutes. You would need to complete this within 24 hours of your audiologist appointment. The consent form that you sign will include your contact details so that the researcher can contact you to organise a time to interview you. The interview will take 30 mins – 1 hour maximum, and can be done at your home, at the University of Canterbury Speech and Hearing Clinic, or via phone. At a later date you will also be asked to complete another short questionnaire (30 minutes maximum) which will relate to whether you have or have not been fitted with hearing aids. All information you provide will be kept strictly confidential.

All individuals who complete both questionnaires and the interview will go in the draw to win a \$50 petrol voucher or 5 cards of batteries (30 batteries) of your size donated by ReSound, Starkey, Unitron and Widex.

Please take the time to read the attached information sheet. If you have any questions, please ask the audiologist or contact the researcher on 0800 864 837 extn 3342. Your involvement in the study will be much appreciated, however if you choose not to take part, it will not affect any current or future care or treatment.

Thank you for your time.

Kind regards

Katrina Light

The University of Canterbury – Department of Communication Disorders
Information Sheet for Participants in Research
Reactions to the diagnosis of a hearing loss in adults



Researchers: Katrina Light, Masters of Audiology Student,
Ph: 0800 864 837 ext: 3342, email: kjl81@student.canterbury.ac.nz
Valerie Looi, Supervisor, Lecturer in Audiology,
Ph: (03) 364 2987, ext: 3051, email: valerie.looi@canterbury.ac.nz
Janet Carter, Supervisor, Lecturer in Psychology
Ph: (03) 364 2987, ext 8090 email: janet.carter@canterbury.ac.nz

Introduction:

You are invited to take part in a research study investigating reactions to the diagnosis of a hearing loss in adults. Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part, this will not affect any current or future care or treatment. You would be free to withdraw from the study at any time and withdraw any information already supplied, without having to give a reason and this will in no way affect your continuing or future care.

Inclusion Criteria:

- Adults aged > 18 years who have not previously been diagnosed with a hearing loss
- AND presence of a progressive or gradual hearing loss which has not arisen from one single incident in time, for example, head trauma
- AND a mild or greater level of hearing loss as determined by the audiologist
- All participants must use English as their main form of communication.

Participants:

At least 50 adults who have been diagnosed with a hearing loss for the first time.

Aims of the research:

The first aim of this study is to describe some of the common reactions that occur following a first-time diagnosis of hearing loss in adults. This has not previously been investigated and will aid audiologists in counselling the patient through the diagnosis of a hearing loss. The second aim of the study is to examine how satisfied patients are with the audiological counselling they receive. Results obtained will assist in the development of an audiological training workshop in counselling based on what patients appreciate in the care they receive, and also what they would like to see improved.

Description of the procedure:

If you agree to be involved in the study you will be given a questionnaire to take home. We ask that you complete the questionnaire within 24 hours of your first appointment. The questionnaire should take no longer than 30 minutes to complete. The Principal Researcher, Katrina Light, will contact you within 48 hours of your appointment and organise a time to interview you. The interview may be done at the University of Canterbury clinic or at your home, and should take no longer than an hour. The interview will ask about your experience of the hearing loss, your reaction to being told you have a hearing loss and your intentions regarding hearing aids. Those who decide to have hearing aids will be sent another questionnaire in the week following the fitting of

APPENDIX C
CONSENT FORM



Researchers: Katrina Light, Masters of Audiology Student,
Ph: (03) 366 7001 ext: 4816, email: kjl81@student.canterbury.ac.nz
Valerie Looi, Supervisor, Lecturer in Audiology,
Ph: (03) 364 2987, ext: 3051, email: valerie.looi@canterbury.ac.nz
Janet Carter, Supervisor, Lecturer in Psychology
Ph: (03) 364 2987, ext 8090 email: janet.carter@canterbury.ac.nz

I have read and I understand the information sheet (February 2009) for volunteers taking part in the study designed to investigate reactions to the diagnosis of a hearing loss in adults. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and withdraw any information already supplied, and this will in no way affect my future health care, continuing health care, academic progress and/ or employment.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had the time to consider whether to take part.

I know who to contact if I have any side effects to the study.

I know who to contact if I have any questions about the study.

I give permission for the researcher to access my audiological records for the purposes of this study.

I give permission for the researcher to contact me at a later date for further information if necessary regarding this study.

I _____ (print full name) hereby consent to take part in this study.

Contact details: **Address**

Phone number

Signature: Date:

Witnessed By: Signature:

Please fax this completed form to (03) 364 2760 (Attn: Katrina Light)

APPENDIX D

CONTACT DETAILS FORM FOR THOSE WHO HAVE NOT YET READ THE INFORMATION SHEET

The University of Canterbury – Department of Communication Disorders

Reactions to the diagnosis of a hearing loss in adults

**CONTACT DETAILS FORM FOR THOSE THAT HAVE NOT YET READ THE
INFORMATION SHEET**



Researchers: Katrina Light, Masters of Audiology Student,

Ph: (03) 366 7001 ext: 4816, email: kjl81@student.canterbury.ac.nz

Valerie Looi, Supervisor, Lecturer in Audiology,

Ph: (03) 364 2987, ext: 3051, email: valerie.looi@canterbury.ac.nz

Janet Carter, Supervisor, Lecturer in Psychology

Ph: (03) 364 2987, ext 8090 email: janet.carter@canterbury.ac.nz

I..... (print full name) willingly provide my contact details below and authorise the researcher to contact me to further discuss this study. I know that this form does not commit me to be involved in the study.

Signature: _____

Number and Street Address: _____

Suburb: _____

Phone number: _____

Witnessed By: Signature:

Please fax this completed form to (03) 364 2760 (Attn: Katrina Light)

APPENDIX E
INITIAL QUESTIONNAIRE

THE UNIVERSITY OF CANTERBURY:
DEPARTMENT OF COMMUNICATION DISORDERS

INITIAL REACTION QUESTIONNAIRE

ID:.....(researcher to fill in)

Date:.....

Please complete this questionnaire within 24 hours of your audiologist appointment

1. Were your results from the audiologist what you expected? Yes No Partly

Any comments.....
.....
.....

As a result of being told that you had a hearing loss, to what extent did you experience the following emotions

(please tick the most appropriate description):

	Not at all		Somewhat		Very much so
2. Shock	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Anger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Sadness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Sense of loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Surprise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Disbelief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Apathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Compared to how you felt prior to the audiologist appointment, how did your level of the following emotions change

(please tick the most appropriate description):

	Reduced greatly	Reduced slightly	No change	Increased slightly	Increased greatly
11. Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Guilt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Resignation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Optimism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Embarrassment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Fear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Vulnerability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Did you have any other emotions that were not listed above? Yes No

If yes, what?.....

For the next two questions, please circle the most appropriate answer

19. Are you glad to have an official diagnosis?

Not at all Somewhat Very much so

20. Did you feel that your emotional response to the test results meant that you had difficulty taking in other information the audiologist told you?

Not at all Somewhat Very much so

Thinking about your appointment with the audiologist, please tick the most appropriate response:

	Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree
21. In explaining the results to me the audiologist used language that I could understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. The audiologist discussed how my hearing loss would affect my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I found the amount of information the audiologist gave me overwhelming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. The audiologist allowed me to express my feelings regarding the diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tick here if not applicable <input type="checkbox"/>					
25. I felt I could ask questions when I wanted to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. The audiologist answered my questions clearly and completely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I felt the audiologist was supportive during the consultation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The audiologist was empathetic during the consultation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. The audiologist seemed condescending	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I felt I could trust the audiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. The audiologist dealt with the fears and concerns I had about my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. The audiologist seemed aloof, detached and / or irritable with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. The information provided was relevant to my situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree
34. The audiologist listened to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I was satisfied with the information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. The audiologist was patient with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. The audiologist seemed to understand my experience of hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I felt comfortable talking with my audiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. The audiologist went at a pace that was appropriate for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Insufficient time was given to explaining the results and implications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. The audiologist made me feel embarrassed about my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. The audiologist seemed to trivialise the issue of my hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I would recommend this audiologist to a friend in a similar situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I feel that I am better informed about how to cope with my hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any comments:

THANK YOU FOR YOUR HELP WITH THIS STUDY

Please bring this completed questionnaire to your interview

If you have any questions, contact Katrina Light on 0800 864 837 extn. 3342 or email

kjl81@student.canterbury.ac.nz

APPENDIX F
INTERVIEW SCHEDULE

THE UNIVERSITY OF CANTERBURY:
DEPARTMENT OF COMMUNICATION DISORDERS

INTERVIEW

ID:.....

Date:.....

Thinking about prior to your hearing appointment...

1. Did you feel you had a hearing loss? Yes No Perhaps

2. If yes, how severe did you feel the hearing loss was?
 Mild Moderate Severe Very severe

3. To what extent did your hearing loss cause problems?
 Not at all A little Moderately so Very much so

4. Where did most of these problems occur?.....

5. When were you first aware of your hearing loss?.....

6. Who made you aware of your hearing loss (if not yourself)?.....

7. Have other people commented on your hearing? Yes No Sort of

8. Is your hearing loss due to noise exposure?
 No Occupational Recreational Both Unsure

9. What proportion of your friends do you think have a hearing loss?
 None Some Approximately half Majority All

During the appointment

10. Which of the following emotions did you feel immediately after the audiologist told you your hearing test results:

	Yes / No	Has this emotion increased or decreased since then? Or has there been no change?
Shock		
Anger		
Sadness		
Anxiety		
Guilt		
Resignation		
Optimism		
Relief		
Sense of loss		
Embarrassment		
Surprise		
Fear		
Vulnerability		
Disbelief		
Hopelessness		
Apathy		

11. Is there anything the audiologist could have done better to improve how they:

Explained your results.....

.....
.....
.....

Explained the consequences of your hearing loss.....

.....
.....
.....

Explained how to communicate better or cope with the loss (i.e. listening tactics).....

.....

.....

.....

.....

12. Did they detail any non-hearing aid alternative options.....

.....

.....

.....

13. Did the audiologist ask you if you understood what he /she was saying before moving on to the next topic? Yes No Sometimes

14. Did you become distressed during the appointment? Yes No

Why was this?.....

.....

.....

How did the audiologist react to your distress?

.....

.....

Could the audiologist have done anything to improve his / her reaction?

.....

.....

.....

15. What degree of hearing loss did the audiologist say you had?

Mild Moderate Moderately-severe Severe Profound Don't know

16. Did you question the accuracy of the diagnosis? Yes No

If yes, why?.....

.....

17. Have you done any research yourself into hearing loss and/ or possible treatments? Yes No

.....

18. How did your significant other, ie. partner / wife, react to the news?.....

.....

.....

.....

19. Have you told any friends? Yes No
If yes, how many? A few Approximately half The majority

What was the most common reaction?.....

.....

If no, do you plan to tell them? Yes No Maybe

How do you think they would react?

.....

.....

.....

Other information

20. What led you to see an audiologist?

- a. You thought you had a hearing loss
- b. Your partner told you that you had a hearing loss
- c. Your family told you that you had a hearing loss
- d. Your friends or colleagues told you that you had a hearing loss
- e. You were required to for work
- f. You had pain or discomfort
- g. Other.....

21. Why did you choose this hearing clinic?.....

.....

.....

.....

22. What would have encouraged you to have had your hearing checked earlier?.....

.....

.....

.....

Future

23. Do you intend on getting a hearing aid? Yes No Undecided

If not, why not?.....
.....
.....
.....

If yes, why?.....
.....
.....
.....

24. Prior to the appointment had you decided that you would get a hearing aid if you had a hearing loss, or that you would not get a hearing aid regardless of the result, or were you undecided?
a. Decided would get an aid if needed
b. Decide would not get an aid
c. Undecided

25. Did the audiologist say anything to influence your decision? Yes No Partly
If yes, what?.....
.....
.....

Demographic information

Age: _____ (in years)

Gender: Male Female

Ethnicity:

NZ European Other European Maori Pacific Islander Asian

Other.....

Marital status: Unmarried married/co-habiting divorced widow/widower other

Employment status: fulltime part-time retired unemployed student

General health: poor satisfactory good very good

Approximate annual income: <\$40,000 \$40-60,000 \$60-80,000 \$80-100,000 \$100,000+

Finally....

Was your hearing test a screening test OR a full diagnostic assessment?

Have you applied for funding? No Yes If yes, ACC OR Enable

APPENDIX G

HEARING AID FITTED QUESTIONNAIRE

	Do not agree	Slightly agree	Moderately agree	Considerably agree	Extremely agree
12. The audiologist answered questions clearly and completely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The audiologist clearly described the process of follow-up appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The audiologist made it clear when I should return for a follow-up appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The audiologist clearly explained the pros of hearing aid use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. The audiologist clearly explained the cons of hearing aid use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. The audiologist seemed aloof, detached and/ or irritable with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I found the amount of information the audiologist gave me overwhelming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that the audiologist treated me as an individual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I am satisfied with the information I have about what kinds of improvements I can expect with my hearing aid(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I would go back to this audiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I would recommend this audiologist to a friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. Were you satisfied with the amount of information you received?

Yes No Somewhat

Comment.....

.....

24. Do you feel you have enough knowledge to use the hearing aids?

Yes No Somewhat

Comment.....
.....

25. Are you hesitant or unclear about any part of the whole process (i.e. hearing loss or hearing aid issues)? Yes No

If yes, what are you unclear about?.....
.....
.....
.....

26. Are there any improvements that you would like to see in the service that you received?

Yes No

If yes, what?.....
.....
.....
.....

27. Is there anything that you particularly appreciated in the service that you received?.....

.....
.....
.....
.....

28. Was there anything that you were expecting from the audiologist that did not occur?

Yes No

If yes, what?.....
.....
.....
.....

29. How satisfied are you so far with your new hearing aid(s)?

Very satisfied Satisfied Neutral Dissatisfied Very dissatisfied

Comment.....
.....

30. What would have lead you to get a hearing aid sooner?.....

.....
.....
.....

Any extra comments:

THANK YOU FOR YOUR HELP WITH THIS STUDY

All completed questionnaires will go in the draw to win a \$50 petrol voucher or 5 cards of batteries (30 batteries) of your size donated by ReSound, Starkey, Unitron and Widex.

If you have any questions, contact Katrina Light on 0800 864 837 extn. 3342 or email kjl81@student.canterbury.ac.nz

APPENDIX H
NON-HEARING AID FOLLOW-UP QUESTIONNAIRE

THE UNIVERSITY OF CANTERBURY:
DEPARTMENT OF COMMUNICATION DISORDERS

Non-Hearing Aid Follow-up Questionnaire

ID:.....(researcher to fill in)

Date:.....

1. You previously chose not to have a hearing aid fitted, have you changed your mind since then?

If so, why?.....
.....
.....
.....

.....Please answer Questions 18 - 28

2. If not, is it still for the same reasons that you originally chose not to have hearing aids?

Yes No

If no, what are your reasons now?.....
.....
.....
.....

3. What would need to change for you to consider getting a hearing aid or a pair of aids?

.....
.....
.....

4. When did you decide that hearing aids were not an option for you?
(please circle the appropriate answer)

- a. Before you had your hearing test
- b. During your hearing test appointment
- c. After your hearing test
- d. After the hearing aid(s) had been ordered
- e. During the hearing aid fitting appointment
- f. After your ACC application was declined

5. Did the audiologist say anything that influenced your decision? **Yes** **No**

If yes, what?.....
.....
.....
.....

6. How are you coping with your hearing loss? (please circle the appropriate answer)

- a. With no difficulty
- b. With some difficulty
- c. With quite a bit of difficulty

7. Do you use any assistive listening devices or other methods of assistance for listening?

Yes **No**

If yes, what?.....
.....
.....

8. Have you participated in any aural rehabilitation programs?

Yes **No**

If yes, what?.....
.....

.....
.....
Has this helped? Yes No

9. Have you adopted any new listening tactics?

Yes No

If yes, what?.....
.....
.....
.....

Has this helped? Yes No

10. Have you contacted or used any service(s) related to helping individuals with a hearing loss?

Yes No

If yes, what?.....
.....
.....
.....

Was this helpful? Yes No

11. Who have you told about your hearing loss? *(please circle all that apply)*

- a. Partner
- b. Close family
- c. Extended family
- d. Some of my friends
- e. Majority of my friends
- f. Boss / supervisor / employee
- g. Work colleagues

12. Do you generally tell people when communicating with them that you have a hearing loss?

Yes No Sometimes

Comment.....
.....

13. What do your partner, family and / or friends think about your decision not to get a hearing aid?

.....
.....
.....

14. Do you think your hearing levels have changed since your hearing test?

Yes No

If so, how have they changed? Improved Worsened

By how much? Slightly Moderate A lot

15. Do you plan to get regular hearing tests in the future?

Yes No Unsure

If yes, when do you expect you will go for your next hearing test?.....

16. Do you have any expectations regarding your hearing in the future?.....

.....
.....
.....

Please answer the following questions if you decided to get a hearing aid and have already had it fitted:

17. How long have you had them?.....

18. At which hearing clinic did you get them fitted?.....

19. Were you satisfied with the amount of information you received?

Yes No Somewhat

20. Do you feel you have enough knowledge to use the hearing aids?

Yes No Somewhat

21. Is there anything that you particularly appreciated in the service that you received?

.....
.....
.....
.....

22. Are there any improvements you would like to see in the service that you received?

.....
.....
.....
.....

23. Was there anything that you were expecting from the audiologist that did not occur?

Yes No

If yes, what?.....

.....
.....
.....

24. How satisfied are you so far with your new hearing aid(s)?

Very satisfied Satisfied Neutral Dissatisfied Very dissatisfied

25. What would have lead you to get a hearing aid sooner?.....

.....
.....
.....

26. If the clinic where you were fitted with your hearing aids was not the same clinic that you were first seen for your hearing test (when you joined the study), what were the main reasons for changing clinic?

.....
.....
.....
.....

Any extra comments:

THANK YOU FOR YOUR HELP WITH THIS STUDY

All completed questionnaires will go in the draw to win a \$50 petrol voucher or 5 cards of batteries (30 batteries) of your size donated by ReSound, Starkey, Unitron and Widex.

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APPENDIX I

QUALITATIVE COMMENTS FOR THE QUESTIONNAIRES AND INTERVIEWS

I. QUALITATIVE COMMENTS FOR THE QUESTIONNAIRES AND INTERVIEWS

I.1 Initial Questionnaire

I.1.1. Question 1: Were your results from the audiologist what you expected?

Confirms what I have been aware of for some time

I felt my hearing loss would be more and was pleased it was moderate - hearing aids will improve my hearing and my family won't have to keep turning the TV up for me and repeating themselves

I had no worries about my hearing, was looking to get musicians earplugs to protect my hearing, but know that at my age some hearing loss was likely

I knew I had a problem, but did not think it would be quite so bad

I knew I had hearing loss in my right ear but was not expecting such a considerable loss in the left ear as well. That was something of a shock

I knew that I had some hearing loss, but the loss of the higher frequencies surprised [me]

I thought I had a slight hearing loss. But it seems the loss was greater than I was prepared for

My hearing loss is apparently what is to be expected of someone my age

Wasn't sure what to expect but thought I may have a little hearing loss

I.2 Interview

I.2.1 Question 4: Where did most of these problems occur?

Comment	Coding
Amongst a group of people and had to turn TV louder	Groups, TV
At cards night (group situations)	Groups
At golf , with strangers, and the TV was too loud for others	Groups, TV
At home talking with husband	Conversation
At meetings, watching TV	Groups, TV
At social gatherings	Groups
Buzzer at work, films, social events, grandchildren	Groups, theatre, grandchildren
Classroom, meetings of 2+ people	Groups
Couldn't heard grandkids, and when travelling in the car	Grandchildren, car

Crowds, when not facing the speaker	Groups
Husband, TV, theatre, radio	Conversation, TV, theatre, radio
In background noise	Noise
In public	Groups
In the car - when there is background noise	Car, noise
Listening to radio, missed conversations especially the start of sentences and consonants	Radio
Needed TV louder and people complained, meetings and with groups of people	TV, groups
Talking to people, not so bad with strangers one-on-one	Conversation
Talking with others	Conversation
TV	TV
TV, from other room, own voice volume	TV
Watching TV - volume was okay, but couldn't understand them	TV
Watching TV with others, at meetings, when there are speakers	TV, groups
With 1 - 2 people or groups	Conversation
With family – in groups and with two other people	Groups
With family, at shops, TV is too loud according to family	Groups, TV, noise

I.2.2 Question 11A: Is there anything the audiologist could have done better to improve how they explained your results?

Suggested improvements:

What graph means

Explain fricatives

Opportunity to ask questions

Didn't explain how it could be helped. The audiologist was in a bit of a flap and running late and couldn't find the response button. Wasn't much of an explanation

No suggestion:

No, they were tremendous. They were better than expected

No, think they were wonderful

They were excellent

No - just a screening check

No - pleasantly surprised that I will be getting a report

No, she was excellent
No, very good man
No, thought she was very good
No, did it very well
No, he is good
No, he was excellent
No, the lady was very very good
No, they were very good
Not really - he did a very good job
They did it well

I.2.3 Question 18: How did your significant other react to the news?

Told you so
We knew that - weren't surprised
Accepting
Accepting of it
Agreed, glad mum went
Children said "yah" and husband didn't say much
Confirmed what they had been telling me for a while - agreed with the results
Friend she went with was not surprised cause she herself had gone earlier and gotten musicians earplugs
Haven't told children yet and husband dead
He just accepted it "Told you so"
It was good news and glad that he was doing something about it
Laughed and identified with her
Not bothered
Not overly surprised
Overjoyed
Pleased
Pleased that she had gone
Reacted very well; it was a welcomed thing that we had gone to get it tested
She expected it and so it was no great shock
She just grinned
Son and daughter were matter-of-fact
Son said "I knew you should have gone ages ago"
They expected that result

They laughed

Weren't surprised

Wife was more sad about the news than me. I tried to explain that it was aging

I.2.4 Question 19: Have you told any friends? If yes, what was the most common reaction?

That's right - not surprised

Acceptance

Agreed with the hearing test result. Accepting of it

Didn't take a lot of notice - just laughed

Expecting it

Had realised that she doesn't hear as well

They are in a similar situation

Matter-of-fact

Most don't show interest

Not overly surprised

Nothing - he believed it

Pleased for me

Quite overjoyed cause have to shout at him

Supportive

Supportive, understanding

Took it as a matter-of-fact

Weren't surprised

If you have not told your friends but plan to tell them, how do you think they would react?

Say "normal farmer"

Accept it

Accepting of it

Doesn't see need to cause got 100% on speech test

Don't think that it'll be a problem

Humour

Probably say that I don't need them

Take it in their stride

Think they will be quite supportive - have talked about it when others have got HAs

I.2.5 Question 21: Why did you choose this hearing clinic?

Comment	Coding
Don't know. Maybe put off by experience of a friend who went to another audiologist	Don't know
Advertising	Advert
Because thought they would possibly be superior to other clinics who could be biased by commercial reasons and they teach the audiologists	University clinic
Convenient, TV advert	Advert
Doctor referred him for a free examination	Doctor referral
Don't know	Don't know
Friend's recommendation, suspicious of commercial	Friend's recommendation
Friend recommended it	Friend's recommendation
GP recommended	Doctor referral
GP recommended it	Doctor referral
GP suggested to go there	Doctor referral
Husband goes there too	Family member
Husband had been there	Family member
Location	Location
Husband had been there	Family member
Location	Location
Location and been here before	Location
Mail drop for a free hearing test for you and a friend	Advert
Nearest to where he lives	Location
Nearest to where I live and another friend recommended it	Location
On hospital waiting list	University clinic
Recommended by a friend	Friend's recommendation
Referred there by a visiting audiology clinic	Location
Sister goes there	Family member
TV advert	Advert
Was advertised in the newspaper	Advert
Was free	Advert

I.2.6 Question 22: What would have encouraged you to have your hearing checked earlier?

Comment	Coding
Absolutely nothing	Nothing
Can't think of anything	Don't know
Don't know	Don't know
Any earlier deterioration	Worse HL
Did have hearing checked earlier - 6-7yrs ago	N/A
Didn't think it was necessary, only gotten worse this year	Worse HL
Don't know	Don't know
Don't know	Don't know
Don't know if would have bothered. Probably would've left it	Nothing
Hearing been worse	Worse HL
Hearing being worse	Worse HL
If had had a scare at any point - not been an issue of danger	Medical reasons
If hearing was worse	Worse HL
If more people had said something about it	Others commented
If other people had encouraged her to go	Others commented
If worse than is - more substantial hearing loss. If had more of a need / difficulty	Worse HL
If it had become more embarrassing	Others commented
Maybe if there had been a sign in the doctor's waiting room recommending hearing tests for > 50 year olds	Medical reasons
Not thought too much about it	Don't know
Nothing	Nothing
Nothing	Nothing
Nothing, besides wife's complaining	Nothing
Pain had occurred earlier	Medical reasons
Probably nothing cause just noticed it and mentioned it at my regular GP check	Nothing
Probably wouldn't have bothered	Nothing
Tried to go 8 months earlier but had to cancel the appointment and they said they would ring me to book another appointment and they have never rung	N/A

Was coping with it but when other people started noticing it, I thought I should go	Others commented
---	------------------

I.2.7 Question 23: Do you intend on getting a hearing aid? If yes, why?

Comment	Coding
Audiologist recommended it and a fear of losing more hearing	Audiologist recommended
Because hate missing out on conversations around me	Hear conversations
Because I need one and often thought about it	Generally hear better
Can participate in conversations and group activities	Hear conversations
Cope better	Generally hear better
For group situations - at the pub and meetings, and watching TV so people don't growl	Conversation, TV
For teaching and lifestyle (so don't have to have TV loud and not need headphones). To be able to hear at the theatre beyond front 2 rows	TV, Generally hear better
Hear what grandchildren and customers are saying. Don't want to have difficulties like my husband who has a profound hearing loss and can't get the hearing aids fitted well	Grandchildren, work
Help hear things better, ie. conversations, music	Generally hear better
If financially in my grasp. So can hear better and save embarrassment of asking people to repeat themselves	Avoid asking for repeats
Need to hear what people are saying and what is going on	Hear conversations
Partly for own benefit and for people that I mix with - to avoid asking for repetition	Avoid asking for repeats
So can hear conversations	Hear conversations
So can hear speech better	Hear conversations
So don't have to ask for things to be repeated and can hear at meetings	Avoid repeats, work
To be able to follow conversations in a group	Hear conversations
To hear grandchildren and hear in the car and in a crowd	Grandchildren, conversation
To hear people speaking better, but depends on cost	Hear conversations
Want to hear better	Generally hear better

I.2.8 Question 23: Do you intend on getting a hearing aid? If no, why?

Comment	Coding
95% of situations I don't have any difficulty	Don't feel need it
Cause still got a good ear	Don't feel need it
Cost	Cost
Hear of people that keep them in the drawer and I don't think my hearing is bad enough	Don't feel need it
Not really needed cause did okay on speech test. If needed, I may hesitate cause of appearance issues	Don't feel need it
Not until exostoses removed and financial issue	Cost
Not vanity, just don't feel like need it at the moment	Don't feel need it
Understands everything	Don't feel need it

I.3 HA Follow-up Questionnaire

I.3.1 Question 23: Were you satisfied with the amount of information you received?

Felt the information was clear but it was different when I was coping by myself
 Was assured of help if required
 Yes, but the audiologist is a very good friend to my second daughter and such a lovely girl

I.3.2 Question 24: Do you feel you have enough knowledge to use the hearing aids?

As long as I can actually master getting them in my ears
 Had enough knowledge and was shown how to use the aids - and followed the instructions myself
 I feel I need a little time to become familiar and used to the slight discomfort
 I guess so, it's early days yet
 I suppose I'll come to grips with it all - if other people can, I can
 I was well taught on how to use my hearing aid

I.3.3 Question 27: Is there anything that you particularly appreciated in the service that you received?

Genuine, friendly and relaxed time with audiologist. An interesting experience

On having the test and the result of the hearing loss I felt there was help to overcome that loss. At the moment I am pleased I have proceeded with having hearing aids

That the audiologist comes to Gore now, closer to home

The audiologist who fitted and tested hearing aids was very clear and helpful. Showed me and explained how they work and how to look after them

The closeness and the camaraderie

Yes. Receiving my hearing aids

I.3.4 Question 29: How satisfied are you so far with your new hearing aid(s)?

I am a little slow at inserting the aids due I think to my arthritic hands

I can hear extremely well now

Ok

Still getting used to them but they are very comfortable, I don't know they are there

Too early to tell

Yes they improve TV listening and people speaking, just a case of getting used to them

I.3.5 Question 30: What would have led you to get a hearing aid sooner?

Don't know. Felt it was the right time

I can't answer this question. I feel I am young enough to be wearing them even though the very young can wear them

It's having to deal with the realisation that you actually need hearing aids

Nothing, felt able to hear most things but a sister who has hearing aids took me along for a free hearing test - and now I have hearing aids

Some hesitation at actually making the initial appointment

I.4 Non-HA Follow-up Questionnaire

I.4.1 Question 3: What would need to change for you to reconsider getting a hearing aid or pair of aids?

At present, I do not have difficulty hearing

Hearing deteriorate
Hearing deteriorate considerably
Hearing loss sufficient to impair communication
More hearing loss
My hearing to deteriorate severely
My hearing would have to deteriorate much more
Removal of exostoses, finances, problems from hearing loss

I.4.2 Question 13: What do your partner, family and/or friends think about your decision not to get a hearing aid?

Accept it. Most of my friends don't believe I have a hearing loss because I don't usually have a problem talking with them
Accept my decision
Agree
I think they understand my situation
Not concerned
Not sure. They didn't know whether I need a hearing aid or not
Supportive
That it is my decision
They've not made any comment

I.4.3 Question 16: Do you have any expectations regarding your hearing in the future?

I expect it will get worse gradually
I expect it will worsen as I have two older brothers who use aids (late 70s) and my father struggled with one in his 80s!
I hope that with hearing aids I will be able to communicate more readily - and enjoy music more
I would like to see a specialist to get more information
Needs watching. Not likely to get better, and I'm not getting younger
None
Probably worsen with age but will keep "problem" under review
Will eventually get worse
Will use hearing aids in the future