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"I just wasnae me anymore": Individual Experiences of  
Identity Loss, Identity Negotiation, Acceptance and  
'Adjustment' in Acquired Hearing Loss

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## Abstract

**Objectives:** There appears to be growing evidence that living with acquired hearing loss (AHL) results in people experiencing increased psychological distress. However, there is currently a dearth of research examining psychological adjustment to AHL. The available models assume that psychological adjustment to AHL is a sequential process. Personal accounts of AHL and evidence regarding other disabilities suggest that psychological adjustment is a far more complex process. Consequently, the present study aimed to explore individuals' experience of the process of psychological adjustment to AHL. In addition, individuals' understandings of the concept of adjustment were also explored.

**Method:** Ten semi-structured interviews were conducted with individuals who had acquired a moderate, severe or profound hearing loss in adulthood. These were transcribed and analysed for recurrent themes using Interpretative Phenomenological Analysis.

**Results:** Data analysis revealed that 9 super-ordinate themes represented participants' experience of adjustment to AHL. Findings indicated that AHL resulted in participants experiencing identity loss and changes in the dynamics of their relationships. Participants suggested that acceptance was a difficult but vital process that reduced psychological distress. Acceptance was hypothesised to be a multi-dimensional continuum along which participants moved back and forth. Identity negotiation appeared to be an important psychological process associated with acceptance. Participants believed that there was a "right" way to "adjust" but none felt their experiences matched this ideal. Consequently, it appeared that there was a discrepancy in the way participants and the researcher understood the concept of "adjustment."

**Discussion:** The findings suggested that psychological "adjustment" to AHL was a complex dual-directional process. Participant narratives appeared to be consistent with the recurrent model of acceptance and adjustment proposed by Newsome and Kendall (1996). It was suggested that findings regarding participants' perceptions of "adjustment" had important implications for clinical practice and these were described. It was recommended that future qualitative research should attempt to explore individuals' assumptions regarding "adjustment" in more detail.

## 1. Introduction

The following chapter presents information on the prevalence, measurement, causes and types of hearing impairment. The chapter then discusses the available literature regarding acquired hearing loss and presents two models of psychological adjustment. Current literature regarding adjustment to life events, chronic illnesses and disabilities is also considered. Finally, the aims of the present study are illustrated and discussed.

### 1.1 Prevalence of hearing impairment

Current estimates suggest that hearing impairment affects approximately 9 million people in the UK (RNID, 2008). Between 50 and 70 thousand of these individuals were born profoundly deaf, while the majority (around 8.3 million) acquired their hearing impairment sometime after the age of 16 (Davis, 1995).

As depicted in Table 1, the prevalence of hearing loss increases dramatically with age. Estimates suggest approximately 47% of people aged 61-80 have some level of hearing impairment. However, approximately 2.3 million people in the UK acquired a hearing loss between the ages of 16 and 60 (RNID, 2008).

**Table 1:** Estimated percentages of the UK population who have each level of hearing impairment across the adult age range (RNID, 2008).

Level of hearing impairment	Age 16 - 60	Age 61-80	Age 81 -
Mild	4.6	28.1	18.4
Moderate	1.6	16.5	57.9
Severe	0.2	1.9	13.2
Profound	0.1	0.4	3.6
All levels	6.6	46.9	93.2

## 1.2 Measuring hearing impairment

Hearing sensitivity is measured by finding the quietest sound that an individual can detect.

An audiologist records the quietest sound, across different frequencies, that prompts a response from the listener and this level is called their hearing threshold. Hearing thresholds are measured in decibels (dBHL). A threshold between 0 and 20 dBHL, across all frequencies, is considered to be “normal hearing.” The greater the hearing threshold or larger the number of dBHLs, the more severe the hearing impairment. Hearing impairment is categorised as mild, moderate, severe or profound (Katz, 2001).

**Table 2:** Categories of hearing impairment with corresponding hearing threshold (in dBHL) and definition (RNID, 2008).

Category of hearing impairment	dBHL	Definition
Mild	25-39	Some difficulty in following speech, mainly in noisy situations. Hearing aids may not always be beneficial.
Moderate	40-69	Difficultly following speech without a hearing aid.
Severe	70-94	Severe difficulty following speech even with a hearing aid.
Profound	95 or more	Hearing aid of limited benefit for distinguishing speech. Heavy reliance on lip reading. British Sign Language may be first or preferred language.

Hearing impairments are hard to describe accurately and descriptions in terms of decibels are meaningless unless the frequencies that the loss affects are indicated (Woodcock and Aguayo, 2000). Some people have an equal decibel hearing impairment across all frequencies, while others have a different loss at each different frequency. For the majority of people, the most important factor is the amount of hearing impairment within the frequencies for speech. It is therefore perhaps more useful to describe a hearing impairment in terms of a person’s ability to hear speech (Woodcock and Aguayo, 2000).

### **1.3 Causes of hearing impairment**

There are many possible causes of hearing impairment. These can be divided into two basic types; conductive and sensorineural hearing losses. Conductive hearing loss is caused by anything that interferes with the transmission of sound from the outer to the inner ear.

Prognosis is often good as conductive hearing loss is often caused by conditions that can be treated (Katz, 2001). Sensorineural hearing loss is due to damage in the pathway that sound impulses take from the hair cells of the inner ear to the auditory nerve and brain. The prognosis for sensorineural impairment is generally poor and often no treatment is offered (Woodcock and Aguayo, 2000). Mixed hearing losses include some conductive and some sensorineural impairment. Impairment can occur on one side (unilateral) or on both (bilateral) (Katz, 2001). Table 3 outlines the possible causes for both types of hearing impairment.

Hearing impairments can be present at birth or have a sudden (with an acute or rapid onset), or progressive (gradually becomes increasingly worse over time) onset at any stage in life. They can also be stable or fluctuate in severity over time (WHO, 2006).

### **1.4 Pre-lingual and post-lingual hearing impairments**

Hearing impairments are often categorised according to age of onset. Those who were born with or develop a profound hearing impairment before they acquire language are frequently referred to as being pre-lingually or congenitally deaf (Luey, 1980). Pre-lingual deafness has major developmental consequences in terms of language acquisition, information processing, reading and writing skills and assimilation into mainstream culture (Rutman, 1989). People who are pre-lingually deaf may attend specialist deaf schools (Stewart-Kerr, 1992).

**Table 3:** Type of hearing impairment and associated possible causes (WHO, 2006).

Type of hearing impairment	Possible cause
Conductive	Infections in the middle ear
	Collection of fluid in the middle ear e.g. glue ear
	Blockage of the outer ear, most commonly with wax
	Otosclerosis (a condition in which the ossicles of the middle ear harden and become less mobile)
	Damage to the ossicles through infection or head injury
	Perforated eardrum caused by infection, head injury or blow to the ear
Sensorineural	Age-related hearing loss, partly caused by loss of hair cells in the cochlea
	Acoustic trauma caused by loud noise which damages the hair cells
	Viral or bacterial infections e.g. mumps or meningitis, leading to loss of hair cells or other damage to the auditory nerve
	Ménière's disease
	Use of ototoxic drugs, including some antibiotic and anti-malarial drugs, can cause damage to the cochlea
	Acoustic neuroma, a benign tumour affecting the auditory nerve
	Neurological conditions such as multiple sclerosis, stroke, or a brain tumour.
	Inheriting either a dominant or recessive gene for deafness
	Before or during birth e.g. premature birth, mother contracts certain infections during pregnancy, or complications during birth
	Physical trauma e.g. head injury or injury to the ear

Within pre-lingual deafness there are two broad groups, these are denoted by either using a lower or upper case letter d. People who are deaf generally regard their deafness as a disability and are more likely to use spoken language and lip-reading as their primary method of communication (Laszlo, 1994). Conversely, people who wish to be known as Deaf regard their deafness as a difference and a cultural choice (Austen and Coleman, 2004). People who are Deaf tend to communicate through sign language and view themselves as part of a cultural and linguistic minority. Being Deaf is therefore very much part of the person's self-image and identity (Rutman, 1989). For those included, the Deaf community is thought to provide a sense of belonging and social support (Austen and Coleman, 2004).

People who acquire a hearing loss after they develop language are referred to as post-lingually deaf. There are a number of terms used to describe people with an acquired hearing loss (AHL). ‘Hard of hearing’, refers to someone with any degree of hearing loss. However, in practice the term is frequently used to describe someone who has a mild-to-moderate loss and no significant problems with communication (this may be with the help of a hearing aid). Deafened or adventitiously deaf refers to people who acquire a severe or profound hearing loss in adulthood (David and Trehub, 1989).

The majority of people within the post-lingual group acquire their hearing impairment in adulthood and have consequently grown up as a hearing person with mainstream society (Hallam, 2008). People with AHL generally communicate through spoken language and may use lip-reading and hearing aids. Most individuals with AHL do not understand sign language. For example, Kyle and Wood (1983) reported that 98% of informants with AHL did not wish to attend sign language classes.

The majority of people with AHL continue to live and work within their already established hearing social networks, attempt to preserve their “normal hearing identity” and to function at parity with the hearing majority (Hallam et al, 2008).

Weisel and Reichstein (1990) asked a sample of 92 people with pre- and post-lingual hearing impairments, “if it were possible to cure hearing impairment with an operation, to whom would you recommend such an operation?” They found that the Deaf group tended to reject the operation for themselves and for other groups of deaf people. However, the people with

AHL overwhelmingly favoured the operation for themselves and for others. These responses highlighted the differences in the way each group thought and felt about deafness. Weisel and Reichstein (1990) proposed that these differences indicated that the Deaf people demonstrated greater adjustment and acceptance of their hearing impairment than those with AHL.

As discussed above, pre-lingual and post-lingual individuals constitute two distinct groups with very different life experiences and needs. While most pre-lingually deaf people have never experienced hearing, AHL represents a major change and loss in a person's life (Rutman, 1989). In terms of research into the impact of hearing impairment, it is therefore necessary to consider pre- and post-lingual deafness as two discrete groups.

Although the number of people with AHL is much larger than the Deaf population, it seems that this smaller population has received greater interest from researchers and the general public (in terms of social awareness) than those with AHL (Laszlo, 1994). It is unclear precisely why this has been the case but Laszlo (1994) suggested that perhaps the differences in language and culture make Deaf people a more visible and attractive group to study. As AHL has received less consideration, the present study will focus on people within this group.

## **1.5 Age of onset in acquired hearing loss**

The population of people with AHL is heterogeneous. For example, there are often profound differences between people who lose their hearing in young and middle adulthood and those who have age-related hearing loss or presbycusis (David and Trehub, 1989). Given its prevalence, AHL is a major concern for many older adults (Gomez and Madey, 2001). Consequently, there has been increasing interest into research aimed specifically at investigating age-related hearing loss (Heine and Browning, 2004). Research has focused on understanding the impact of age-related hearing loss and how older adults cope. For example, research has found that age-related hearing loss has a significant impact on quality of life and is associated with increased rates of depression and anxiety (Capella-McDonnall, 2005; Lupsakko et al, 2002). It has also been shown to have important affects on interpersonal functioning including increased social isolation, decreased socialisation and changes in personal roles and family dynamics (Donaldson et al, 2004; Heine and Browning, 2002; Smith, 1997). In comparison, AHL in young and middle aged adults has been largely neglected and as a consequence the present study will concentrate on this group.

## **1.6 The impact of acquired hearing loss**

The literature regarding AHL can be divided into two sections. One part includes formal systematic research and the other is associated with informal personal accounts written by people with AHL and professionals working with them (Stewart-Kerr, 1992). The majority of systematic research has concentrated on two main issues. One aim has been to establish the impact of AHL on people's lives by means of quantitative measurements of mental health difficulties (Hallam et al, 2006; Thomas, 1984). The second issue addressed is the effect of AHL on individual's communication, interpersonal relationships and employment (Aguayo and Coady, 2001; Jones et al, 1987; Kyle and Wood, 1983).

The informal accounts contain a wealth of information about the experience of living with AHL and give valuable insights into the day-to-day issues individuals face (Ashley, 1985; Savil, 1988; Wooley, 1987). Accounts from professionals working with this client group generally draw on clinical experiences and reference the autobiographical accounts of those with AHL. The majority of professional accounts provide brief reviews of the available literature and give some recommendations regarding how a particular professional group should work with people with AHL (Luey, 1980; Rutman and Boisseau, 1995).

Overall, the two literatures are compatible rather than contradictory and generally agree upon the challenges faced by people with AHL (Rutman and Boisseau, 1995). Consequently, the evidence from both literatures can be easily combined. The main themes highlighted by both literatures will be discussed below. While word constraints prevent this discussion from being a systematic or comprehensive review of the literature, it aims to provide an overview of the main themes associated with AHL. Additional literature will be discussed within the context of the present study's results.

### **1.6.1 Communication**

The most fundamental effect of AHL is on an individual's ability to communicate.

As Stone argues; "hearing impairment strikes at the very essence of being human because it hinders communication with others," (Stone, 1987, p.116). Even with the use of hearing aids and lip reading, people with AHL may struggle to participate in any meaningful conversation (Rutman and Boisseau, 1995). Consequently, individuals may frequently misunderstand, misinterpret and constantly have to ask for information to be repeated. Personal accounts

indicate that such situations frequently result in feelings of embarrassment, frustration and inadequacy (Ashely, 1985; Wood, 1987). Communication therefore becomes labour intensive and anxiety-provoking.

For many people with AHL “socialising becomes an ordeal,” (Orlans, 1987, p.100) and therefore social isolation may emerge as a principle problem (Stevens, 1982). Participants in Aguayo and Coady’s (2001) interview-based study described feeling neglected, shunned or discriminated against by others. In addition, many learned to conceal their deafness from others or to ‘bluff’ understandings of verbal dialogue. In an effort to cope, all respondents used strategies of social withdrawal or selective avoidance of anxiety-provoking situations where communication would be required. Feeling unable to participate in communication may leave an individual feeling cut off from a once familiar world (Rutman and Boisseau, 1995). The consequences of difficulties with communication have far-reaching consequences and have been shown to affect all aspects of a person’s psychosocial world (Woodcock and Aguayo, 2000).

### **1.6.2 Interpersonal relationships**

Impediments to convenient conversation caused by AHL often result in damage to relationships (Jones et al, 1987). For example, Hogan (2001) reported that 18 out of 38 participants reported a break-up of a significant relationship after the onset of AHL.

Furthermore, a grounded theory study of people with AHL and one of their significant others found evidence of interpersonal stress in at least half of their sample (Hallam et al, 2008).

AHL has been found to alter the structure and quality of interpersonal relationships in subtle and complex ways (Jones et al, 1987). Hallam and colleagues (2005) discovered that roles

within relationships frequently change. For example, among their sample hearing partners took on additional responsibilities such as acting as an interpreter, while the person with AHL became increasingly dependent. Difficulties with communication also led to reduced intimacy and poorer conflict resolution.

It seems that communication difficulties often result in social isolation, avoidance of social situations and have a negative impact on people's close relationships. These are important findings, as perceived social support is a significant protective factor for psychological distress (Brown and Harris, 1978). Furthermore, for many people seeking emotional and practical social support is a primary method of coping with crisis. It appears that for many people, AHL makes it difficult for individuals to use such strategies and therefore may make coping much more complex (Champion and Goodall, 1994).

### **1.6.3 Employment**

The majority of research regarding employment indicates that people with AHL are no more likely to be unemployed than hearing people (Kyle and Wood, 1983; Jones et al, 1987).

However, Hallam and colleagues (2005) found that 9 of their 24 respondents with profound AHL had to give up work and 2 took early retirement as a direct result of their hearing loss.

Similar results have been found by other small sample studies and it therefore appears that participation in employment varies according to the level of AHL (Thomas et al, 1982).

Evidence suggests that AHL has repercussions for the quality of people's working life and may affect prospects for career progression (Kyle and Wood, 1985). However, Stewart-Kerr

(1992) found that despite experiencing work-related difficulties respondents felt it was important for people with AHL to work and highlighted positive aspects of employment such as social contact.

#### **1.6.4 Psychological issues**

Personal accounts suggest that the experience of AHL results in the powerful negative emotions of loss, grief, anger and fear (Ashley, 1985; Cooke, 1984). Ashley explains:

“...I was painfully and permanently aware of what I had lost. My perception of that loss is a lifelong burden,” (Ashley, 1985, p.61).

Feeling unable to function and participate in society, as they did prior to AHL, seems to contribute to the development of feelings of stigmatisation and worthlessness and affects self-efficacy, self-esteem and self-identity (Rutman and Boisseau, 1995). It therefore seems that AHL has profound psychological consequences. Unfortunately formal research has merely focused on demonstrating that the prevalence of mental health problems is higher in individuals with AHL than in the general population.

##### **1.6.4.1 Increased prevalence of mental health problems**

A number of studies suggest that AHL is related to an increase in levels of emotional distress (Sherbourne et al, 2002, Thomas, 1984, Thomas and Gilholme-Herbst, 1980). For example, Hallam and colleagues (2006) found the rate of clinically significant depression was 4.8 times

greater in a sample of people with profound AHL than in the general population. Results of the same study indicated that 14% of the sample achieved scores indicating they were experiencing post-traumatic stress disorder as measured by the Los Angeles Symptom Checklist. De Graaf and Bijl (2002) interviewed 523 people with pre- and post-lingual deafness and found women who were post-lingually deaf were more likely than pre-lingually deaf women, to report mental distress. In addition, results within the post-lingually deaf group, suggested those with a progressive hearing loss experienced higher levels of depression and anxiety than those with a sudden loss. Across the whole sample, low self-esteem and poor acceptance of one's hearing loss emerged as important predictors of mental distress. Hallam and colleagues (2007) found distress associated with profound AHL was related to the use of avoidance as a coping strategy and a tendency to engage in self-blame and wishful thinking.

Overall, research indicates that the prevalence of mental health related difficulties is higher in individuals with AHL than in the general population. However, despite indications from personal accounts, there is very little research that investigates why psychological distress is so common and what the psychological processes behind this distress are.

### **1.6.5 Limitations of AHL literature**

Literature on the impact of AHL indicates that it fundamentally affects the way in which an individual interacts with the world and those in it. However, Rutman argues:

“Given the large percentage of all hearing impairment, the paucity of well-controlled research on acquired deafness is appalling...relatively little theorising has been published on the reasons why deafened people are likely to suffer from psychosocial problems; moreover, the “empirical” research is fraught with methodological weaknesses and is dominated by autobiographical reports, case studies and investigators’ clinical impressions,” (Rutman, 1989, p.306).

Although there have been a number of more recent empirical studies, Rutman’s comments can still be applied to the majority of AHL literature. Even though personal and professional accounts give valuable information they often cannot be generalised. Those who write personal accounts seem to have managed to cope with and adjust to AHL and their experiences may therefore not be representative of the AHL population (Rutman and Boisseau, 1995). Finally, much of the literature dates from before the availability of digital hearing aids and cochlear implants and may therefore be somewhat outdated.

### **1.7 Models of adjustment to acquired hearing loss**

The majority of the literature focuses on the consequences of AHL and demonstrates that it has a significant impact on all areas of an individual’s life (Woodcock and Ayuagyo, 2000). As AHL represents a profound change, it is also valuable to explore how people adjust to it.

In terms of hearing loss, adjustment can be described as how an individual changes (in terms of behaviour, beliefs, relations or interactions) over time in response to AHL (Jones et al, 1987).

Although people with AHL are faced with the challenge of adjustment, there is a paucity of research in this area (Schlau, 2004). However, two models that do consider adjustment to AHL will be discussed below.

### 1.7.1 The five stage model of grief

Kübler-Ross (1969) described a five stage model of the process by which people deal with grief and tragedy. She proposed that this model could be applied to any form of catastrophic personal loss. Consequently, the model has been applied to deafness by a number of authors (Woodcock and Aguayo, 2000). Luey (1980) suggests that at some point a deafened person undergoes a crisis and experiences all the stages of adjustment outlined in Kübler-Ross' model. Luey's adapted five stage model is presented in Table 4.

**Table 4:** The five stage model of grief. Adapted from Kübler-Ross (1969)

Stage	Key thoughts
Denial	This can't be happening
Anger	Why me? It's not fair
Bargaining	I'll do anything, just let me hear a bit
Depression	What's the point? Why bother with anything?
Acceptance	I am deaf and I will try to learn how to cope with it

Luey (1980) proposes an individual in the stage of denial may refute their diagnosis or be constantly searching for a miracle cure. Individuals within this stage may refuse to learn skills such as lip reading and may not wish to associate with other deafened people. Within the next stage, a person's anger may be directed at services for failing to restore their hearing or not providing appropriate services. Anger can also be focused at society for treating deafened people unfairly or at individuals for being poor communicators. Luey (1980) explains "bargaining" may be expressed directly, "If only my ears hurt. I'd gladly stand the pain, if I could just have my hearing back," (p.260) or more indirectly, by hoping that obtaining certain equipment or practising certain behaviours will make their distress go away. She suggests the stage of depression can result from the consequences of communication breakdown and interferes with an individual's ability to try to learn new skills.

In the final stage, "After a person acknowledges his loss as reality and experiences all of the feelings the loss inspires, he is able to adapt constructively to his deafness," (Luey, 1980, p.261). Kübler-Ross (1969) proposed that the stages did not necessarily have to be experienced in a specific order, or that an individual had to experience them all. However, Luey (1980) seems to propose that all stages are experienced by every individual in this particular order. Furthermore, as with much of the literature regarding AHL, Luey (1980) bases her model on a limited number of personal accounts of AHL and her own professional experience.

One of the difficulties with multi-stage models is the presumption that stages represent the "right" way to adjust and that any deviation represents maladjustment (Woodcock and

Aguayo, 2000). However, given the heterogeneity in terms of types and rates of loss, the variety of different life circumstances and individual characteristics of people with AHL, it is unlikely that any one model could capture the process of acceptance and adjustment for all individuals.

### 1.7.2 Model of deafened adjustment

Woodcock and Aguayo (2000) acknowledge that it is inappropriate to apply one model rigidly to everyone but state that stage models provide professionals with a framework for making suggestions when “adjustment seems to be faltering.” Although they indicate that grief models may be useful, they suggest that AHL may also be experienced as a threat to self-identity. Consequently, they attempt to unify grief-based models with concepts of identity transition and propose a model of adjustment to deafness. The stages of Woodcock and Aguayo’s model are outlined in Table 5 and described below.

**Table 5:** Model of deafened adjustment proposed by Woodcock and Aguayo (2000, p.47)

Stage	Key thoughts
Identity confusion	What is going on?
Identity comparison	Am I deaf?
Identity concession	I am deaf, technically
Identity recognition	I am deaf
Deaf activism	I am deaf, dammit!
Depression	I can't change the world
Identity synthesis	Acceptance

The first stage of the model is identity confusion. This stage occurs around the time of onset of AHL and involves the person being unsure about the cause and permanence of the loss. During this stage an individual may deny they have an AHL or, particularly with sudden onset, be in shock and unable to process their diagnosis.

During identity comparison a person begins to recognise that other deaf people exist but feels as if they do not identify with those who are pre-lingually deaf. This often leads to a sense of isolation and feelings of anger. During this stage people may search for explanations for their deafness and seek medical cures.

Identity concession involves an individual recognising that their deafness is incontestable. However, during this stage individuals still have some uncertainty about their identity. They may take steps to acquire specialist equipment (e.g. flashing door bells) or access services but wish to maintain their hearing identity and feel they are “not really deaf.”

In the identity recognition stage the person internalises the identity of being deaf and re-orientates their core identity. They are no longer a hearing person who cannot hear but a deaf person. Although an individual may still identify with hearing people they may learn lip reading and socialise with other deaf people.

Deaf activism is an intensification of the consciousness developed in the identity recognition stage and deafness becomes central to identity. Activism enables a person to transfer the

responsibility for difficulties from themselves to an inaccessible society and working on campaigns enhances feelings of control and validation. Despite some benefits, activism carries the risk of complete rejection of a previous hearing identity and allowing deafness to supersede all other priorities.

Although there can be depression throughout the other stages, the depression stage could be conceived as a marker of true acceptance. During this stage an individual realises they cannot change the world or their hearing loss.

In the final stage of identity synthesis deafness has become part of an individual's core identity but is no longer a central concern. The deafness takes its place within the whole person, which also accommodates family, meaningful activity and other interests (Woodcock and Aguayo, 2000).

Woodcock and Aguayo (2000) propose that an individual may find complete satisfaction at any level of the model. Furthermore, people do not necessarily have to experience every stage and may drift back and forth between stages.

Although Woodcock and Aguayo (2000) give full descriptions of the possible cognitions, emotions and behaviours associated with each stage of the model, little information is given regarding how individuals negotiate and achieve transitions between stages. As the model was developed to give professionals a framework for making suggestions when "adjustment

seems to be faltering” the lack of this type of information seems problematic. Furthermore, as in the previous model, Woodcock and Aguayo appeared to have based their model on a limited amount of formal research and seemed to have relied heavily on personal accounts and their own experiences as deafened professionals.

It seems that what is missing from the stage models is information regarding why individuals move between stages, what prompts stage transitions and how individuals experience the process of transition. Information regarding what helps and hinders people in achieving adjustment would be useful to professionals working with AHL.

In addition, Hallam and colleagues have argued that “a focus on individual adjustment also neglects to consider how the family of the affected person fits into this developmental picture,” (Hallam et al, 2008, p.36).

### **1.7.3 Grounded theory study of adjustment**

Schlau (2004) conducted a grounded theory study of the process of adjustment in AHL. Data was obtained from 24 participants via interviews and email surveys. Schlau found that for all her participants, the process of adjustment began with strong emotional reactions but that the later stages varied according to individual characteristics. She proposed that AHL represented a change in reality and in order to successfully adjust, a person must construct a second “deaf” reality. Participants were grouped into three categories, along a continuum of adjustment, ranging from “struggling” with, “resigned to” or “accepting” their deafness. Schlau indicated that approximately one third of her sample achieved “acceptance.” She

explained that these individuals had achieved acceptance through a process of “double-loop learning” (examining aspects of their lives and internalising changes that were needed), knowing and interacting with deaf people and giving up their hearing selves to become truly deaf. Participants that were “struggling” were on Disability Allowance, did not have deaf friends and were not prone to use “true reflection.” People in the “resigned” category had often sought specialist equipment and services but had not managed to reflect and internalise changes in their identity.

Schlau (2004) proposes that adjustment to acquired deafness does occur in stages but states that individuals do not “just pass through one stage to the next.” Instead, she argues people must learn, grow and make changes to achieve acceptance and adjustment.

While Schlau’s study provides some valuable information regarding individual’s experience of adjusting to AHL, the final grounded theory seems to indicate that there is a “correct” way to achieve acceptance and adjustment. For example, Hallam and colleagues argue:

“her view that it is desirable for the person concerned to accept a new identity as a deafened person who goes through a defining moment of acceptance, learns to sign, finds deaf friends, and accepts deaf ways, is unlikely to be accepted,” (Hallam et al, 2008, p.36).

Furthermore, throughout Schlau’s study it is often difficult to determine if her theory is primarily based on her participant data or on her own experiences as a deafened person.

Although she does declare her perspective and acknowledges the difficulties of conducting insider research, it is often unclear how much of her own narrative has been used within the analysis. For example, “While the data support reflection as having some effect on adjustment, I believe it is vital,” (Schlau, 2004, p.172). Schlau presents reflection as one of the key steps to acceptance but it is unclear if this is based on her beliefs and experiences or those of her participants.

Although Schlau’s study represents an attempt to investigate the process of adjustment it appears that further research is required. It seems that existing models fail to provide detailed information regarding how people negotiate acceptance of and adjustment to AHL. Furthermore, there appears to be a lack of research considering what the concept of adjustment means to people with AHL.

#### **1.7.4 Summary of AHL adjustment literature**

Literature regarding adjustment to AHL seems to assume it is a fundamentally sequential process. However, there currently appears to be a dearth of research examining this assumption. Furthermore, at present there is virtually no evidence regarding how an individual negotiates the process of adjustment and what the concept of adjustment actually means to those faced with this task. As the available literature regarding adjustment to AHL is limited it seemed necessary to consider literature regarding adjustment to other life events.

## **1.8 Adjustment to life events, chronic illness and disability**

There is a plethora of literature examining adjustment to various life events, chronic illnesses and disabilities. Consequently, it is not possible to provide a comprehensive review within this chapter. However, the following section aims to provide an outline of the main themes found within the relevant literature.

Adjustment can be defined as a response to a change in the environment that allows an individual to become more suitably adapted to that change (Sharpe and Curran, 2006). This definition implies that adjustment is a process that occurs over time. However in psychology, adjustment often refers to a desirable endpoint (Brennan, 2001).

Early theories described adjustment in terms of movement through a series of stages. Several authors have offered sequential or stage theories of adjustment (Livneh, 1991; Roessler and Bolton, 1978; Shontz, 1965, 1975). Generally, these authors view adjustment as evolving through a series of stages (such as shock, denial, anger and depression) culminating in an individual achieving psychological adjustment (Garske and Turpin, 1998). According to this linear approach the appearance of later stages is predicated on the resolution of earlier ones (Kendall and Buys, 1998). Scales developed to measure adjustment usually assess the achievement of specific outcomes including emotional equilibrium (Dunn et al, 1997), vocational performance and social role functioning (Morrow et al, 1978) (Sharpe and Curran, 2006). Adjustment to illness and disability has also been defined as achieving good quality of life, well-being, vitality, positive affect, life satisfaction and global self-esteem (Sharpe and Curran, 2006).

Silver and Wortman (1989) suggest beliefs regarding stage theories of adjustment are strongly held within our culture. However, they argue that stage theories are not supported by empirical evidence and are insufficient to represent adequately the complexity of the adjustment process. Stage models have also been criticised because they fail to identify the motivating force behind an individual's movement through the stages and represent individuals as passive entities rather than active agents (Kendall and Buys, 1998). Furthermore, the concept of a final stage of adjustment has been repeatedly rejected as unrealistic (Bishop, 2005).

Limitations of the stages models have led researchers to recognise the inappropriateness of "time bound" definitions of the adjustment process (Kendall and Buys, 1998). Consequently, the process of adjustment following acquired disability has been described as chronic or recurrent (Stewart et al, 1986). In the recurrent approach, adjustment is a gradual process of learning to tolerate an almost intolerable set of circumstances (Kendall and Buys, 1998). Adjustment therefore becomes a continuous life transition rather than a time-limited process where certain states (such as grief) are considered pathological (Silver and Wortman, 1989).

Newsome and Kendall (1996) explain recurrent adjustment using the concept of schemas<sup>1</sup>. They propose that the unexpected shift in life circumstances, following acquired disability, challenge the usefulness of an individual's existing schemas. Although existing schemas are no longer adequate, individuals continue to use them to interpret the world and may therefore

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<sup>1</sup> Cognitive theories of psychosocial well-being are based on the notion of schemas. Schemas are the fundamental beliefs and assumptions about the self, others and the world that an individual uses to filter and interpret their experiences, particularly at times of stress (Beck et al, 1979).

appear to deny or distort reality (Kendall and Buys, 1998). Initially, individuals are likely to be overwhelmed by their inability to interpret their experiences and this may result in powerful negative emotions. However, as more information about their new circumstances is gathered, new schemas are gradually developed (Kendall and Buys, 1998). Adjustment is therefore recurrent because new schemas are developed incrementally and are revised, modified and re-structured as the individual negotiates his or her new position in life (Newsome and Kendall, 1996). The process of adjustment is likely to be iterative as different aspects of the new environment are discovered (Kendall and Buys, 1998).

Modification of schemas is likely to be guided by three themes: (1) the search for meaning in disability and post-disability life; (2) the need for a sense of mastery and control over the disability, the environment and the future; and (3) the effort to protect and enhance the self and one's post-disability identity (Kendall and Buys, 1998; Taylor, 1983). Kendall and Buys (1998) suggest that the process of adjustment, within each theme, can be best represented as a pendulum motion which gradually moves from one extreme to the other and tends towards the centre point over time. For example, in a qualitative study of identity among adults with traumatic spinal cord injury, Yoshida (1993) found individuals moved between "pre-disability" and "post-disability" identities and that there was no limit on the number of times this process occurred.

Research indicates that there is considerable variation, both within and across individuals, in terms of how the adjustment process is negotiated (Kendall and Terry, 1996). Consequently, there is a growing body of literature which aims to identify individual (e.g. personality and

beliefs about illness and behaviour change [Crowley et al, 2003; Livneh, 2000; Walker et al, 2004]), illness (e.g. perceived controllability [Felton and Revenson, 1984; Helgeson, 1992]) and environmental characteristics (e.g. social support and financial security [Hatchett et al, 1997; Kaplan, 1990]) which promote “successful” adjustment.

Although such research provides useful information concerning the individual variables associated with adjustment, studies are often very specific in their focus (for example, examining the association of one or two variables with a specific illness or disability). Furthermore, results are generally not presented within an integrated framework or model and consequently the literature on the individual variables associated with adjustment is somewhat fragmented (Wright and Kirby, 1999). Although such research does give some indications regarding the factors important in adjustment, it gives little information on the process or experience of it.

Limitations of the stage models and quantitative investigations into single variables, have led an increasing number of researchers to employ qualitative methodologies to explore the process and experience of psychological adjustment to chronic illness and disability (Wright and Kirby, 1999). For example, Hayeems and colleagues (2005) used grounded theory to explore people’s experience and adjustment to progressive loss of visual function.

Hayeems and colleagues (2005) found six themes emerged from the data, namely: (1) diagnostic experience and reactions; (2) search for meaning; (3) personal identity; (4) course of action; (5) behaviour change; and (6) self-esteem. They proposed that these six themes

interacted to explain the process and experience of psychological adjustment to progressive vision loss. Data suggested adjustment was a dynamic process composed of a series of inter-related steps. Hayeems and colleagues (2005) found “adjustment was achieved” when individuals identified themselves as visually impaired, revealed their vision loss to others, used assistive devices and made lifestyle choices in order to regain self-esteem and independence. They suggested lifestyle, behavioural and psychological changes were contingent upon their personal identity (as either a sighted or visually impaired) and it was therefore deemed to be the core category within their model.

### **1.8.1 Summary of adjustment literature**

Despite the plethora of literature, adjustment seems to have remained an elusive and ill-defined construct (Sharpe and Curran, 2006). However, qualitative research appears to provide useful information on the experience of adjustment and provides the potential to integrate theoretical models with the literature on individual variables associated with adjustment. In comparison to the wider adjustment literature, it appears that models regarding adjustment to AHL have not moved beyond the early stage theories. It therefore seems that there is a need for further research exploring psychological adjustment to AHL.

### **1.9 The present study**

As described above there is a paucity of research investigating the psychological impact of AHL and how individuals experience the process of adjusting to it. Consequently, the present study aimed to explore individuals’ experiences of the process of psychological adjustment to AHL. In the present study, adjustment was defined as an individual’s response to AHL that allowed them to become more suitably adapted to their hearing loss (Sharpe and

Curran, 2006). Psychological adjustment was defined as changes in the psychological factors (such as cognitions, beliefs, attitudes and emotions) that were associated with adaptation to AHL. While the distinction between general adjustment and psychological adjustment is somewhat artificial (as it would be expected that behavioural and psychological adjustments would constantly interact with one another), the present study aimed to focus specifically on psychological factors because these had been largely neglected by previous AHL research.

A qualitative approach seemed to be the most appropriate methodology to achieve this aim for a number of reasons. First, qualitative research tends to be interested in how individuals make sense of the world and how they experience events (Willig, 2001). Qualitative research is concerned with obtaining information about the process, quality and texture of individual experience rather than identifying cause-effect relationships (Willig, 2001). As the researcher was explicitly interested in the lived experience of individuals with AHL it seemed appropriate that a qualitative methodology was employed.

Qualitative research is interested in the meanings attributed to events by the research participants. Consequently, it does not tend to work with variables that are defined by the researcher before the research process begins (Henwood, 1996). Furthermore, the prediction of outcomes is not a meaningful goal for qualitative research and consequently a researcher is not required to specify hypotheses prior to beginning the research (Denzin and Lincoln, 1994). Qualitative research is therefore particularly suited to examining areas, such as adjustment to AHL, with a dearth of previous research (Woolgar, 1996).

Current literature on adjustment and personal accounts of AHL indicate that psychological adjustment to AHL is a complex process which is inadequately described by stage models. Consequently, it was hoped that using a qualitative approach would help to enrich current understandings of adjustment to AHL by providing in depth evidence regarding how individuals negotiate the process.

Overall, it seemed that using a qualitative approach would bring together the two strands of previous AHL research. The approach would allow the consideration of individual narratives and experiences but would provide a methodological framework that included interpretation of experiences and analysis across participants.

## 2. Method

### 2.1 Design

The present study used a qualitative methodology to explore people's experiences of the psychological impact of AHL. Discourse Analysis, Grounded Theory and Interpretative Phenomenological Analysis (IPA) were all considered as possible approaches. However, IPA was chosen as the most appropriate methodology. A description of IPA and the reasons for its selection are outlined below.

#### 2.1.1 Interpretative Phenomenological Analysis

IPA is a relatively new qualitative methodology developed by Smith (1996). The aim of IPA is to explore individuals' lived experiences and to examine how people make sense of their personal and social world. IPA draws on three main theoretical traditions, namely phenomenology, hermeneutics and idiography<sup>2</sup>. IPA is phenomenological because it acknowledges that individuals construct different realities according to their experience of the world (Giorgi, 1995). It assumes that researchers cannot get an objective account of an event or object, but can find out about the way in which the event or object is perceived or experienced by individuals (Smith et al, 1999).

IPA emphasises that research is a dynamic process in which the researcher takes an active role. While the aim is to try and achieve an "insider's perspective" (Conrad, 1987), IPA assumes the researcher cannot do this directly or completely (Smith, 1996). Access to a participant's experience depends on and is complicated by the researcher's own conceptions and therefore a double hermeneutic is involved. As Smith and Eatough describe,

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<sup>2</sup> See Smith (1996) for a detailed discussion of the theoretical underpinnings of IPA.

“The participant is trying to make sense of his/her world and the researcher is trying to make sense of how the participant is trying to make sense of his/her world,” (Smith and Eatough, 2007, p. 36).

IPA assumes that there is a chain of connection between people’s talk, cognitions and affective state (Smith, 1996). It therefore is compatible with current cognitive models within psychology. Furthermore, Smith (2004) recommends the results of an IPA analysis should be discussed within the context of existing psychological literature. Conversely, Discourse Analysis assumes meaning is socially constructed in interaction and that the language people use does not necessarily reflect their thoughts or social reality (Dallos and Vetere, 2005). As the present study was interested in individuals’ experiences of the psychological impact of AHL it was assumed that exploring people’s thoughts and feelings would be central to the process. Discourse Analysis was therefore deemed an unsuitable approach.

IPA examines individual case studies and is therefore an idiographic mode of enquiry (Smith and Eatough, 2007). Within an IPA study it should be possible to learn something about the important generic themes across a group of individuals but also about the narrative of individual participants (Smith, 2004). Grounded Theory and IPA both start with individual accounts and use similar analytical techniques. However, Grounded Theory aims to extrapolate beyond the individuals participating in the study and generate theories that explain broader aspects of human experience and behaviour (Willig, 2001).

Glaser and Strauss (1967) developed Grounded Theory to allow researchers to study social processes and there are now several different versions of the method. IPA was designed as a method of gaining insight into individuals' psychological worlds and is therefore a specifically psychological research method (Willig, 2001). At present there is little variability in how IPA is used and it is therefore considered particularly suitable for the novice qualitative researcher (Braun and Clarke, 2006). Given that the researcher was a novice to qualitative enquiry and that the study aimed to explore individual's psychological worlds following hearing loss, IPA was deemed to be the most appropriate qualitative approach. IPA generally uses transcripts generated from semi-structured interviews and consequently data was collected this method.

## **2.2 Ethical considerations**

### **2.2.1 Ethical approval**

The Borders Research Ethics Committee approved the present study (Appendix 1). The Committee made two recommendations regarding alterations to the participant consent form; that the consent form should seek consent to an additional statement regarding the recording of the interview and also that participants should be asked to initial each individual statement. During the research process there were a number of ethical issues that merited consideration.

### **2.2.2 Prevention and management of emotional distress**

Qualitative interviews aim to explore an individual's personal experiences and consequently often touch upon sensitive topics. Discussing such topics may provoke participant anxiety or distress and it is often difficult for the researcher to predict accurately when this could occur

(Richards and Schwartz, 2002). A number of steps were taken to address this issue and these are outlined in the research procedure.

### **2.2.3 Informed consent**

Informed consent is a central issue for all research (Orb et al, 2000). A minimum requirement for an interview study is that written consent should be obtained after participants have been given a detailed description of the study both verbally and in writing (Richards and Schwartz, 2002). Participants should also be given time to consider their participation and ask questions of the researcher.

It is the nature of qualitative research that unexpected themes can arise during the interviews and it therefore seemed appropriate that obtaining consent was treated as an ongoing process rather than a one-off event (Richards and Schwartz, 2002). Details of how informed consent was achieved are included in the subsequent sections.

### **2.2.4 Anonymity and confidentiality**

Interview transcripts contain multiple clues (such as names, employment details and family circumstances) to a participant's identity. It therefore seemed extremely important that the author removed as many identifying features (such as names of places or family members) as possible from the transcript prior to analysis. In addition, when reporting on the analysis pseudonyms were used and caution was taken not to give information that would make the participant identifiable.

## **2.3 Participants**

### **2.3.1 Sample size**

Although IPA can be employed with larger samples, such studies are generally conducted using relatively small sample sizes (Smith and Eatough, 2007). A small sample size enables the researcher to retain an idiographic focus and to fully engage with detailed case-by-case analysis (Smith, 1996). It is recommended that between six and ten participants is an appropriate number for an IPA study (Smith and Eatough, 2007).

### **2.3.2 Sampling**

IPA research uses the principles of purposive sampling to recruit a closely defined group of participants for whom the research question will be significant (Smith et al, 1999). This approach does not aim to establish a random or representative sample but deliberately seeks to identify individuals who have the required expertise of living with AHL and in particular, those most likely to provide theoretical insights into the research question (Flowers et al, 1997).

In keeping with the principles of stratified purposive sampling the researcher aimed to recruit a sample of males and females representing a range of ages (Flick, 2007). Furthermore, sampling also aimed to incorporate people with different experiences of: hearing technology; causes and types of onset; and duration of living with hearing loss. How these objectives were achieved will be described below.

### **2.3.3 Inclusion and exclusion criteria**

Individuals who had acquired a moderate, moderate-severe, severe or profound hearing impairment in adulthood (over the age of sixteen) were included within the study. People who had a mild hearing impairment were excluded. Those who had been born with a hearing impairment, had a hearing impairment acquired in childhood or an age-related hearing impairment were not included in the study.

Age-related hearing loss was defined as a gradual loss of the ability to hear high frequencies. Age related hearing loss is generally diagnosed in adults aged 65 and over. However, it can begin when an individual is in their fifties (O’Neil et al, 1999). Consequently, individuals who reported a gradual hearing loss which began after the age of 50 were excluded from the study. Individuals were excluded if they had additional sensory impairments (for example, were deaf-blind). Individuals who could not speak English or were not capable of giving informed consent were also excluded.

Audiograms are often not made available to individuals with hearing loss (Woodcock and Aguayo, 2000). Consequently, the author made a decision not to base the inclusion criteria on an individual’s audiogram but on their self-reported level of AHL. Participants’ level of hearing loss was assessed at two different stages and is outlined below.

## **2.4 Procedure**

### **2.4.1 Development of interview guide**

Smith and Eatough (2007) argue that preparing a semi-structured interview schedule, prior to data collection, forces researchers to think explicitly about their idea of interest, question wording, the difficulties that may arise during the interview and how these difficulties may be handled. They suggest that addressing these issues in advance allows the researcher to concentrate on the participant's narrative. However, they indicate that any interview schedule should be regarded only as a guide which facilitates access to the participant's psychological and social world and not as a strict schedule which dictates the content of the interview (Smith and Eatough, 2007). As the author was an inexperienced qualitative researcher it seemed advantageous to develop a semi-structured interview guide.

The interview guide (Appendix 2) was developed with reference to guidelines presented by Smith and colleagues (1999) and the previous research presented above. Initial questions aimed to gather relevant demographic information. Later questions were designed to be open-ended and relatively neutral with the aim of encouraging participants to give rich experiential accounts of their AHL. The guide was not intended to be prescriptive and it was assumed that not all of the questions would be asked during every interview, that questions did not have to be asked in any particular order and that the majority of questions conducted during the interview would be responses to the participants' narrative. General prompts such as "Can you tell me more about that?" were included within the guide.

### **2.4.2 Pilot interview**

The interview guide was piloted with an individual with AHL who was already known to the researcher. Feedback from the participant on the interview was obtained and consequently a question regarding the impact of AHL on significant others was added to the guide. The interview recording was listened to and reflected upon by the researcher. These reflections were used to refine the researcher's interview technique.

### **2.4.3 Recruitment**

Participants were recruited from three different sources: the LINK Centre for Deafened People; the Scottish Borders Council Social Worker for People with Hearing Impairments; and a social group for women with AHL. Each recruitment source will now be discussed in detail.

#### **2.4.3.1 The LINK Centre**

The LINK Centre for Deafened People is a charity providing specialist services for adults living with acquired profound hearing loss (APHL) throughout the UK. In Scotland, LINK provides intensive rehabilitation programmes, self-management courses and social groups for adults with APHL. In addition, they provide deafened awareness training, a helpdesk service and train adults with experience of APHL to become outreach volunteers supporting other people with hearing loss. LINK assesses a potential service user's hearing loss through a combination of audiogram information and self-reported impact of AHL, on the person's daily functioning. As LINK only works with people with severe or profound hearing loss acquired in adulthood, the researcher assumed that all participants recruited from LINK would meet the inclusion criteria regarding age of onset and level of AHL.

Participants were recruited via LINK in two ways. First, the researcher attended and observed a three day group-based self-management course in Glasgow. During the course the group facilitator informed delegates about the research and asked them to approach the researcher if they were interested in participating in the study. Interested delegates were then given a description of the study by the researcher and were asked to leave their email or postal address. An information sheet was then sent via email or post and potential participants were requested to contact the researcher if they wished to participate in the study (Appendix 3).

Secondly, the LINK Scotland Manager was provided with an invitation email (Appendix 4) and electronic information sheet. She agreed to email this to all outreach volunteers. Outreach volunteers were asked to contact the researcher directly if they were interested in participating in the study.

#### **2.4.3.2 Social Worker**

As part of Sensory Services in the Borders General Hospital, the Social Worker for People with Hearing Impairments provides a service to individuals with a wide range of hearing related difficulties across the Scottish Borders. The researcher met with the Social Worker and provided information on the study, including its inclusion and exclusion criteria (Appendix 5). The Social Worker agreed to send invitation letters (Appendix 6) and information sheets (Appendix 7) to people on her current caseload that met criteria for inclusion in the study. Interested individuals were then asked to contact the researcher directly if they wished to participate in the study.

### **2.4.3.3 Social group**

Participants were also recruited from a social group for women with hearing related impairments run in the Scottish Borders. The above Social Worker and the researcher set up this group in 2007 as a way of promoting social contact between local women with hearing impairments. As group members were already known to the researcher, women who met inclusion criteria for the study were contacted, by the researcher, via email or letter. Potential participants were emailed or sent an invitation letter (Appendix 8) and information sheet and were asked to contact the researcher if they would be interested in participating. As the participants already knew the researcher, extra care was taken within the information sheet to ensure the women did not feel pressured to take part.

### **2.4.4 Selecting the sample**

The three methods of recruitment were carried out simultaneously. The researcher received 15 emails from individuals interested in participating in the research. However, it was felt that given time constraints it would not be possible to include all 15 volunteers within the sample. Consequently, the researcher emailed each volunteer and asked them to give a brief description of their age, duration of and type of AHL. All volunteers responded with this description and the researcher then selected a sample of 11 participants. The sample was selected to include males and females representing a range of ages, with different experiences of hearing technology, causes and types of onset and duration of living with AHL. It was also ensured that the sample included participants from each of the three recruitment methods. The remaining four volunteers were sent an email which thanked them for their interest but explained that they had not been selected as participants.

## **2.4.4 Interviews**

### **2.4.4.1 Consideration of communication needs**

Prior to conducting the interviews the researcher attended a training event for psychotherapists on communication tactics with deaf people. The event was run by the Scottish Council on Deafness and gave information on improving communication with different groups of deaf people. Throughout all the interviews the researcher attempted to use the appropriate communication strategies and sought guidance from the participants on how best to maximise communication (see Appendix 9 for a list of communication strategies used).

When arranging an interview, the author asked participants if they required communication support (such as an electronic note taker or lip speaker) during the interview. None of the participants felt they needed additional support. However, one participant asked if his wife could attend the interview in case he required an informal lip speaker. All interviews were conducted in spoken English.

### **2.4.4.2 Interview setting**

Interviews were conducted in a setting chosen by the participant. Participants were asked to select a venue that would meet their communication needs and would encourage them to be relaxed during the interview. Table 6 outlines the interview settings chosen by participants.

**Table 6:** Interview setting chosen by each participant.

Interview Setting	Number of Participants
Participant's home	2
Café chosen by participant	1
Researcher's work place (community hospital)	5
Participant's voluntary work place	1
Interview room within local public library	2

#### 2.4.4.3 Procedure during interviews

All interviews were conducted by the researcher and were recorded using a digital recorder.

At the beginning of each interview the participant was given written information presenting the aims of the interview and some of the questions they might be asked (Appendix 10).

Presenting written information ensured it was received correctly without the influence of hearing difficulties. It was felt that providing participants with the interview guide would facilitate communication during the interview and reduce participant anxiety (regarding what they were going to be asked and if they would manage to hear the questions they were asked) (Hallam et al, 2005). It was also hoped that it would allow participants to make an informed decision about whether the interview would cause them distress. It was acknowledged that providing a list of questions might decrease the breadth of participant narrative and might lead to them to believe they should only discuss information relating to these. In an effort to decrease this possibility the researcher emphasised that the questions provided were only a guide, they did not all have to be answered and that the aim of the interview was to gain an understanding of the participants' personal experiences.

The written information was then discussed verbally and participants were encouraged to ask any questions they had about the research. Informed consent was then sought (Appendix 11) and each participant was asked to give details of a professional whom the researcher could

contact if concerned about the participant's mental health (Appendix 12). It was stated that people should not participate if they would not want the researcher to contact the professional.

At the start of each interview participants were asked to provide some demographic information such as age, marital status and employment status. They were also given written information on audiological categories (Appendix 13) and they were asked to identify which category best described their hearing loss.

The interview style was flexible and non-directive, and a process of reflecting and probing was employed (e.g. "Could you tell me more about that...") (Smith, 1995). In this way, the researcher attempted to allow participants to shape the content of the interview and tried to facilitate the disclosure of the interviewee's perspective (Flowers et al, 1997). Not all the questions on the interview schedule were asked of every participant and questions were not always asked in the same order. The researcher monitored how the interview was affecting the participant and modified the questioning accordingly. For example, if a participant appeared to be uncomfortable answering a particular question the researcher would ask them if they would prefer not to discuss this topic and would move on to a different area of questioning. Throughout the interview the researcher encouraged participants to inform her if they felt uncomfortable with anything they were asked.

During the interviews, the researcher used her training in clinical psychology to remain sensitive to the participant's mood and also to assess any potential distress or underlying mental health related difficulties. While the researcher's professional background was useful

in assessing distress, it was necessary for her to be clear about her role with participants (Richards and Emslie, 2000). Participants were told that the researcher was a Trainee Clinical Psychologist but it was made explicit that the interview would not be the same as a therapeutic intervention. If a participant did become distressed during the interview they were given the option of terminating it (and the recorder being switched off). The researcher then encouraged some discussion regarding the participant's distress and if appropriate provided them with some advice and information regarding services they could contact (Orb et al, 2000). A named professional would not be contacted unless it was discussed with the participant first.

During the interviews 3 participants described experiencing symptoms of clinical depression. Two of these participants were currently prescribed anti-depressant medication and were not distressed during their interview. Following their interviews, both participants were given information regarding psychological treatments for depression. One participant was emailed self-help materials and the other agreed to ask their GP for a referral to psychology.

One participant became emotionally distressed and consequently the interview was terminated after 20 minutes. Following the interview, the researcher spent time with the individual discussing their distress. The participant admitted they had a history of recurrent depression and felt they were experiencing a depressive episode. They agreed to contact their GP (their named professional) the following day and seek treatment. The researcher sent a follow-up email including self-help materials and advice relating to depression. The participant's response explained they had seen their GP. As the interview was terminated

after only 20 minutes the researcher felt that it did not provide sufficient information to be included in data analysis and consequently it was excluded.

All participants were offered the opportunity to discuss any issues brought up by the interview, after the digital recorder had been switched off. Interviews lasted between 45 minutes and 2 hours 23 minutes (the mean interview time was 65 minutes.)

Following each interview the researcher recorded her responses and reflections in her reflective diary. Reflecting on her role in the interview allowed the author to develop her skills and enhance her interview technique.

## **2.5 Data management**

### **2.5.1 Transcription**

The voice files from the digital recorder were transferred to a computer and were transcribed verbatim using appropriate notations presented in Coelho (2005). The notation used is documented in Appendix 14. All interviews were transcribed by the researcher. This ensured confidentiality and also familiarity with the transcripts. Identifiable features such as names of people and places were omitted during transcription. Once transcribed, an interview was re-read and any unusual sentences were checked against the recording.

During transcription the author kept a record of potential points of interest, initial thoughts, comments and reflections regarding the text within her reflective diary (Smith and Eatough, 2007). It was felt that these comments would be useful to return to and check against later interpretations during the process of analysis.

### **2.5.2 Confirmation of transcript**

Each transcript was emailed or posted to the corresponding participant. Participants were asked to read through the transcript and confirm it was an accurate account of their interview (Poland, 1995). They were also requested to consent via email to it being used within the analysis. Participants were encouraged to share their reflections and responses to the transcript and the author recorded these.

### **2.5.3 Confidentiality**

Once a participant gave his or her consent, the transcript was anonymised and allocated a pseudonym. Consent forms were kept separate from the transcripts in a locked cabinet. Prior to analysis the interview transcripts were transferred on to NVivo 7.

## **2.6 Analysis**

### **2.6.1 Computer software and NVivo 7**

The use of computer software packages in the analysis of qualitative data is a controversial issue (Bazeley, 2007). Critics of software packages express concerns that the use of computers can physically distance researchers from their data and consequently reduce their ability to engage with it (Smith, 1996). Furthermore, some believe that the use of software encourages quantitative analysis of qualitative data (St John and Johnson, 2000). Conversely, a growing number of researchers claim that computer software is in fact not designed to replace the thought processes of the researcher but provides an efficient, convenient and flexible way of storing and organising data. It is argued that these functions actually facilitate the interpretation process by providing possibilities, which are unrealistic and too time consuming for manual methods (Welsh, 2002). As Marshall suggests,

“When recoding data involves the laborious collation of cut-up slips and creation of new hanging folders, there is little temptation to play with ideas, and much inducement to organise a tight set of codes into which data are shoved without regard to nuance. When an obediently stupid machine cuts and pastes, it is easier to approach data with curiosity – asking “what if I cut it this way?” knowing that changes can be made quickly,” (Marshall, 2002, p.67)

She argues software therefore makes it more likely that researchers will produce a more systematic and comprehensive analysis.

After consideration of the issues concerning the use of computer software the researcher concluded that its use would promote efficient data management and could be used as a tool to support in-depth engagement with, reflection on and interpretation of the data. However, not all manual methods were rejected and a detailed research diary was still kept in addition to the use of NVivo 7.

NVivo 7 is a computer software programme developed by QSR International. NVivo is designed to support researchers in managing, analysing and interpreting qualitative data. The researcher chose this particular program because it was available within her University and is also widely used by qualitative researchers.

## **2.6.2 Process of analysis**

The interview transcripts were analysed in accordance with the general principles of IPA outlined by Smith (1996) and Smith and colleagues (1999). However, as IPA is not a prescriptive approach but a set of flexible guidelines that can be adapted by individual researchers, the process of analysis is outlined below (Smith and Eatough, 2007).

### **2.6.2.1 Analysis of individual cases**

The first stage of analysis involved the researcher closely reading the transcript several times. Several detailed readings of the text allowed the researcher to become immersed in the transcript and ensured analysis was grounded in the data (Willig, 2001). The researcher then went through the transcript line by line and created exploratory codes which included descriptions of the content, initial interpretations and comments on language use. Although Smith and colleagues (1999) recommend exploratory coding should be recorded in the left hand margin of the text, the researcher chose to create tree nodes in NVivo for each code (see Appendix 15). Further notes on why particular codes were created, comments on significant issues, questions regarding the text and reflections on tone (Smith et al, 1999) were recorded in an NVivo memo linked to the transcript (Appendix 16).

During the second stage of analysis the researcher attempted to identify emergent themes from the initial exploratory codes. As with the first stage of analysis, the whole transcript was treated as potential data and no attempt was made to select or omit particular passages for special attention. Identifying emergent themes was a simultaneous task of reducing the volume of data while maintaining the complexity and the relationships within the exploratory codes (Flowers, 1997). Throughout this process the author tried to capture more concisely

the essential psychological quality present in the participant's words and the author's interpretations within exploratory codes (Smith and Eatough, 2007). Instead of using the right hand margin of the text, (Smith et al, 1999) the tree nodes representing the exploratory codes were grouped together within NVivo to represent emergent themes. Thoughts regarding each emergent theme were documented in the NVivo memo.

The third stage involved the researcher looking for connections between emergent themes. It was found that some themes appeared to cluster together while others seemed to form hierarchical relationships. As each new connection emerged the researcher checked back to the transcript to ensure it reflected what the person actually said. Consequently, the process of analysis involved a close interaction between the researcher and the text. The researcher attempted to understand what the person was saying while drawing on her own interpretative resources.

This stage of analysis highlighted emergent themes that were either not well represented in the text or did not fit with the emerging structure of themes. Such themes were excluded from the analysis. The researcher's decisions regarding exclusion of emergent themes were documented in NVivo memo. Clusters of themes were given a descriptive label which conveyed the conceptual nature of the themes within the cluster. Whenever possible an in vivo term found within the original text was used. The descriptive label was then called a super-ordinate theme. For each super-ordinate theme a new "tree node" was created within NVivo. The "tree nodes" representing the corresponding emergent themes were organised within the super-ordinate "tree node".

During the fourth stage of analysis the researcher produced a master table of themes (Appendix 17). Within the table, super-ordinate themes were presented outlining the sub-ordinate themes of which they were comprised. Alongside each theme, extracts from transcripts, page and line numbers indicated where themes could be identified within the text. This process was repeated for each individual transcript.

#### **2.6.2.2 Cross-case analysis**

The 10 master tables of themes (produced from the individual case analyses) were integrated into an overall table which reflected the experiences of the whole group of participants. As in individual case analyses, the process of integration was carried out in a cyclical manner. Any emerging higher order themes were checked and tested against each individual transcript. Often, themes which had been sub-themes within an individual case analysis emerged as super-ordinate themes across the whole group. Furthermore, checking each possible super-ordinate theme with every transcript meant new themes (that had not been apparent for an individual case) often emerged. New themes were incorporated back within the individual analyses master tables.

### **2.7 Ensuring quality in qualitative research**

There is now a plethora of literature that provides guidelines for ensuring quality in qualitative research (Elliott et al, 1999). While these guidelines have been criticised as overly prescriptive and often counterproductive, it seems that they may be useful in improving rigour if they are used within a broader understanding of qualitative research design and

analysis (Barbour, 2001). Consequently, some guidelines and their application in the present study are discussed below.

### **2.7.1 Transparency and audit trail**

Inherent within qualitative research is the premise that subjectivity is inevitable.

Consequently, qualitative researchers are encouraged to seek out their own subjectivity while the research is in progress (Peskin, 1988). For example, in “good” qualitative research a researcher should specify his or her theoretical orientations and personal anticipations prior to beginning the research and also as they become apparent during the process (Law et al, 1998). This encourages researchers to recognise their values, interests and assumptions and the role that these play in their understanding, interpretation and shaping of the research process (Elliott et al, 1999). This disclosure increases transparency and helps readers to interpret the data, consider possible alternative conclusions and assess the role of the researcher in the research. The current researcher attempted to meet this criterion in two ways; first by incorporating a statement regarding her theoretical position, experiences and assumptions regarding the experience of acquired deafness; and secondly, by keeping a detailed reflective diary throughout the entire course of the research (Peskin, 1988). Within the diary the researcher documented her thought processes, decisions and reflections on the research process. During analysis details of decisions regarding the creation or exclusion of codes were documented within an NVivo memo. This provided a clear audit trail and allowed the researcher to constantly check between the transcript, codes and memo to ensure the interpretation was reflective of the data.

### **2.7.2 Triangulation**

Triangulation refers to an approach to data collection in which evidence is deliberately sought from a wide range of different and independent sources (Mays and Pope, 1995). The essential rationale is that using a number of different methods or sources means results are more likely to be more accurate (Smith, 1996). The researcher sought to triangulate her interpretation of the data in a number of ways.

#### **2.7.2.1 Supervision**

The process of analysis was discussed with an experienced qualitative researcher as part of supervision. Prior to supervision sessions the supervisor read over five of the transcripts and made a note of important themes. The supervisor then read over the researcher's corresponding NVivo memos and codes. During supervision possible interpretations of the text were explored and different ways of organising the themes were discussed. Overall, the supervisor encouraged the researcher to become more interpretative in her coding and promoted the consideration of alternative interpretations of the data. Supervision formed a key part of the process of analysis and was used throughout the individual and cross-case analyses.

#### **2.7.2.2 Multiple coding**

Multiple coding is similar to the quantitative concept of "inter-rater reliability" and is a response to the queries of "subjectivity" sometimes levelled at the process of qualitative data analysis (Barbour, 2001). Multiple coding involves the cross-checking of coding strategies and interpretation of data by independent researchers. Two transcripts were chosen at random by the researcher and were emailed to another trainee clinical psychologist. The

trainee clinical psychologist was also conducting her first piece of research using IPA but was independent of this study. Sections of the transcripts were then chosen at random by the independent researcher and were analysed in accordance with the procedure outlined above. The researcher then met with the independent researcher and both presented their analysis. Unlike inter-rater reliability, multiple coding does not result in a statistical value of concordance. However, it did allow the researchers to discuss disagreements and become aware of potential competing interpretations (Barbour, 2001). By the end of the discussion both researchers agreed on an interpretation of the transcripts that was then used in subsequent analyses.

### **2.7.2.3 Previous literature**

At the final stages of analysis, previous literature was consulted as a method of validating or challenging interpretations. Discussions regarding how each super-ordinate theme relates to previous literature can be found within the Results section.

### **2.7.2.4 Respondent validation**

Respondent validation involves cross-checking the researcher's interpretation of the data with participants. This often helps to refine explanations and provides further validity to the analysis (Elliott, 1999). Respondent validation was initially considered but it was felt that asking participants to check their transcripts (which often required the researcher to remind participants numerous times) and then later validate themes would demand too much of participants' time.

### **3. Reflective Preface**

As discussed in the previous chapter, it is good practice for qualitative researchers to reflect on his or her experiences and assumptions related to the research (Law et al, 1998). My experiences and assumptions related to the current study are outlined below.

I am a female trainee clinical psychologist in my last year of training. I do not have a hearing impairment and my family and friends are all hearing. Prior to training as a clinical psychologist I worked as a support worker with a supported living service for people experiencing mental health problems. Part of my role was to support a woman who had been profoundly deaf since birth. Although her first language was English she preferred to use British Sign Language (BSL) to communicate. Consequently, my employer funded me to attend an introductory BSL course which was taught entirely by Deaf people. Over a number of years I obtained a BSL Level 2 qualification. During my time as a support worker and BSL student I developed an awareness of the communication issues facing deaf people and also an understanding of Deaf culture. I began to develop an interest in deaf people's experience of mental health problems and worked with a number of deaf clients and their interpreters during my training.

In my first year I was asked to see a woman who was experiencing depression associated with a work related hearing loss. Although I considered myself to have a reasonable understanding of deafness, this was the first time I had met someone with a severe hearing loss acquired in young adulthood. This client gave me an insight into the psychological issues (such as grief and isolation) associated with AHL.

After working with this client, I attended a course for counsellors on Communication Tactics with Deaf People. This gave me additional insights into the dearth of specific services and lack of awareness regarding AHL and its consequences.

Around that time I was approached by a social worker, who worked with people with hearing impairments, regarding the possibility of setting up a social group for younger women with AHL. She had noticed that many of her clients were socially isolated as a result of communication problems. Consequently, we set up a monthly group which aimed to provide the opportunity for women to socialise but also meet others with similar difficulties. Talking to the women gave me an insight into the impact AHL had on self-confidence and social relationships. For example, on the first night of the group one woman asked me “does my voice sound all right? I usually let my husband do all the talking.”

This experience consolidated my interest in AHL and made me wonder if research specifically investigating the psychological impact of AHL had been completed. I conducted a literature review and discovered that there was a distinct lack of psychological research. My experience of working with AHL encouraged me to believe that the psychological issues associated with AHL was an important and interesting area that required further research. I therefore decided to make people’s experience of psychological adjustment to AHL the subject of my clinical doctorate thesis.

I approach this research with an assumption that AHL has psychological implications. I am interested in people’s understanding, interpretations and appraisals of hearing loss and how

people negotiate, accept or adjust to it. However, throughout the research process I will endeavour to be led by the experiences of participants.

Although I would like to consider myself an eclectic practitioner my training has primarily focused on Cognitive Behavioural Therapy. I am therefore familiar with emphasising the role of meaning and cognition and their influence on emotions and behaviour. As I am approaching the research with the intention of bringing a psychological perspective I assume my therapeutic orientation will influence my interpretation of the research process.

Finally, I have no prior experience of qualitative research. I therefore expect that I will find this research challenging and believe it will a steep learning curve.

## 4. Results

### 4.1 Response rates

Table 7 displays the number of people that were invited to take part in the study across each method of recruitment. Overall, 29 people were invited and 15 volunteered to take part. As described in the previous chapter, 11 of the 15 volunteers were selected as participants. One interview was excluded from analysis because it was terminated before sufficient information had been gained. After reading her transcript, a further participant felt uncomfortable with the amount of information she had disclosed and asked to be removed from the study. The final sample therefore included 9 participants.

**Table 7:** Number of participants recruited across recruitment methods

Recruitment method	No. of people invited to take part	No. of people who volunteered to take part	Percentage of people invited who volunteered to take part
LINK email to outreach volunteers	11	5	55%
LINK self management course	6	3	50%
Clients of social worker	8	4	50%
Members of social group	4	3	75%
All methods	29	15	52%

### 4.2 Characteristics of the sample

#### 4.2.1 Demographic information

Of the 9 participants, 3 were female and 6 were male. The age of participants ranged from 31 to 73, with a mean age of 49. Seven of the participants were married, 1 lived with her partner and 1 was single. Three participants were employed and 1 was a full-time mother. Two participants did not work because of their AHL. Three participants were retired (2 of these participants had taken early retirement because of their AHL and 1 had retired early because of another physical disability).

#### 4.2.2 Hearing loss characteristics

Table 8 displays information on the AHL of each participant. In terms of level of hearing loss, 1 participant had a moderate, 6 had a severe and 2 had a profound AHL. Five participants had a progressive loss, while four had experienced a sudden AHL. The approximate duration of living with AHL ranged from 18 months to 43 years. The mean duration was approximately 21 years.

**Table 8:** Hearing loss characteristics for each participant

Participant*	Level of AHL	Type of AHL	Approx. duration of living with AHL	Cause of AHL
Ben	Severe	Sudden then progressive	42 years	Road traffic accident
David	Severe	Progressive	18 years	Possibly work-related
Ian	Severe	Progressive	28 years	Genetic
Jenny	Moderate	Sudden	14 years	Virus
John	Severe	Sudden then progressive	3 years	Ménière's disease
Laura	Profound	Sudden	18 months	Unknown
Lynn	Severe	Progressive then sudden drop	20 years	Genetic Osteosclerosis
Steven	Severe	Progressive	43 years	Unknown
Tom	Profound	Progressive	20 years	Unknown

\* All participant names have been changed to protect confidentiality

Two of the participants had a family history of hearing loss. Three participants did not know what had caused their AHL while 1 participant had been given a possible cause. Five participants had been told what caused their AHL. Four participants experienced additional problems related to AHL including balance problems, hyperacusis<sup>3</sup> and tinnitus<sup>4</sup>.

<sup>3</sup> Hyperacusis is a health condition characterized by an over-sensitivity to certain frequency ranges of sound.

<sup>4</sup> Tinnitus is the perception of noise in the ear or the head which is generated inside the body rather than coming from outside.

Two participants had a cochlear implant and the remaining 7 participants all used hearing aids. All the participants communicated verbally. Two participants had attended a lip-reading class and only 1 participant had opted to learn British Sign Language. One participant had a hearing dog.

### **4.3 Analysis**

Smith and Eatough (2007) recommend an IPA study should include an interpretation of the important generic themes in the analysis but should also provide information on the narrative life of individual participants. This section will present the findings of the cross-case analysis. However, each theme will be illustrated using verbatim extracts from individual transcripts and it is therefore hoped readers will still be able to follow individuals' narratives throughout analysis.

Individual case analyses produced nine structures that included relevant super-ordinate and sub-themes (See Appendix 17). Across individual case analyses, the number of super-ordinate themes ranged from 5 to 8, with a range of 2 to 5 sub-themes per super-ordinate theme. During the cross-case analysis individual summary structures were compared and integrated into a list of master themes that aimed to reflect the experiences of the whole group.

Cross-case analysis revealed 11 super-ordinate themes. However, 3 of these super-ordinate themes ("Losing my hearing," Physical Problems and "I can't do the things I used to do") are not presented here (Appendix 18). "Losing my hearing" and Physical Problems were

excluded from presentation because they represented descriptions of the physical sensations and complications associated with AHL. As the study was interested in psychological aspects of AHL these themes were deemed less relevant. “I can’t do the things I used to do” represented a list of the activities that participants could no longer engage in. It was felt information of this nature was already well documented in the AHL literature and consequently the researcher decided not to present this theme here.

The remaining 9 super-ordinate themes are presented in Table 9. Table 9 displays each super-ordinate and sub-theme and indicates if they are present within each individual narrative. The following section presents analysis of the 9 cross-analysis super-ordinate themes. A diagram and description of how 8 of the super-ordinate themes interact is presented in Appendix 19.

Each super-ordinate theme and its corresponding sub-themes will be discussed in turn. Analysis of each theme is subdivided into two sections. The first section provides a description and interpretative analysis of the experience inherent in participants’ accounts. The second section considers the implications of the analysis in relation to existing literature. Although each theme is considered separately, most are inter-related. The following analysis is therefore presented as one possible interpretation of the data. Throughout the section care has been taken to highlight where alternative interpretations may be possible.

**Table 9:** The relevance of the nine super-ordinate themes and corresponding sub-themes to each individual participant

Theme	Sub-theme	Ben	David	Ian	Jenny	John	Laura	Lynn	Steven	Tom
A hidden disability		✓	✓	✓	✓		✓	✓	✓	✓
Suddenly everything changes	I don't know what to do	✓			✓	✓	✓	✓		
	My life is over	✓			✓	✓	✓	✓		
	Searching for meaning		✓		✓	✓	✓	✓		
Identity and Loss	Loss of identity	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Loss of future	✓			✓	✓		✓		✓
	Loss of control		✓			✓	✓	✓	✓	
Negotiating identity	I'm not deaf		✓				✓	✓		✓
	Not one thing or the other	✓			✓	✓	✓	✓		✓
	Identity reconstruction	✓	✓	✓	✓		✓			
	Integrating deafness	✓		✓						
Relationships with others	Changes in roles		✓	✓		✓	✓	✓	✓	
	I withdraw		✓		✓	✓	✓	✓	✓	✓
	Others withdraw from you		✓	✓					✓	✓
Roles in relation to hearing loss	Agent vs recipient		✓			✓	✓			
	I have to change vs nobody to help		✓			✓				✓
	Lucky vs let down	✓	✓	✓	✓	✓	✓	✓	✓	✓
Disclosure	I try to hide it				✓			✓		✓
	I should tell people		✓		✓	✓	✓	✓	✓	✓
	I tell people	✓	✓	✓		✓	✓		✓	✓
Acceptance	I don't want to accept it				✓			✓		
	I need to accept it	✓	✓	✓	✓	✓	✓	✓		✓
	Managing acceptance	✓	✓	✓	✓	✓	✓		✓	✓
Conceptions of "adjustment"	Adjustment as an ideal	✓	✓		✓			✓	✓	✓
	Adjustment as survival			✓	✓	✓	✓			

## 4.4 Theme 1: A hidden disability

### 4.4.1 Discussion and analysis

All participants believed that AHL had specific characteristics that made it a particularly challenging disability to live with. This theme therefore represented an overarching issue that ran throughout participant narratives and across all other themes.

For all participants, developing an AHL was a life-changing experience that had far-reaching consequences in terms of an individual's daily functioning<sup>5</sup>. However, participants felt their families, friends and the general public did not understand or recognise the extent of their difficulties.

**Extract 1:** Jenny, 260-261<sup>6</sup>

...my friends and family actually forget that there's anything wrong with me...

**Extract 2:** Ben, 137-140

...a lot of them didn't understand or want anything to do wi' it. Eh, they couldnae understand why you couldnae hear them and a lot of them were mair or less laughing behind yer back and things like that.

Participants suggested that other people viewed AHL as a "minor inconvenience" and did not acknowledge their "constant struggle." The perception that close family and friends "forgot" about their deafness seemed to prompt participants to question whether there was something significantly "wrong" with them. Furthermore, it was hypothesised that this led to identity confusion (For example, "if people don't think there is anything wrong with me, am I deaf?

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<sup>5</sup> Changes in functioning were represented by the theme "I can't do the things I used to" contained within Appendix 18.

<sup>6</sup> Throughout the remainder of the thesis verbatim extracts will be presented in the following way:  
Extract number: Name of participant, Line number (s)

Am I disabled?"). The impact of AHL on participants' identities will be discussed in Themes 3 and 4.

Participants suggested that misunderstandings often arose because AHL was a hidden disability. Participants explained that unlike other disabilities such as blindness, AHL was not an obvious disability that was immediately noticeable.

**Extract 3:** James, 90-92

If you're I mean, God forbid I would hate to be blind, I think that must be terrible but usually when people are blind its very obvious whereas when people have a hearing problem or are deaf that's not quite so obvious...

Participants explained that there was often nothing to identify them as deaf. The invisibility of deafness meant that people often misinterpreted AHL as stupidity, ignorance or a social snub.

**Extract 4:** Lynn, 471-473

...initially people don't know that you've got a hearing problem, unless they can see a hearing aid or something em, whereas if someone's blind or something you can see straight away and they don't think "she's got hearing loss," they think "she's stupid."

**Extract 5:** Ian, 404-409

I mean it is a difficult thing to have because people are not aware of it em, you know, people say if the guy's got a hearing aid then we'll need to speak up a bit but if you don't have any hearing aid and you're deaf then there's nothing, I mean you don't have this sign that says "deaf, speak up" but a blind person will usually walk with a stick and people will help you across this, that and the other, you know this sort of thing, it's a visible thing whereas, this isn't...

The researcher felt that participants' experiences regarding the invisibility of deafness had a number of implications that were relevant to the 8 other super-ordinate themes (particularly Theme 7). First, it seemed that assumptions regarding other people's perception of deafness (for example, that it was "minor inconvenience") often led individuals to question whether they were making a "big deal about nothing." Although this was never made explicit, participant narratives seemed to reflect an underlying concern and uncertainty that perhaps it was only them that struggled with AHL. This anxiety influenced participants' self-perceptions and interpretations of social interactions.

Second, the invisibility of deafness seemed to lead to participants experiencing constant anxiety that social interactions would result in embarrassment or other people perceiving them as "stupid", "grumpy" or "snooty." This appeared to lead to participants experiencing some level of social anxiety.

Finally, the hidden nature of deafness meant that individuals had to negotiate the possibility of disclosing their AHL to others (this will be discussed further in Theme 7).

#### **4.4.2 Discussion in relation to literature**

Participant narratives regarding the invisibility of deafness are consistent with the experiences documented in autobiographical accounts of AHL (Rutman and Boisseau, 1995). A qualitative study of 27 deafened adults also found that participants perceived the hidden nature of deafness to be a major problem that led to difficulties in social interactions (Hallam et al, 2005).

Research on other hidden disabilities (such as epilepsy, diabetes and brain injury) suggests that people with a hidden disability must contend with different challenges from those with visible disabilities. Invisibility has been found to be “both a blessing and a curse,” (Burke and Aimee, 2007). Whilst individuals describe it as providing a positive sense of anonymity, qualitative research suggests that the possibility of strategic self-disclosure can result in an inner struggle to sustain both a “private and public self” (Cleaver, 2008, p.144). As described in extract 4, participants in the present study seemed to believe that the hidden nature of deafness had negative consequences. These consequences will be discussed in relation to the theme of disclosure (Theme 7).

## **4.5 Theme 2: Suddenly everything changes**

### **4.5.1 Description and analysis**

Four participants experienced a sudden hearing loss. Sudden AHL meant that individuals who previously had perfect hearing developed a significant hearing loss within a matter of minutes, days or weeks. Suddenly participants were unable to communicate, function or participate in their lives and this was accompanied by powerful negative emotions.

**Extract 6:** Laura, 121-128

I was in a daze, I was absolutely in a daze and completely overwhelmed, you know, I mean you just don't expect any news like that at all [ ]<sup>7</sup> I was just devastated, absolutely devastated, [ ] I couldn't talk to anybody; I couldn't do anything, I just felt completely cut off.

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<sup>7</sup> As noted in Appendix 14 (Transcription Notation) [ ] indicates that some of the intervening narrative is missing either to shorten the extract or remove material of less relevance. If more than 3 words has been omitted from the extract, the omitted lines are indicated within square brackets e.g. [lines 10-12 suppressed]

Participants described AHL as being completely unexpected, unpredicted and overwhelming. Hearing loss seemed to represent a traumatic event and this was reflected in the narratives of participants.

Conversely, participants who experienced a gradual loss did not seem to perceive AHL as something traumatic or unpredicted. This is perhaps not surprising since individuals had become aware of their AHL before it began to impact significantly on their lives. Five participants experienced a gradual hearing loss. In contrast to sudden onset, there was no discrete onset to their AHL.

**Extract 7:** Ian, 57-60

I mean its very vague when it started, I was probably missing odd things but never aware of it em, [ ] then gradually over the years it just got worse and its been going slowly down.

Furthermore, 2 individuals had a family history of AHL and described it as being normalised within their families.

**Extract 8:** Lynn, 144-146

...because mum had always had a hearing problem it maybe wasn't as bad [ ] the whole family was so kind of used to speaking up for my mum, granny and sister...

#### **4.5.1.1 “I don't know what to do”**

The consequences of sudden AHL left participants feeling overwhelmed and unable to cope.

**Extract 9:** Lynn, 312-317

...it was the first time I had been in the situation where there were times I just couldn't hear at all, I was overwhelmed, I felt totally lost and I didn't know how to cope. I just wandered around the house during the day cause I didn't know what to do and I was too scared to go out in case someone spoke to me and I didn't know what they were saying.

**Extract 10:** Laura, 204-216

I had no experience of trying to cope without hearing and had no idea what to do, what was the right thing to do? How to communicate? [ ] I was really pretty thrown into it, so I didn't have any coping strategies or communication skills.

Both Lynn and Laura described feeling unprepared and unable to deal with the consequences of AHL. It seemed both felt they had no previous experience to draw on and did not believe they had the resources or knowledge to cope with the difficulties associated with hearing loss. Fundamentally, Lynn and Laura did not know how to react or what to do and this appeared to have a significant impact on their daily functioning. It was therefore hypothesised that AHL challenged Laura's existing schemas about the world and left her feeling overwhelmed and unable to adequately interpret her experiences.

#### **4.5.1.2 "My life is over"**

The sudden change in circumstances altered participants' views of the world, themselves and the future. All participants acknowledged that the consequences of AHL had led to depression and for some, the possibility of suicide.

**Extract 11:** Laura, 177-180

... it nearly killed me, the thoughts of, I guess there was a point when I just felt really sorta bleak and possibly even quite suicidal because I, I just couldn't imagine the future sort of reaching ahead of me.

**Extract 12:** John, 127-131

I was contemplating finishing it like [ ] No doubt about that, a couple of times, I was kinda stuck in my car in the middle of nowhere, really, really em, really, really depressed cause I couldn't see any end to it, I couldn't see any way forward.

**Extract 13:** Ben, 46-47

It was very very difficult, very difficult thing, there's times that you even felt like suicidal.

**Extract 14:** Lynn, 320-321

I I felt very, I felt useless really, and just ...of no value in life and I think I did feel very suicidal and very depressed...

John , Laura, Lynn and Ben described feeling hopeless and unable to face the prospect of living without hearing. All of them appeared to experience a sense of helplessness and it seemed that at times they not perceive any possible solutions or alternative ways of living with AHL.

**4.5.1.3 Searching for meaning**

Participants with both sudden and gradual onset AHL spoke of engaging in a process of questioning why they had lost their hearing. Most individuals expected medical professionals would provide an explanation. However, some people were not told what caused their AHL, others believed explanations were insufficient and most felt their expectations were not met.

**Extract 15:** Jenny, 378-383

I was just mad, I was just mad at, I was just, I did, I didn't know, I think part of it was they couldn't explain why it'd happened to me either, they couldn't say this has happen [ ] and that's why that's happened, they didn't know why, it was just a viral illness, you know, taken away my hearing and they couldn't, there was no explanation that was it, em, they didn't know why I'd been so unwell and then I was just mad at the whole thing.

Jenny perceived the explanation of a viral illness as insufficient. This perception was associated with anger directed towards the medical profession. Experiences of inadequate explanations were shared by participants with both sudden and gradual AHL. However, gradual onset participants did not appear to experience such intense emotions and some did not believe explanations were important.

In their search for meaning, sudden onset participants described a process of continually ruminating about the causes of their AHL. Some raised existential questions about why this had happened to them and two searched for an internal cause.

**Extract 16:** Lynn, 506-507

Its just according to this little despair, you know, why me, why has it happened to me?

**Extract 17:** John, 131-134

The other thing that was niggling away at me all the time was “why has this happened see” like, “why has it happened” is there something in my head that’s the problem? Have I got maybe a cancer in there?”

Rumination led John to develop anxieties about his health, resulting in attempts to alleviate these preoccupations.

**Extract 18:** John, 398-401

I was getting MRI scans and everything, trying to alleviate my thoughts [ ] I ended up I didnae believe anybody, I wasnae having it, there had to be a reason for this, there had to be a reason.

For individuals with sudden onset AHL, the unexpected and overwhelming nature of onset appeared to have made it difficult for individuals to process their experiences. Participants’ search for a existential cause or medical explanation for their AHL could be interpreted as an attempt to understand, interpret and assign meaning to their experiences. It could therefore be hypothesised that this searching for meaning reflected individuals’ attempts to gather new information that could be used to modify their existing schemas about the world.

Lynn experienced a gradual hearing loss until an operation, supposed to improve her hearing, left her totally deaf in one ear. Although Lynn felt she had coped with a gradual deterioration

in her hearing, the unexpected failure of the operation led her to experience all of the above themes. In addition, she engaged in a process of self-blame and questioning whether she had done the right thing.

**Extract 19:** Lynn, 539-557

...maybe if I'd thought about it I would have thought I'm better not to get the operation until my hearing was worse [lines 541-555 suppressed ] maybe I was naïve but I just didn't think of it at the time, never ever for one second thought it would be completely deaf in my right ear after that operation.

#### **4.5.2 Discussion in relation to literature**

Overall, it seemed that sudden onset AHL was experienced by participants as a traumatic event which interfered with every aspect of their daily functioning (those who experienced a progressive loss did not seem to describe its onset as a traumatic event). The psychological experiences described by participants are supported by cognitive theories of trauma.

Cognitive theories propose that people actively create internal representations of the world and that new experiences are assigned meaning based on these models. Janoff-Bulman (1992) suggests that three major internal assumptions may be shattered by traumatic events: a belief in personal invulnerability; the assumption that the world is meaningful (predictable, controllable and fair) and a perception of one's self as positive or worthy.

Participant narratives suggested that the unpredictable and uncontrollable nature of AHL challenged their beliefs about the world and their future in it. Participants' search for and preoccupation with explanations for their AHL could be interpreted as a response to the "shattering" of these assumptions. Furthermore, engaging in a process of questioning why traumatic events have happened is a common experience for trauma survivors and chronically

ill individuals and has been understood as a reflection of their internalised state of shock and bewilderment (Charmaz, 1990; Janoff-Bulman, 1992). Furthermore, research suggests that questioning why events occurred appears to be one of the ways individuals modify their schemas about the world (Kendall and Buys, 1998).

Using cognitive theories of trauma to explain the experiences of participants with sudden AHL is compatible with Newsome and Kendall's (1996) recurrent model of adjustment. Both models suggest that an unexpected shift in life circumstances renders prior schemas inadequate and as a consequence individuals experience cognitive disintegration and anxiety (Janoff-Bulman, 1992). Schema focused theories seemed to fit well with the experiences reported by participants.

The emotional reactions of participants, such as shock, depression and anger, seem consistent with stage models of adjustment proposed by Luey's (1980) and others (Livneh, 1991; Shontz, 1975). However, participants seemed to experience shock, anger and depression almost simultaneously and not in the discrete stages proposed. In addition, the participants who experienced sudden AHL did not describe responses that could be conceptualised as denial. Participants with progressive AHL did not appear to experience the same intense traumatic reaction and this appeared to have implications regarding acceptance and adjustment.

## 4.6 Theme 3: Identity and loss

### 4.6.1 Description and analysis

All participants described experiences relating to identity and loss. For some participants this theme captured their current experiences and for others, it represented a previous episode in their lives. Overall, this theme seemed to become prominent immediately after a sudden hearing loss, or when an individual began to perceive a progressive AHL as having a significant impact on their functioning. The theme therefore seemed to be directly related to what individuals could or could not “do.” Although some individuals described developing different perspectives on identity and loss, these will be described within subsequent sections.

#### 4.6.1.1 Loss of Identity

All participants described experiencing a loss of identity as a direct result of AHL.

**Extract 20:** Laura, 461-464

... I know I didn't have nothing but I felt I had nothing. I had no hearing and I didn't have a job so I couldn't define myself and I didn't have an identity, it was like, “who am I?”

Laura felt she no longer had an identity because she was unable to engage in employment.

Laura's role in employment appeared to be a central part of her self-concept. It seemed that the consequences of AHL challenged her previous definitions of self and prompted her to question who she was. For others, changes in identity were related to changes in their social interactions.

**Extract 21:** David, 267-272

I'm more introvert now, [ ] because I don't get involved with other groups and other people now, I've lost the techniques and [ ] when you go into a crowd of people there's a certain amount of acting and bravado, cause otherwise it wouldn't even happen and all that confidence has gone completely. I could get it back, if I could get my hearing back. It's not gone forever, it's just dormant.

David associated loss of identity with a deterioration in confidence. Prior to AHL David worked as a senior manager and spent most of his free time interacting with others. David's proficient social skills and confidence were therefore central to almost everything he did. Losing his confidence was therefore a significant change for David and meant he was not he used to be. However, as with all participants, he believed these changes could be reversed if he regained his hearing. In addition to confidence, participants' feelings of self-worth were also affected.

**Extract 22:** Lynn, 320-321

I felt very, I felt useless really, and just (3)<sup>9</sup> of no value in life.

The consequences of AHL led individuals to feel they could no longer contribute to relationships and to society. Feelings of worthlessness seemed to have a negative effect on participants' self-esteem. Again, for most individuals loss of identity seemed to be associated with participants' inability to "do" or perform their previous roles. It therefore seemed participants' identities were constructed around "doing." AHL prevented individuals "doing" and therefore seemed to take away a definitive part of participants' identities.

Throughout the narratives, participants emphasised that changes in their identity had not occurred through choice. It seemed that participants felt powerless and believed that fundamental changes in their self-concept were an inevitable part of AHL.

**Extract 23:** Jenny, 468-470

...it does change me, it changes you in what you're gonna do, what you enjoy, you know and how you approach situations as well.

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<sup>9</sup> As noted in Appendix 14 (Transcription Notation) numbers in parenthesis indicate elapsed time in second (2) or a dot in parenthesis indicates a tiny (less than 1 second) but noticeable pause (.)

Jenny described hearing loss as having changed every aspect of her life. However, she did not suggest that she played an active part in these changes and attributed them to an external force over which she had no control.

#### **4.6.1.2 Loss of future self**

In addition to loss of current identity, AHL also appeared to impact on participants' perceptions of the future (for example, who they were going to be in the future?).

**Extract 24:** John, 544-546

...I'll never be the same, I can't come to terms with that, [ ] I'll never be the same, you see that's a major disappointment to me, definitely.

John expressed despair that he would never regain his former identity. While he acknowledged that things had changed, John appeared to experience a process of grieving for his past and also his future self. Other participants described envisioning a problematic future, where their AHL would always cause them difficulties.

**Extract 25:** Jenny, 116-118

I suppose it was a reckoning that you were never gonna be that, you know that you could hear all the time and you knew that you wouldn't have any problems and it's just not gonna be like that any more.

Tom felt his hearing loss had forced him to make significant choices which meant he had to give up his imagined future.

**Extract 26:** Tom, 406-417

...I think I would have been (1) married and a parent and I'm neither and that's entirely because of my hearing loss. [lines 408-413 suppressed]...after I got diagnosed [ ], well basically I had congenital hearing loss I then thought quite definitely, "if I have a congenital hearing loss that means if I have kids they're quite likely to have a congenital hearing loss" and felt very strongly that I didn't really want to have kids.

Other participants felt they should be looking forward to particular events (such as retirement) but explained that thoughts about the future merely filled them with dread.

**Extract 27:** Lynn, 355-358

...if my left ear does start to go down any more, what, what will I be able to do? I know it's terrible, but I just keep trying not to think about it, cause I don't really want to think about it cause, you know, I don't know what you would do.

Lynn expressed concern regarding the deterioration of her hearing and it was hypothesised that she used cognitive avoidance as a coping strategy. Most individuals with progressive AHL experienced fear and anxiety regarding the uncertain progression of their hearing loss. Many believed they would be unable to cope if their hearing deteriorated any further but none knew that this would definitely occur.

**4.6.1.3 Loss of control**

Participants had no control over the progression of their AHL and some felt they could not control its impact on their lives. Some participants believed their communication difficulties rendered them unable to control their daily lives.

**Extract 28:** Laura, 362-365

It's just like you are spectating on your own life, [ ] it's like you're in a glass tank, you can see everything you just can't touch it, you're kind of locked in this place and everything is flying about by your eyes and you just can't reach out and get it.

Laura described feeling trapped, cut off from the world and unable to assert control.

Although she could see the world around her she felt unable to intervene and become active and involved in her own life. Her description indicated that she felt alone and almost trapped in a different reality, unable to connect with the world she once knew. Through this powerful image, Laura demonstrated that she was no longer an agent but just a spectator in *her* own life. Unable to become an agent, Laura became dependent on her partner.

**Extract 29:** Laura, 355-357

My partner was doing everything, things like picking up the phone and phoning. I felt like a child really, I lost a lot of independence and that had a knock-on effect on my self-confidence.

Laura's relationship with her partner changed, her role and identity as an independent, contributing adult transformed into that of a powerless "child". This appeared to have significant implications for Laura's self-esteem and self-efficacy. All participants acknowledged that they were reliant on assistive technology for everyday living.

**Extract 30:** Ian, 471-473

I'm very conscious of it, [ ] I think if it packs in then I have a problem, [ ] but yeah, I'm really aware of it.

Ian was constantly aware that he was dependent on hearing aids. Negative feelings regarding reliance on others and assistive technology appeared to reinforce feelings relating to lack of agency and control. However, some participants explained that they did not want to rely on hearing aids and medication.

**Extract 31:** John, 375-377

Eh, I constantly feel sick, that's what these tablets are for, I didnae take them like, cause then I would be relying on them...

Although it would alleviate his symptoms (relating to balance problems) John did not want to become reliant on medication. John's decision could be interpreted as an attempt to regain some control over a potentially uncontrollable situation. For him, becoming reliant would mean surrendering all control.

#### **4.6.2 Discussion in relation to literature**

Participants' experiences of loss of identity are well supported by literature. For example, evidence from personal accounts suggests the most devastating consequence of AHL is its impact on self-identity (Rutman and Boisseau, 1995). Wood (1987) suggested people develop well-established roles and self-identity throughout their interactions with family, friends and work. AHL interferes with an individual's ability to perform these roles and therefore challenges definitions of self.

Charmaz (1990) proposed that loss of self is a fundamental form of suffering for chronically ill persons. She described a process where by a person observes their former self-image "crumbling away without simultaneous development of equally valued new ones" (Charmaz, 1990, p. 1161). Chronic illness causes individuals to experience restriction on their lives, social isolation, feelings of being discredited and being a burden to others and it is this combination of factors that threatens self-identity (Charmaz, 1983; Orano, 1990).

Hearing loss seemed to have impacted on a wide range of aspects of identity across public and private spheres, including: identity as a hearing person; employee; friend; partner; parent and as an independent person (Lemp et al, 2006). The aspects of identity loss varied across

individuals; however, the overall meaning of this loss seemed similar in terms of its impact on self-esteem and self-efficacy.

Participant narratives suggested loss of identity had an impact on their perceptions of the future. Charmaz (1990) proposed that when a person's goals for the future are lost (due to chronic illness or disability) their hoped-for possible self is also lost. Individuals may therefore find it impossible to imagine a positive future self (Pettie and Triolo, 1999). This supports the experiences of some participants who perceived their future as inherently negative and consequently considered the possibility of suicide.

Perceived control over illness has been shown to be associated with psychological adjustment in a range of chronically ill groups (Thompson et al, 1993). Studies have demonstrated that when people believe that they have some degree of personal control (internal-locus of control) over aspects of their illness, such as overall course of progression, they report better psychological adjustment to illness (Griffin and Rabkin, 1998). Conversely, an external locus of control (the belief that outcomes are determined by chance or fate) has shown to be associated with psychological distress.

The majority of participants seemed to view hearing loss as unpredictable and uncontrollable. Although, this view was in some respects realistic, it appeared to cause intense psychological distress. Lack of control was associated not only with onset and progression of AHL but also with individuals' perceived ability to control their lives. Garstecki and Eler (1998) suggested that hearing loss particularly exacerbates feelings of loss of control because it

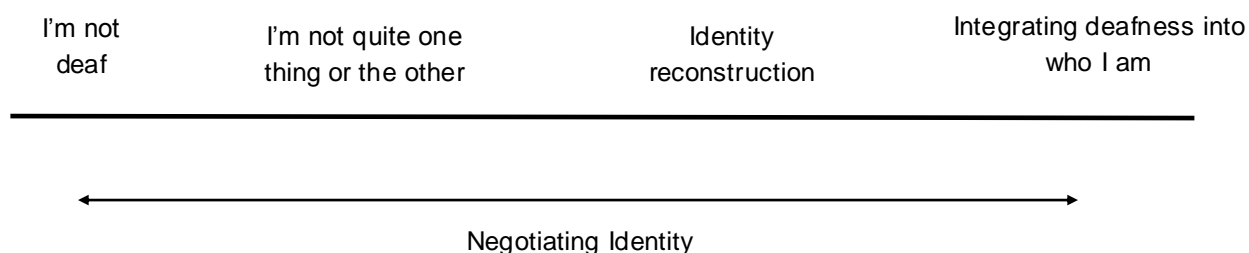
impairs communication with others and often results in a discrepancy between what is said and what is understood.

It was hypothesised participants' experiences of losing their identity (past and future) and the prospect of achieving their future goals challenged the usefulness of their existing schemas. An inability to interpret experiences effectively may have enhanced participants' perceptions of AHL as uncontrollable. For participants with sudden AHL, this theme represented a further psychological threat, which challenged the way they related to themselves, others and the world.

## **4.7 Theme 4: Negotiating identity**

### **4.7.1 Description and analysis**

Most participants seemed to feel that their previous identity no longer fitted with their abilities and experiences. Consequently, they faced the task of negotiating and developing a new identity. Across participants, identity negotiation, appeared to be the core psychological process related to acceptance of and adjustment to AHL. Participants' experiences appeared to represent a continuum of identity negotiation which can be described by four sub-themes. Figure 1 presents the continuum of sub-themes and indicates how participants moved both back and forth along it.

**Figure 1:** Continuum of sub-themes in negotiating identity

#### 4.7.1.1 “I’m not deaf”

Most participants had, at some point, felt that deafness was not and could not be part of who they were.

**Extract 32:** Laura, 367-368

...my identity was really affected because I couldn’t relate to myself as a deaf or deafened person. I just wasn’t, I was a hearing person that suddenly lost their hearing.

Although Laura was painfully aware of her AHL and its consequences, she rejected the possibility that she was deaf or deafened. It appeared that she did not perceive herself as fitting with her internal representation of a “deaf” person. It therefore seemed possible for Laura to acknowledge her profound AHL but at the same time insist it was not part of her identity. This seemed to have led to identity conflict.

David described a time in his life where he did not want to admit he had an AHL. He explained he felt more comfortable blaming others for not speaking clearly than recognising that he was struggling because he had a hearing loss.

**Extract 33:** David, 55

I was annoyed at people asking, um, having to repeat themselves, but annoyed at me having to say to them “what was that?” “what did you say?” So, I felt annoyed at everybody else first of all, I didn’t want to admit it wasn’t because of how they were speaking but that it was because I couldn’t hear.

Other participants reported that they did not identify themselves as deaf to other people.

**Extract 34:** Tom, 296-297

I used to be very self-conscious about it and I would go out my way to describe myself as something that wasn’t deaf, I didn’t use the word deaf...

Tom appeared to indicate that describing himself as deaf would mean acknowledging to himself (and to others) that he was in some way “weak” or deficient. Incorporating hearing loss into his identity would therefore mean he would have to accept something he felt ashamed of.

#### **4.7.1.2 “I’m not quite one thing or the other”**

Although some participants did not perceive themselves as deaf, all participants acknowledged that they could no longer be described as hearing. Laura explained that she felt as if she was neither deaf or hearing but was something in between.

**Extract 35:** Laura, 369 - 372

So, I kinda looked at the, you know, BSL users and deaf culture and all that and they’re very insular, they don’t tend to kind of straddle that boundary its very much deaf with a capital D you know, us sort of stragglers who kinda find ourselves not knowing what we’re gonna do, [ ]. So, I was kind of straddling the boundary between hearing and deaf.

**Extract 36:** Jenny, 64-82

I’m kinda not one thing or the other and that makes it more difficult, it makes it worse...not born that way, [ ] a lot of the groups you go to are mostly signing. I mean I could learn it but I don’t think that’s the point. There seems to be a group of people in the middle that are

kinda you know, sorta floating about ((laughter)) [lines 67-79 suppressed] ... you just come up against people that have been born, you know and they don't understand what the issue is with me or anybody like me, so it's a bit kinda, in the middle.

Jenny felt a new deaf identity was unavailable. For her, experiences of meeting Deaf people confirmed she was different. She could not communicate effectively with hearing or with Deaf people. She felt excluded from the Deaf community and believed they did not perceive her to be deaf. It appeared that she was straddling the boundary between two identities and neither seemed to fit.

While negotiating her identity Jenny described occasions where she would test out her former identity.

**Extract 37:** Jenny, 190-193

I like to just throw caution to the wind, I get into a car and I'll play music quite loud and it hurts and it hurts and I think I don't care, I don't care but, yeah you gotta do that sometimes ((laughter)), it's a bit mad isn't it ((laughter))? Oh dear, that's the person I was.

Jenny described a process of moving between identities, trying to work out who she was.

Returning to her former identity could be interpreted as an attempt to deny her AHL.

However, it seemed that this process allowed Jenny to confirm that her former identity was inadequate but also reassured her that part of her former self continued to exist. Jenny's account indicated that participants did not experience identity as a stable construct but as something much more fluid.

In an attempt to reconstitute their identity participants appeared to begin to develop alternative ways of defining themselves. However, this did not appear to be a conscious strategic process and for some it was a case of trial and error.

**Extract 38:** Lynn, 268-273

I didn't feel it was severe enough so that I could put on my application form that I had a disability cause I felt with my hearing aids, I should be able to cope with most situations, but now I'm thinking should I say it's a (.), you know (.), I know it's kind of a fine line because I kinda felt that if I put it was a disability on the application form it would be even harder to get the job.

Lynn had decided not to describe herself as disabled when applying for a job. However, difficulties at work had caused her to re-evaluate this decision and she had begun to recognise that perhaps she did have a disability. Some participants believed that describing themselves as "disabled" would prompt others to question this identity and perceive them as trying to deceive the system by "jumping on the disability band wagon," (Jenny, p.8, 264).

Narratives regarding this issue seemed to reflect uncertainty. For example, when compared to other themes, dialogue discussing identity tended to contain more incomplete sentences and pauses.

**Extract 39:** Laura, 300-304

...to all intents and purposes I am a hearing person when (2) or maybe just hard of hearing person, (1) um. I don't regard myself as deafened, and I wouldn't (.), I might have gone too far the other way, (.) em, maybe trying to deny that I've actually got a hearing loss but these are just things that you have to kind of try out for yourself.

Within her narrative Laura seemed to be working through her various possible identities and acknowledged that she was unsure who she was. It therefore seemed that identity

reconstitution was a complex and gradual progress during which participants experimented with different possibilities.

#### **4.7.1.3 Identity re-construction**

All the participants reported that meeting other people with AHL had a positive impact on identity development.

**Extract 40:** Jenny, 345-351

... getting involved with [ ] people like me who had become deafened. That was the adjusting thing for me, when I started meeting other people, cause then my life did change, I wasn't, I think I was sort of struggling trying to keep friends with my normal friends but you know, I wasn't like that anymore (2), it doesn't make a lot of sense, but I wasn't and then I met new people and that really helped and then I felt like I had two bits of my life I was that and then I was that, so that's kinda how I got through it.

Jenny indicated meeting other deafened people, with whom she could identify, enabled her to acknowledge the inadequacies of her former identity while providing her with an alternative.

Positive feelings of belonging appeared to have facilitated the development of a deafened identity. However, this new identity did not supersede her former identity but, as commented above, became part of a range of possibilities.

For some, meeting other deafened people also provided an opportunity to become involved in meaningful activity.

**Extract 41:** Laura, 456-458

I wanted to volunteer well. Cause I thought that's a great opportunity to you know, be able to use my own experience to help other people and also get back into a place of, where people work but they also understand, I mean its ideal, you know?

**Extract 42:** David, 275-280

**I:** How would you describe yourself in relation to your hearing loss?

**P:** Well, I've become an RNID volunteer, [ ], I'm trying to get into it and involved with it, helping other people who are worse than me, in a way it is helpful to me to think, "hey I'm actually in amongst a group of people now who don't have all these problems with me," ((laughter)) so I feel kinda like I'm back up near the top again of this group...

Six participants indicated that they had become involved in some level of voluntary work related to hearing loss. It seemed that voluntary work provided participants with a sense of purpose, an opportunity to establish new roles within a safe environment and also to develop a new identity. In addition, it gave participants a chance to use aspects and skills from their former identity within identity reconstruction.

**Extract 43:** Ian, 503-509

I ended up on a group that were preparing a publication for the (name of place), em, about hearing loss about what to do and who to see. So I got involved with that, eh, which was quite good and it just made me see, there are always people worse than you are but it made me see that all the options were there and also I felt as if I wanted to contribute something em, to go along to people and say, you know, "there's people out there who can't hear you, there's people out there who want to be able to come into the bank or whatever and talk to you" [ ], so I like to champion the thing now rather than keep it a secret.

Voluntary work also allowed participants to engage in downward comparisons with others. Perceptions that others were "worse off" appeared to increase participants' sense of self-esteem and self-efficacy.

#### 4.7.1.4 Integrating deafness into who I am

Two participants appeared to have integrated deafness into their identities. Both participants described themselves as being deaf and having a disability.

**Extract 44:** Ian, 433

I'm deaf, I'm disabled, without a doubt.

However, each individual seemed to have incorporated deafness differently. For Ben, deafness had become a central part of his identity.

**Extract 45:** Ben, 289-290

...I've got to say that I am disabled, I've got to call myself that, I'm a disabled (sportsperson), I played for Scotland at disabled (name of sport).

It appeared the majority of Ben's time was spent engaged in voluntary activities (helping other deafened people, giving lectures of deaf awareness and contributing to committees) relating to AHL. These activities gave Ben a sense of fulfilment that he had never experienced during his previous employment. Furthermore, voluntary activities allowed Ben to develop a role as an expert in hearing loss, which appeared to strengthen his identity as a deafened person.

As a result of his AHL, Ian had experienced positive changes in his employment situation (he had changed from a high-pressured job to one he enjoyed doing). However, Ian viewed deafness as only one part of identity (I'm deaf but that's not all I am). While he described himself as deaf, the majority of his relationships and activities (such as employment) did not focus on deafness. For him, deafness appeared to be just one facet of his identity.

**Extract 46:** Ian, 649-650

I'm not hung up about it, I was in the past but I'm not at all now, its more of an irritation and I would rather I didn't have it.

Ian viewed deafness as part of his identity but explained that he would rather it was not. Ian therefore demonstrated that it was possible to accept and integrate into his identity something that he did not like. Acceptance of hearing loss and how individuals manage to integrate something with which they are unhappy are discussed further in theme 8.

**4.7.2 Discussion in relation to literature**

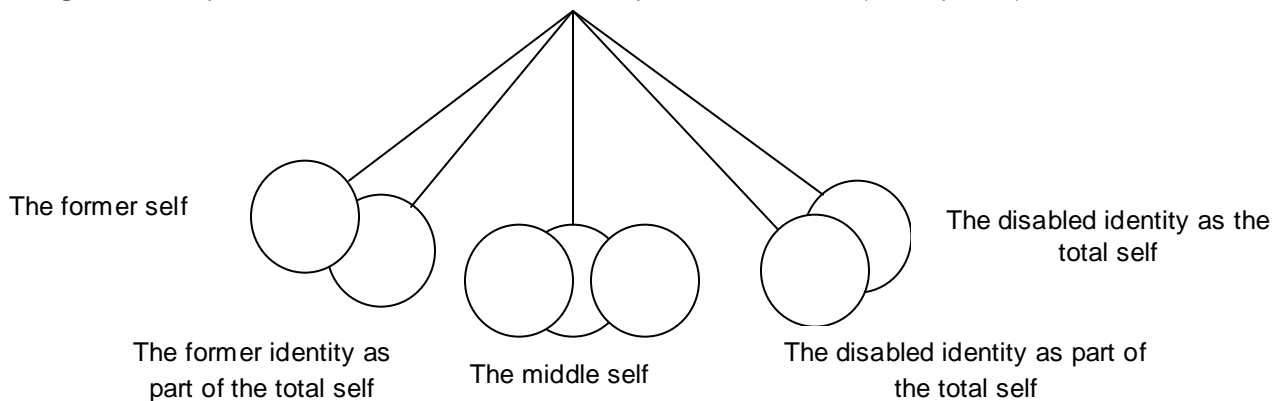
Negotiating identity appeared to be a core psychological process associated with adjustment. Negotiating identity seemed to be best represented as a continuum of identity states. This finding is supported by adjustment literature relating to other disabilities, such as vision loss and rheumatoid arthritis (Hayeems et al, 2005; Lempp et al, 2006)

Participants' experiences supported Woodcock and Aguayo's model of deafened adjustment. Woodcock and Aguayo (2000) proposed 7 stages of identity development, with progression from stage to stage representing adjustment. Across participants, experiences that matched each of the stages were described (for example, extract 10 matched depression, extract 33 was similar to identity comparison and extracts 39,40 and 41 fitted with identity synthesis). However, descriptions did not fit exactly with the 7 discrete stages. For example, Woodcock and Aguayo's model described depression as the final stage prior to identity synthesis and was conceived as a marker of true acceptance. Within the present study, participants generally experienced depression as an almost immediate reaction to AHL and its associated

losses. For participants, depression seemed to be a factor that hindered identity development rather than promoted it.

Yoshida (1993) proposed that identity reconstruction following acquired disability was a continuously evolving and dual-directional process. Using interview data from 35 people who had experienced a spinal cord injury, Yoshida suggested that the process of identity reconstruction involves individuals swinging back and forth, like a pendulum, between non-disabled and disabled aspects of self. Between the outer positions on the pendulum, individuals may pass through and experience different degrees of the nondisabled and disabled selves. Identity reconstruction is always in motion as individuals interpret and take action in the world.

**Figure 2:** The pendular reconstruction of self. Adapted from Yoshida (1993, p. 223).



The swing from former self to disabled identity is likely to be prompted by the failure of the former identity in representing experiences. However, within the disabled identity

individuals see themselves only in negatives terms, leading to diminished self-worth and depression (see extracts 10, 11 and 21).

Over time, Yoshida suggested that the pendulum gradually oscillates less and less and converges on the middle self. The middle self is an integration of the former and disabled identities in which the individual is able to acknowledge the limitations of their disability while developing their total self.

Yoshida's model appeared to support the identity related experiences of participants. Sub-themes 1-5 seemed to represent a process of reconstructing identity, going back and forth between the former identity and their perception of a negative disabled self. When neither identity was adequate individuals engaged in a process of testing out various identities. The final sub-theme of integrating deafness appeared similar to that of the middle self.

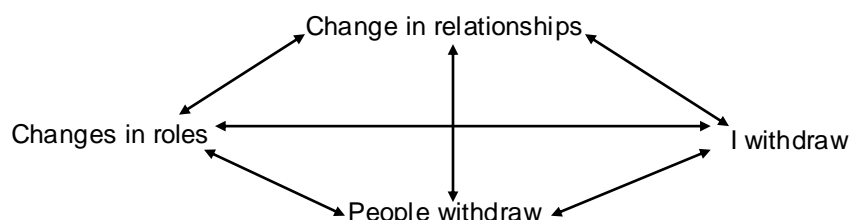
The pendular model of identity reconstruction fits well with the recurrent schema focused model of adjustment proposed by Kendall and Buys (1998).

## 4.8 Theme 5: Relationships with others

### 4.8.1 Discussion and analysis

As a result of AHL, all participants experienced significant changes in their relationships with others. These experiences were represented by three interacting sub-themes. Figure 3 presents theme 5 and its three sub-themes. The diagram also attempts to explain how the themes interact with each other.

**Figure 3:** Interaction between changes in relationships and the three sub-themes.



#### 4.8.1.1 Changes in Roles

Most participants described changes in the roles performed by themselves and others. The majority of the descriptions of the role changes experienced by participants link closely with the sub-theme “loss of control” presented in Theme 3 (Identity and loss). It would therefore have been possible to present this sub-theme as a way in which participants lost control of their lives. However, while changes in roles did represent a loss of control for participants data analysis suggested that these changes were generally discussed in the context of their relationships with others. The evidence therefore suggested changes in roles should be presented as a sub-theme of Theme 5 (Relationships with others).

**Extract 47:** Laura, 476-478

I'm quite independent and I think they realised how dependent I was when I wasn't independent and I did rely on them for a lot of things, acting as an interpreter a lot of the time sitting there with a note book for me...

Laura described that she shifted from an independent to a dependent role, (see also extract 28) and her partner adopted the new roles of interpreter and caregiver. This appeared to have been challenging for both individuals and changed the dynamic of their relationship. Across participants, the most reported role shift was from an active, contributing partner to passive, dependent "burden." For example, prior to AHL David was a successful manager responsible for supervising others and making executive decisions. However, as his hearing deteriorated he took early retirement and became dependent on his wife.

**Extract 48:** David, 119

I need my wife with me if I go anywhere.

David felt as if he was no longer a contributing partner but a "burden" who could not leave home without his wife. Such a dramatic change in role seemed to shift the balance of power within the relationship and it was hypothesised that this had significant psychological implications in terms of self-esteem, self-efficacy and identity.

#### 4.8.1.2 "I withdraw"

Communication problems resulted in the majority of participants withdrawing from social situations.

**Extract 49:** Lynn, 486-487

...socially as well there were things that I used to go to, you know, when I could hear, that I just avoid now.

Participants indicated that avoiding social interactions was often “easier” than facing anxiety provoking and potentially embarrassing situations.

**Extract 50:** Steven, 60-64

...has now got to the stage where sometimes I'm just more comfortable if I am on my own. Not that I really want to be but its easier. Its less stressful, its less embarrassing

**Extract 51:** Lynn, 369-371

...I suppose I feel embarrassed cause I don't hear and I, I feel like if I go to a meeting I hate saying to everyone, oh you know, I wear two hearing aids please could you speak up, its embarrassing. It's a worry knowing that I probably won't be able to hear and it makes you want to just avoid things like meetings as much as possible.

Most participants reported that embarrassment and anxiety were permanent features of social interactions. Some therefore made the decision to socially withdraw as a way of minimising distress.

**Extract 52:** Tom, 451

... its easier to withdraw from social situations.

Social withdrawal resulted in participants' social worlds gradually shrinking and therefore decreased their opportunities for meaningful social interactions (and increased their feelings of loneliness and isolation). Social withdrawal appeared to have short-term benefits (by minimising psychological distress). However, it was hypothesised that in the longer term, realistic concerns regarding communication developed into a form of social anxiety, which made future interactions more difficult. For example, the fact that David never left the house without his wife so he could

**Extract 53:** David, 153-154

... avoid even the wildest possibility of things going wrong,

seemed similar to descriptions of an anxiety disorder.

#### 4.8.1.3 “Others withdraw from you”

Participants perceived social withdrawal as a two-way process and believed that other people also withdrew from them.

**Extract 54:** David, 244-248

If I'm in the gym [ ] you like to sort of say “hello” to people, pass the time of day and they'll speak back and you haven't a clue what they're saying and then they'll look at you and you'll think “oh I should have replied to that” you know cause a lot of the times you just laugh and say “oh yeah,” you know and that gets you by but then there's times when that isn't really what you should have said (laugh). And then you go in the gym and all these people won't speak to you again, you know, you can see them coming in and then they go away round, they wave that's fine I can wave ok. So, you do feel...you're not welcome, not, you're not welcome not for negative reasons really just that you're an inconvenience, difficult to talk to.

David described feeling as if people avoided him because his AHL meant people found it difficult to have a conversation with him.

**Extract 55:** Steven, 327-330

...who I considered quite a good friend and he didn't say to me but he said to my wife on one occasion, he says “och I don't bother to speak to Steven anymore cause he doesnae hear what yer saying.” I thought that was a wee bit unkind.

Steven had been told one of his closest friends no longer “bothered” to speak with him. It was hypothesised that he may have felt this meant his friend no longer cared for him, (for example, “if people cannot be bothered to make the effort, then they must not really care.”)

Experiences of this nature led Steven to question his relationships.

**Extract 56:** Steven, 238-240

...you begin to wonder if, at times, you begin to wonder if em, if the people around you, particularly those closest too you, em, no longer find you very congenial or attractive. You begin to wonder if they still love you.

Steven had noticed that his family no longer “sought him out” and wondered whether this was because they no longer loved him. Across participants, the perception that others withdrew their contact appeared to have significant effects on confidence and self-esteem.

Most participants indicated that they did not “blame” other people as they believed others must find talking to them frustrating.

**Extract 57:** Steven, 254-256

I don't think for a moment that its eh, is not predicated on any ill will of any kind its just that they're trying, you know, it's so frustrating, so stressful for the other person that their trying to survive.

Although participants indicated that they understood why others withdrew, it seemed that participants questioned whether people could still love someone they found frustrating. The researcher also wondered whether participants found it difficult to separate frustration directed at their AHL and frustration directed at them. As deafness was now part of who they were, was it actually something fundamental about *them* that others no longer wished to interact with? Questions of this nature may have lead individuals to consider the future of their relationships. The perception that others found them frustrating seemed to lead to participants avoiding social situations and withdrawing further.

#### **4.8.2 Discussion in relation to literature**

Studies have consistently shown that AHL presents severe challenges to the maintenance of close relationships (Hallam et al, 2008). Personal accounts and clinical research suggest that avoiding social situations is a common coping strategy for people with AHL (Hallberg, 1999). However, research indicates that short-term self-protection frequently leads to

loneliness, anxiety and a decrease in quality of life (Hallam et al, 2007). Evidence regarding social withdrawal therefore seemed to be consistent with participants' experiences.

In a qualitative study of people with AHL and their partners, Hallam and colleagues (2005) found AHL resulted in diminution in expressions of intimacy, impoverishment of social activities, conflicts over the amount of control and independence each partner could exert and disagreements over the best way to manage the increased burden that deafness imposed. Although participants in the present study did not report conflict within their relationships they did experience a significant change in the quality of their relationships. It seemed the very nature of deafness and its impact on communication struck at the fundamental base of relationships.

**Extract 58:** Steven, 93-94

...if you're blind it separates you from things but if you're deaf it separates you from people

It was hypothesised that difficulties in relationships would affect an individuals' ability to access and benefit from social support (which requires communication). This is important to consider because social support has been found to be a significant predictor of positive psychological adjustment to chronic illness (Frankel and Turner, 1983).

Hallam and colleagues (2005) also found that the adoption of new roles within the family was found to "upset the balance of power" within relationships. These findings are therefore consistent with participant experiences of the changes in family dynamics and roles following AHL.

In a study of the personal impact of rheumatoid arthritis, changes in social roles and relationships were found to have a significant impact on participants' identity (Lempp et al, 2006). For example, individuals reported shifts in family dynamics and roles that resulted in them questioning their identity as a parent, partner or friend. In the present study, it seemed also that changes in the roles of participants had a significant impact on their identity. As discussed within the theme of "identity and loss", participants felt they lost who they were. A large proportion of these accounts were related to participants' inability to "do" and this was often followed by a shift in their role within their relationships. Identity loss was therefore not merely something an individual experienced in isolation but a process influenced by changes in social relationships.

## **4.9 Theme 6: Roles in relation to hearing loss**

### **4.9.1 Description and analysis**

Participant narratives seemed to suggest that throughout the process of adjustment individuals adopted a range of roles in relation to their AHL. It often appeared that participants could simultaneously assume a number of often conflicting roles. This theme seemed to be characterised by an underlying ambivalence throughout participants' narratives. The researcher found this difficult to describe and conceptualise.

Initially, this theme was described as "me and others" (services, family and friends).

However, it was felt that the tension and ambivalence between the roles adopted by individuals, was an important theme in its own right. It therefore seemed this would be best represented by highlighting three of the role-tensions that ran throughout participant narratives.

#### 4.9.1.1 Agent versus recipient role

Most participants seemed to simultaneously adopt the roles of active agent and passive recipient in relation to their AHL.

**Extract 59:** Laura, 126-132

...I was just devastated [ ] but I knew I had to do something. I couldn't just sit there, I couldn't talk to anybody, I couldn't do anything I just felt completely cut off. So, I googled, em, I put in "deaf" into google and got a list of all the organisations, all the charities and I just wrote them this huge long email saying, "Please help me," and sent it off to every single charity, organisation, em, that I could, I mean there was literally about hundreds.

Throughout her narrative Laura appeared to be take an active role in seeking and obtaining help and engaging in activities to promote adjustment. Laura gave the impression of being an extremely resilient individual who was constantly pushing herself to move forward. In contrast, Laura often emphasised that she "did not do it alone" and frequently referred to the help she received from others. In this extract Laura described the support she received from a member of staff in a voluntary organisation.

**Extract 60:** Laura, 199-204

... she was an absolute god-send at the time. She emailed me everyday, she was just there all the time and she was an absolute angel, just she didn't have to do it but she very much allowed me, em, the facility to just get out what I was feeling. Absolutely, just pouring it out, you know, "what's this? What's that?" It was very child-like in a way, [ ] (name) was fantastic she was just a life-line for me. [ ].

Laura described her "helper" as an almost angelic figure who provided her with a life-line out of crisis. Laura depicted the "helper" as the agent of change and described herself as "child-like." Throughout her descriptions of receiving help Laura emphasises her adoption of a passive role and often tried to suggest that her "adjustment" was not just a consequence of her own actions but that of others.

Throughout her account Laura simultaneously presented herself as both an active agent or survivor and a passive, grateful recipient of others' charity. It seemed that both roles generally resulted in positive outcomes and that both were adaptive for Laura. Furthermore, it was hypothesised that if Laura had only performed one of these roles she would not have adjusted so well.

#### 4.9.1.2 "I'm the one who has to change" versus "There's nobody there to help me"

Throughout his narrative David implied that it was his responsibility to adapt to and cope with AHL.

**Extract 61:** David, 177-178

I'm the one that has to change, I have to find ways and means not them.

Like David, John believed that he was the only person who could promote his adjustment to AHL.

**Extract 62:** John, 579-581

...you've gotta go out there and face everything, that's what you have to do." But there isn't really anybody out there that can make you do that, the only person that can make you do that is yourself.

Both men therefore suggested adapting was the sole responsibility of the individual and implied that no amount of help could "make" you change. This attitude could be interpreted as an acceptance of the role an individual must play in adjusting to AHL. Indeed both men believed that acceptance of AHL and attempting to independently adapt to it was an important aspect of minimising psychological distress (a further discussion of this issue is presented in theme 8 (acceptance)). However, at the same time both David and John expressed anger and disappointment at the fact that they were expected by services and the

general public to cope on their own. Both appeared frustrated and unhappy with the lack of help they had been offered.

**Extract 63:** David, 352-354

I'm still out there swimming on my own, I mean I'm going round in circles for all I know, there's nobody there to help me, there's no rescue boat there. And even my doctor doesn't really understand enough, there is no support for deaf people.

David presented an image of himself as being all alone in his struggle for survival. The contrast and tension between his two accounts led the researcher to wonder "Why is he disappointed about not receiving help when he seemed to believe it was not what he needed?"

It therefore seemed that while David knew he had to make changes, he would have been grateful for some support. It is possible that both John and David emphasised their active role as a response to the lack of help they received. However, it is also feasible that taking "responsibility" allowed them to feel more in control of an uncontrollable situation and thus helped them to minimise psychological distress. The above extract could therefore also represent an example of David feeling helpless and not in control of his situation. Other participant experiences of loss of control are described in theme 3 (identity and loss).

However, analysis suggested an important tension regarding David's and John's attitudes towards help seeking roles and consequently these extracts were presented within theme 6.

#### 4.9.1.3 “Lucky” versus “Let down”

Tom’s description of his feelings about getting a cochlear implant captured the ambivalence of this theme.

**Extract 64:** Tom, 1051-1056

I’m not complaining about it cause in some ways its miraculous, it really is but, for me that sort of, I don’t feel grateful for it because I resent that I didn’t get it sooner, but (2) I am actually quite well aware that I’m lucky that these things exist and that I’m lucky that the operation has been a success and lucky that I’m adapting to it quite well. So, I don’t feel grateful to anyone cause it should have been done three years ago.

Although, only two participants had a cochlear implant, all participants seemed to perceive themselves as “lucky” but also “let down” by services. Generally participants perceived themselves as fortunate in relation to “others” who were worse off.

**Extract 65:** Lynn, 393

I should think I’m lucky, cause I know there is people who have no hearing at all.

All participants were appalled at the lack of support they received from NHS services.

Stories of services failing to acknowledge or meet the needs of individuals were abundant in participant narratives.

**Extract 66:** John, 482-483

...the hearing guy down at the (name of place) is a waste of time, he’s an impostor, he’s wasting people’s time...

**Extract 67:** Lynn, 637-639

But I do feel really let down by the people that did the operation, because, you know to leave someone in that situation, is really not, not really an (.) an appropriate thing to do I don’t think.

Throughout their narratives participants felt anger at the way they were treated. Most expressed disbelief at the lack of after care and support. Many participants recounted stories regarding their diagnosis.

**Extract 68:** John, 73-75

The consultant at the (name of place), “yeah you’ve got a hearing problem, you’re deaf.”  
Quite an intelligent guess actually, cause I couldn’t hear a word he was talking about.

Most participants felt their consultants were unsympathetic and completely unaware of the psychological impact of deafness. It therefore seemed participants viewed themselves as both fortunate and aggrieved. However, it seemed participants’ expression of “luck” could be interpreted in a number of ways. First, participants generally expressed the idea of being “lucky” alongside their descriptions of inadequate care. The expression of luck could therefore be interpreted as reflecting participants’ social concerns (that they might seem unreasonable or ungrateful for what the services they did receive). Using the term “lucky” might therefore have made participants feel more comfortable about expressing their disappointment at services. Another possible interpretation was that downward comparisons (I am lucky compared to them), were a way of suggesting that they “should be adjusting better.” This possible interpretation is developed further in Theme 9.

**4.9.2 Discussion in relation to literature**

It seemed the above role-tensions related to participants’ experiences of help-seeking and receiving help. It seemed that participants could simultaneously adopt multiple (and often ambivalent) roles in relation to “help” and that this was not necessarily a mal-adaptive strategy.

Participants’ experiences of feeling “abandoned” and “let down” by services are consistent with personal accounts and recent research (RNID, 2004; Hallam et al, 2006). Overall, the literature proposed the process of help-seeking is perhaps more complicated (when compared

to other disabilities) for people with AHL for two reasons. First, deafness impairs an individual's ability to effectively communicate their distress and their need for help. Second, research has found that most General Practitioners and professionals working in the NHS (Ear, Nose and Throat, Audiology and mental health services) are largely unaware of the psychological consequences of AHL (Hallam et al, 2006). Therefore it is possible that even when an individual seeks help, professionals might not believe it is necessary. Furthermore, the distinct lack of specialist services for people with AHL might often mean an individual would have to be placed on a long waiting list or be told there is no help available in their locality (Hallam et al, 2005).

## **4.10 Theme 7: Disclosure**

### **4.10.1 Description and analysis**

All participants discussed the issue of disclosing their AHL to others. Attitudes regarding disclosure appeared to be a key factor in determining how participants interacted with others. Decisions regarding disclosure appeared to be closely linked to issues of identity and acceptance.

All participants reported that disclosure was an important concern because AHL was a "hidden disability." The invisibility of deafness meant that participants had to make decisions about whether to inform other people or to conceal their AHL. Participants' experiences regarding disclosure can be represented by a continuum of three sub-themes. Figure 4 displays the continuum represented by the three sub-themes.



Tom described how disclosing his AHL caused him to experience negative emotions.

Similarly, other participants explained that they had not disclosed their AHL because they felt it represented a weakness. Feeling uncomfortable with disclosing AHL therefore seemed to reflect low self-esteem and negative beliefs about deafness. It also appeared to be related to perceptions regarding their identity. For example, disclosure did not fit with the beliefs of participants within the, “I’m not deaf” phase of identity.

Often participants had difficulty articulating their attitudes regarding disclosure and this seemed to represent their uncertainty about their reasons for not disclosing.

**Extract 71:** Jenny, 267-268

(1) I don’t tell them straight away, I don’t and em, (2) cause I don’t know how they’re going to react I suppose ((laughter)) it’s a big thing...

Jenny’s hesitant narrative indicated that decision-making was not necessarily a conscious process but something that reflected her anxieties about others. One of the major anxieties experienced by participants was that disclosure would change other people’s perception of them.

**Extract 72:** Jenny, 304

...maybe I don’t want people to feel sorry for me.

Jenny did not want to be viewed as someone who should be pitied and therefore given “special treatment.” However, she was also concerned that disclosure could never give an adequate representation of her experiences.

**Extract 73:** Jenny, 309-314

...you just go “oh I’m a bit hard of hearing or whatever” they don’t realise the impact it’s got on your life, you know, if you just say “I’m a bit hard of hearing” they go “oh right,” it’s not really just that is it? Or is it? It’s not really just that it’s everything else isn’t it?

Jenny believed that even if she disclosed her AHL people would not understand the immense impact it had on her life. It therefore seemed she was anxious that others would perceive her as worrying about a minor problem. Her rhetorical questions indicated her own uncertainty about whether she was just not coping with AHL and perceiving it as a major issue when it was not. The discrepancy between Jenny’s two predictions seemed to represent her underlying anxiety and confusion about her AHL.

#### 4.10.1.2 “I should tell people”

Although some participants did not disclose their AHL, everyone believed it was the “right” thing to do.

**Extract 74:** Jenny, 278-279

...it’s stupid really cause you could just say to somebody and be done with it...

Although fundamentally Jenny acknowledged that disclosure would improve her interactions with others, she felt unable to manage this task. She therefore demonstrated a discrepancy between what she felt she should do and what she actually did. In addition, her narrative seemed to indicate that she perceived her inability to disclose her deafness as a failure.

**Extract 75:** Tom, 300-302

...after a while you get to the point where you just can’t avoid, um, cause it’s so obvious and then you get to the point where you really should tell people, when you really need to tell people in order to function.

Tom explained that he needed to disclose his AHL in order to function in his daily life. He felt that hiding his AHL would result in his quality of life being impaired.

#### 4.10.1.3 “I tell people”

Seven participants reported that they usually disclosed their deafness to others. Ben believed people should not view their AHL as a weakness but should take an active approach in helping others to understand it. He explained that in his experience other people did not know how to communicate effectively with him. However, he believed that other people were generally willing to help if you told them how to.

**Extract 76:** Ben, 110-111

You're just as good as anybody else, always tell people that you're deaf and tell them the best way to communication wi' you.

Ben's view of disclosure appeared to be related to his good self-esteem, his role as an “expert” on AHL and his strong deafened identity (described in theme 4). However, other participants were not as comfortable instructing others.

**Extract 77:** John, 178-180

I've had to be quite, I've had to get a grip of mysel' and be possibly more forward and abrupt than I was before because I've got to make it to suit me.

John seemed to experience disclosure as a challenge that forced him to be more assertive and insistent than he wanted to be. David felt that often disclosure did not improve interactions and this resulted in frustration.

**Extract 78:** David, 180-183

...some of them with shock because they realise they're going to have to do something if they really want to communicate with me. Others just sort of say “oh yeah right, oh I'm going a bit deaf myself” and then they forget and just carry on as normal...

Most participants believed that disclosure would enhance communications and therefore increase their quality of life. However, they all acknowledged that there had been times

when they had felt uncomfortable disclosing their AHL. Some participants indicated that they had begun to disclose their AHL through necessity.

Several participants felt their hearing loss was so severe that they were unable to interact with others without them being aware of their AHL. Others said deterioration in their hearing had made their AHL so obvious to others that disclosure had no longer seemed an important issue. It will be argued later in Theme 8 that disclosure of AHL related to participant personality, identity and acceptance.

#### **4.10.2 Discussion in relation to literature**

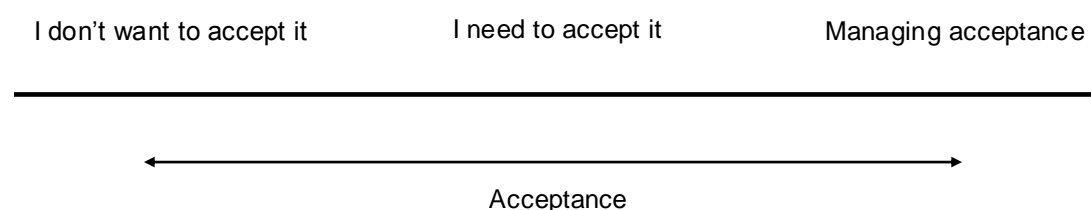
Jones and colleagues (1987) conducted a study of 123 hearing impaired people and found that disclosure was mediated by participants' self-image, view of disability, expectation of response and the perceived rewards and penalties of disclosure. Results were therefore consistent with the experiences of the present study's participants (see extract 65, 66 and 71). Jones and colleagues (1987) attempt to explain the process of disclosure through Goffman's concept of stigma. Goffman (1963) describes an individual who has been disqualified from full social acceptance on the basis of some less desirable attribute as stigmatised. Jones and colleagues (1987) propose that people with AHL are stigmatised and that concealing AHL can be explained as an attempt to "pass" in a hearing world. Disclosure therefore involves identifying oneself as stigmatised and may result in a loss of power and control. Most of the participants described fears relating to the possibility of being stigmatised by others. However, it appeared that many of the participants' anxieties reflected struggles with their own acceptance and identity confusion. This will be discussed further in the subsequent theme.

## 4.11 Theme 8: Acceptance

### 4.11.1 Description and analysis

All participants referred to the concept of acceptance. As with previous themes, the variability in participant narratives seemed to be represented as a continuum of acceptance-related beliefs and experiences. Figure 5 displays the three sub-themes on this continuum.

**Figure 5:** Continuum of the three sub-themes representing acceptance



#### 4.11.1.1 "I don't want to accept it"

Most participants reported times when they did not want to accept their hearing loss. For the majority of participants this theme represented past experiences. For example, Ian described a time when found it difficult to accept that he had a AHL.

**Extract 79: Ian, 677-678**

In the beginning I just did not want to accept that I was going deaf. I didn't want to be seen as some deaf old guy who couldn't hear anymore one.

Although Ian had now managed to accept his AHL (this will be discussed in the subsequent sub-theme managing acceptance) for one individual the feelings Ian described were still a reality.

**Extract 80: Lynn, 427-451**

I still feel I'm at the don't want to accept it stage and, depressed about it and feeling sorry for myself and I don't seem to have got out that stage since the operation was unsuccessful [lines 430-449 suppressed] and (2) I just kind of want to be normal, I don't want to have a hearing

loss, just like I don't really want to be depressed but I can't seem to (.) I can't seem to shake it...

Lynn acknowledged that she could not accept her AHL because she did not want it to be true. For Lynn, acceptance would involve confronting reality and also feeling comfortable with her AHL. She felt acceptance meant she would have to surrender her hatred of AHL and deceive herself into pretending she did not care about it. In addition, Lynn introduced the concept of stages of acceptance. She appeared to suggest she was at the first stage of a journey towards acceptance but felt she could not progress further.

#### **4.11.1.2 “I need to accept it”**

All participants felt that acceptance was the most important stage in living with AHL.

Participants believed that the ideal way to adjust was to accept AHL as quickly as possible.

However, only one participant felt he had no difficulty with acceptance.

**Extract 81:** Steven, 535-555

...I don't think it took me a long time to accept it as I say to varying degrees I have been aware of it for many years but it wasn't impacting on me with quite the severity that it has over the past fifteen years.

The rest of the participants perceived acceptance as a difficult but vital process.

**Extract 82:** David, 223-230

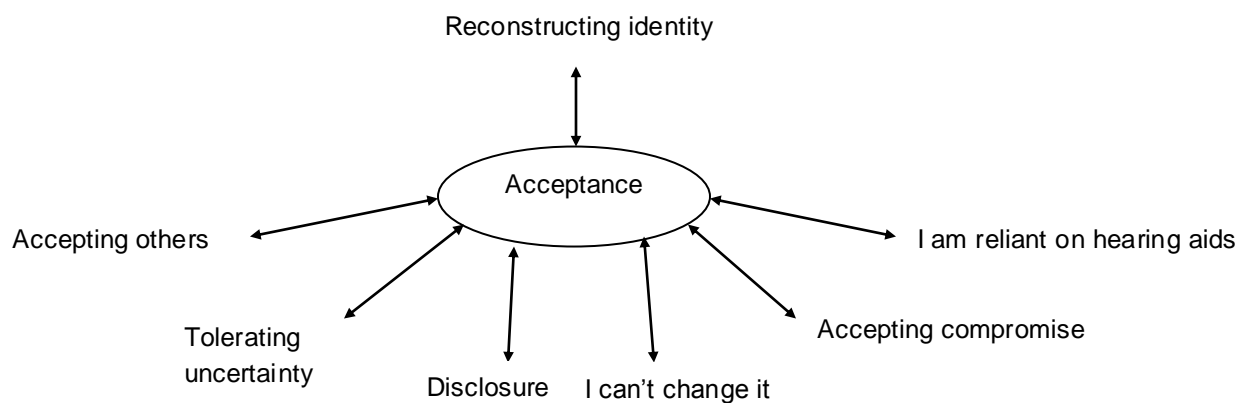
...all my life I don't accept illness, change anything like that, anything that seems defeatist, I am a battler, I fight it, I hate it and so it makes it more difficult for me, well although I say I battle it I still being honest, I have to live with it so, you do it and maybe relatively subconsciously now but do it, so in order for me to live, to want to live, I have to accept it otherwise it's happy farm or something stupid and I'm no way going down that route so yes, you just have to accept that even though I don't like it, I have to accept it.

David explained that he hated accepting his AHL and was explicit that acceptance did not equate with contentment. Although, on some level he felt he would always be grappling, he felt acceptance was vital to maintaining his psychological well-being. He believed that engaging in a constant battle which he could never win would cause him significant distress and he therefore needed to try and accept it. David's narrative demonstrated that participants did not experience acceptance as a dichotomous concept (accepting or not accepting) but a dynamic process.

#### 4.11.1.3 Managing acceptance

Participant narratives revealed that acceptance was a multi-faceted concept. Figure 6 displays the different facets of acceptance. It seemed possible that participants could accept one aspect whilst struggling with others. For example, John acknowledged that his AHL was unchangeable but could not accept his reliance on hearing aids and medication. Similarly, Jenny had accepted the permanence of AHL but did not disclose her hearing loss to others. Each of the facets will now be described in turn.

**Figure 6:** The facets of acceptance described in participant narratives



The majority of participants accepted that they could not change their AHL.

**Extract 83:** Jenny, 417-418

...when these things happen they do change you and you can't, you can't go back, I can't, I can't undo what's happened, I can't, I can't change it...

Jenny explained that accepting the permanence of AHL had taken her many years. Although she believed she had managed to accept it, her hesitant narrative suggested that it was difficult. Viewing hearing loss as unchangeable appeared to be one of the first facets of acceptance participants usually encountered. In general, participants suggested that accepting the permanence of hearing loss was something that happened naturally through time.

Acknowledging that life was often not ideal and being willing to accept compromises appeared to be another important facet of acceptance.

**Extract 84:** Laura, 275-277

Obviously, I would prefer to have natural hearing, cause I still can't listen to music but I think it was probably the best result that I could have got.

Following her cochlear implant, Laura acknowledged that there were some things she could no longer do. However, she recognised that she needed to be willing to accept such compromises. It seemed that acknowledging her life had changed and adjusting her expectations accordingly meant Laura avoided constant psychological distress (such as disappointment and frustration). Adjusting expectations (from those associated with the former self) appeared to be part of identity negotiation (testing out who they were and working out what their expectations should be). It could therefore be hypothesised that this process involved participants revising and modifying existing schemas to fit with life after AHL.

Three participants suggested that they had to be able to accept that other people did not always understand AHL or communicate effectively.

**Extract 85:** Ian, 329-332

...well it's annoying, you know, they, I, I think in sometime in the past, I would probably have felt annoyed by them, "they're doing this on purpose" sort of thing but you know, I know they're not so I don't let it bother me any-more...

Participants suggested that they had to accept the failings of others, contain their irritation and recognise that others were not intentionally excluding them. This appeared to be a difficult task that individuals could not always achieve. However, trying to adopt this attitude allowed participants to negotiate social interactions more effectively and enabled them to protect their self-esteem. Again, participant narratives suggested individuals could move back and forth along a continuum, with anger and frustration at one end and managing to accept people at the other.

Acceptance also involved participants negotiating their reliance on assistive technology and other people.

**Extract 86:** Ian, 472-475

I'm very grateful for having them, I mean I do (.) I see it as a positive thing now whereas if you asked me ten years ago I would have thought it was a very negative thing.

Ian believed that wearing hearing aids "opened up a whole new world." He felt the massive benefit of hearing aids meant he saw them as a positive addition to his life. Ian seemed to view hearing aids as a tool to help him take control, rather than a symbol of dependence. He reflected that, in the past, he had rejected hearing aids for reasons of "vanity". However, he

felt his world view had changed with age and no longer considered “vanity” to be a significant issue.

The researcher also wondered whether Ian’s perception of “being dependent” had altered because of changes in his identity. It was hypothesised that prior difficulties incorporating deafness into his identity (“I’m not deaf”) meant hearing aids were viewed as a symbol of an identity (deafness and disability) he did not want. Reliance on hearing aids could therefore be seen as a challenge to identity and a symbol of his shift in role (from agent to recipient). The struggle against hearing aids could therefore be interpreted as a struggle against deafness. However, as Ian managed to integrate deafness into his identity and regain control, reliance on hearing aids was no longer a symbol of dependence.

Another factor associated with increased psychological well-being was being able to tolerate the uncertain progress of hearing loss. Two participants, who were successfully managing to tolerate this uncertainty, did not raise anxiety regarding deterioration and had to be asked about how they viewed the future.

**Extract 87:** Ben, 514

I say, “well I’ll cross that bridge when I come tae it.”

Although, Ben and Ian hoped their AHL would not deteriorate, they recognised that this was not under their control. Both men appeared to be leading fulfilling lives and this seemed to promote their living in the present and not constantly worrying about the future. As described in Theme 4, both Ben and Ian had appeared to have integrated deafness into their identities.

Finally, participants with a progressive hearing loss explained that acceptance was not a “one-off” task but a constant process

**Extract 88:** Tom, 633-637

...it's been difficult for me because my hearing is constantly going down and every time that I have actually made some level of adjustment to how my hearing was at the time, it only lasted for a few months or a year and then I've had to accept yet another set of problems and so I've, its been chasing a set of moving goal posts which I've never been able to catch up...

Tom described his constant pursuit of acceptance and adjustment as a never-ending and almost impossible task. It was hypothesised that this had significant implications for his sense of control and mastery. Believing that acceptance was vital but feeling as if he could never achieve it probably had a negative impact on his self-esteem and sense of agency. Although, sudden onset appeared to be experienced as more traumatic, such hearing impairments were generally more stable over time.

**Extract 89:** David, 96-97

So, um, it, it wasn't like one day I was ok, the next day I was totally deaf, um, I think if you could have accepted that, that would have been it...

David felt that, in the longer term, sudden hearing loss was easier to accept because what they were accepting did not change. Acceptance seemed like a multi-faceted complex process which was complicated further by changes in hearing and its implications for functioning.

#### **4.11.2 Discussion in relation to literature**

Acceptance of one's illness or disability has been linked to lower psychological distress in a wide range of studies (Austin et al, 1999; Carver et al, 1993; Schiaffion et al, 1998). In addition, McCracken (1998) found acceptance of chronic pain predicted better psychological adjustment on outcome measures. This is therefore consistent with participants' beliefs and experiences that acceptance helps to manage psychological distress.

Until recently, academic and clinical literature appeared to have considered acceptance as being synonymous with adjustment. Consequently, acceptance was presented as a single construct that either was or was not achieved depending on whether someone had adjusted (Nicholas and Asgari, 2006). However, participants suggested that acceptance and adjustment were separate concepts that should be assigned different meanings. Participants seemed to define acceptance as the act of adopting an attitude that acknowledged a certain consequence of AHL and no longer trying to deny or change this consequence. While acceptance could therefore be viewed as an aspect of psychological adjustment (i.e. a change in how an individual's cognitions and attitudes to AHL), participants seemed to have a different view of the concept of adjustment (this will be discussed further in Theme 9).

More recent studies, particularly in chronic pain, lend some support to participant's separation of the two concepts (of acceptance and adjustment) and have begun to focus on acceptance as an important variable in its own right (Esteve et al, 2007). Furthermore, acceptance has now become the focus of psychological interventions such as Acceptance and Commitment Therapy (Hayes, 1999).

In a grounded theory study of adjustment to end-stage renal failure, Wright and Kirby (1999) found acceptance was a complex process that could be “deconstructed” into three components of emotional, cognitive and behavioural acceptance. This seemed consistent with participants’ experiences of acceptance as a multi-faceted construct. The different facets of acceptance detailed above, seemed to fit well with Wright and Kirby’s three components. For example, cognitive acceptance was characterised as “absence of worrying thoughts about illness or treatment.” This appeared consistent with the sub-theme of tolerating uncertainty and perhaps also with accepting compromise.

Wright and Kirby found that all three aspects of acceptance did not have to occur simultaneously. In addition they discovered that individuals often moved between accepting to rejecting their illness. These findings are consistent with the notion that participants could accept one part of their AHL but not another. Wright and Kirby’s study also supports the hypothesis that participants experienced acceptance as a dual-directional dynamic process.

The concept of acceptance will be discussed further in relation to Theme 9.

## 4.12 Theme 9: Conceptions of “adjustment”<sup>10</sup>

### 4.12.1 Description and analysis

In contrast to acceptance, only one participant introduced the concept of adjustment during their interview. However, the interview schedule (Appendix 2) included one question related to the concept of psychological adjustment to AHL. Thus, the concept of “psychological adjustment” was introduced regularly by the researcher during the interviews. In this sense the theme was not participant led but rather maps onto one of the empirical questions raised by the project. This theme was deemed important to include because the researcher was surprised at how some participants made sense of the concept. Furthermore, the theme appeared to have important implications for future research and clinical practice. The structure of the theme reflected the experiences of participants and its content was therefore grounded in the data.

One initial response to questions regarding adjustment was one of uncertainty.

**Extract 90:** Laura, 499-502

**I:** Some people talk about adjustment to hearing loss. What do you think about that and what does that mean for you?

**P:** Um (.), I’m not (3), I don’t know that’s a difficult one (.) I suppose I never really thought about it.

Laura indicated that she had never really considered the concept of adjustment. Her hesitant response could suggest adjustment was not a familiar term. Laura’s response was representative of the response given by another two participants. Given the prevalence of the

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<sup>10</sup> From here on in the term “adjustment” will be referred to using inverted commas to indicate that there was no shared understanding of this concept, between the participants’ and the researcher. If the term is presented without inverted commas (adjustment) this indicates that the concept used is synonymous with that used in current literature.

term in rehabilitation counselling, it was notable that only one participant introduced the term and that at least three of the participants admitted they had not previously considered it.

Another group of participants responded by giving examples of practical adjustments they had made in their lives.

**Extract 91:** David, 211-213

Em, all my working life I've been taught to look at people right between the eyes and now I have to look at their lips.

Consistent with David's narrative, other participants gave examples of the communication strategies and assistive technology that they now used. Participants within this group did not explicitly refer to psychological issues and appeared to view adjustment as merely incorporating changes in their behaviour or environment. This was in contrast to their narratives regarding acceptance that appeared to suggest acceptance was central to maintaining psychological well-being.

#### **4.12.1.1 "Adjustment" as an ideal**

The majority of participants indicated that there was a "right" or "best" way to "adjust" to AHL.

**Extract 92:** Jenny, 377-378

**I:** What would be, you said you didn't adjust very well to start off with, what would adjusting well be, what's adjusting well like?

**P:** Just accepting it straight away probably, accepting that that was that and get on with it.

Participants who felt there was a “right” way, all agreed that immediate acceptance, making the appropriate practical changes and “getting on with it” would be the ideal way to adjust. Participants seemed to describe “good” adjustment as a relatively simple and emotionless process. Descriptions of this “ideal” process significantly contrasted with participants’ rich experiential accounts of losing their hearing. Participants such as Jenny, who described intense psychological distress, fundamental changes to her identity and quality of life and the complex process of identity negotiation, presented “good” adjustment as a simple, non-psychological process. These descriptions could indicate that participants were just unfamiliar with the actual term “adjustment.” However, the discussion below proposes that participants perceived this standard of “good” adjustment as something very different from their own experiences.

The assumption that there was a “right” way appeared to lead participants to compare and evaluate their experiences against this ideal.

**Extract 93:** Jenny, 331

Well (2) I think it took me a long time to adjust, I don’t think I did it very well.

Jenny felt that her emotional distress meant she had not adjusted “well.” This seemed to indicate that she believe “good” adjustment did not involve emotions. The majority of participants reported similar beliefs regarding their adjustment.

**Extract 94:** Tom, 629-632

...well I’ve been very bad about adjusting to deafness. Partly um, because I haven’t done that well I think, partly because I haven’t been given good advice and partly because it was in me not to take advice, it was in me to sort of think that I could overcome my problems which I couldn’t really do.

Tom believed he had been “bad” at adjusting. He felt this was because he had not accepted advice or help and had tried to “overcome” problems which he needed to accept rather than fight. In addition, Tom felt he had not been offered the help he required. Although he attributed some of this failure to others, he thought it had generally been his fault.

**Extract 95:** Tom, 637-642

I kind of blamed myself in a way for not dealing with it better but in some ways it's been very difficult and um, I shouldn't blame myself but you know, it's part my, the way I see myself is that I should have done better, I shouldn't have let it get me down but it did get me down and I should probably have recognised how much it gets me down and done something about it but I didn't.

Tom and other participants engaged in a process of self-blame for not adjusting “well.”

Although, Tom acknowledged he was perhaps being too critical, he still described a list of things he “should have done better.” Tom's ability to reflect on his self-criticism was not representative of other participants. Tom was the only participant who had had contact with mental health services and attributed his “insight” to a course of cognitive behavioural therapy.

Some participants questioned why others could easily adjust when they “struggled.”

**Extract 96:** Lynn, 502-504

I know mum had a hearing problem and she dealt with it very well, em, and she never ever felt sorry for herself or anything, she just got on with things but I seem to (3) struggle.

Lynn suggested her family history of hearing loss made it easier for her to accept AHL.

However, she believed that when compared to other family members, she was failing.

Inherent in Lynn's narrative was an assumption that if others could adjust then she must be doing something wrong. As discussed in the themes 1 and 7 (“a hidden disability” and

“disclosure”), Lynn and other participants therefore seemed to ask “is it just me that finds this hard?”

Some participants compared themselves to “other people” they did not know.

**Extract 97:** David, 253

...there are people a damn site worse off than me.

While downward comparisons seemed to have been helpful for David with regards to reconstructing his identity, in terms of “adjustment,” participants seemed to use comparisons as a way of negatively evaluating themselves.

**Extract 98:** Lynn, 457-465

...other people have had quite terrible things happen to them and they seem to be able to cope with it and get on with their life [ ]. So, I think it is hard with hearing (2) cause it is a loss, I mean it's a bit like, I suppose when someone dies, you've got to, you know, you've got to accept it's happened and then go through the pain.

Lynn also appeared to compare herself to “other people” whom she imagined adjusted to life events “well.” As in extract 74, Lynn described adjustment as a process that occurs in stages. Her perception that there was a “right” way to adjust which occurred in stages was therefore consistent with stage models of adjustment discussed in chapter one.

Comparisons with others led participants to speculate about how others could adjust and they could not.

**Extract 99:** Lynn, 455-460

I think some people, you know they've got very strong personalities and eh, you know its like some people you see that have had illness or something and they feel sorry for their selves and you know, you can see that their just not happy and yet other people have had quite

terrible things happen to them and they seem to, to be able to cope with it and get on with their life, I don't think I'm the type of person that just gets on with it, I sit around feeling sorry for myself and I'm not sure how I can change that

Lynn believed that an individual's premorbid personality played a substantial role in adjustment. She suggested that her "struggle" was a consequence of her "weak" personalities. Lynn appeared to assume that personality was a stable, unchangeable characteristic. She therefore seemed resigned to the fact that she would not adjust "well" to hearing loss and could not see an alternative future.

It appeared that participants perceived "adjustment" as an ideal or standard which they had not achieved. It was interesting that none of the participants felt they had achieved this ideal but all of them believed "others" had. It therefore seemed the assumption that there was a "right" way to adjust was unhelpful for participants and led to negative evaluations of self. This finding seemed to have important clinical implications which will be discussed in chapter 6.

#### **4.12.1.2 "Adjustment" as survival**

Most participants described some experiences which the researcher would perceive as "adjustment." For example, Ian and Ben appeared to have incorporated deafness into their identities, David had begun to establish valued roles and meaningful activities and Lynn and John had returned to employment following their AHL. However, the majority of participants did not perceive these changes as meeting *their* criteria for "adjustment."

**Extract 100:** Laura, 440-445

**I:** So if they weren't adjustment, how would you describe the things that you...?

**P:** ...so it was kinda a survival thing for me. It was like, I've got two choices one of them is to do, is to put myself in situations which are gonna be hard with communication or isolate and I get worse and worse and that's frightening because you can see where that sort of chain of thought and that, those behaviours lead, you know, very bleak and em, yeah, it wasn't so much a choice per sae it was survival I think.

Laura described how she managed to regain agency over her life by gradually exposing herself to anxiety provoking situations. While the researcher would interpret this as a process of adjustment, Laura rejected this concept and suggested that it was neither "adjustment" nor "choice" but "survival." Laura appeared to indicate that this process was merely an attempt to meet her most basic need (to survive) and did not meet the standard of "adjustment." Similarly, John preferred to use the term adaptation and did not view his experiences as "adjustment."

**Extract 101:** John, 379-383

**P:** ...you just gotta adapt, as you say people adapt, you get adaptive, if you get your leg cut off you know, you adapt. Em, its, ah, something you gotta do. That's all I can say about it happening like.

**I:** How do you go about it?

**P:** I don't know how you go about it. I think it comes natural like.

Like Laura, John considered his "adaptations" as something he had to do. He could not explain how he had managed to make these "adaptations" but felt it was something that just happened "naturally." John and Laura's perceptions of this process were extremely different from that of the researcher. Both John and Laura had experienced such psychological distress that they seriously contemplated suicide. Throughout their narratives they came across as resilient and determined individuals who had taken an extremely active role

regarding their AHL. Their portrayal of “adaptation” as something that came “naturally” therefore seemed inconsistent with the rest of their narratives.

It seemed that there was a discrepancy between participant and researcher understandings of “adjustment.” While the researcher viewed adjustment as the psychological and behavioural changes participants seemed to be making, participants understood it differently. It seemed that for participants, “adjustment” was either a term they had never considered or one that represented a simple, non-psychological “ideal” reaction to AHL (which did not fit with their experiences). It seemed that they felt their experiences could not be conceived as “adjustment.” Participants thus allowed the researcher some access to their underlying assumptions regarding “adjustment”. The researcher felt possible assumptions were “adjustment should be simple,” “adjustment is something you chose to do,” “when you do it right, adjustment is easy,” “it is courageous people that adjust,” and “adjustment is something you either do well or do badly.” It was therefore hypothesised that if participants’ experiences did not fit with their assumptions (for example, if they experienced AHL as complex, challenging and their reactions involved “survival” but they assumed “adjustment” should involve decisions, be simple and easy) they then did not interpret them as “adjustment.”

#### **4.12.2 Discussion in relation to literature**

As discussed in chapter one, stage models perceive adjustment as evolving through a series of stages culminating in an individual achieving psychological adjustment (Garske and Turpin, 1998). In psychology, adjustment often refers to a desirable state or endpoint for which

individuals should aim (Sharpe and Curran, 2006). Inherent in stage theories is the notion that there is a “normal” or correct way to adjust (Kendall and Buys, 1998).

Silver and Wortman (1989) argue that there is little empirical evidence to support stage models of adjustment. Despite contrary evidence, they suggest stage theories are still embedded in our “clinical lore” and cultural understandings as representing the “right” and “normal” way to adjust. Consistent with these findings, the majority of participants seemed to believe that there was a “right” or “ideal” way to adjust.

In contrast, qualitative research suggests adjustment is an idiosyncratic process, characterised by continual peaks and troughs (Kendall and Buys, 1998). Adjustment is therefore not seen as a one off task but as a continual process. As described in discussions regarding identity reconstruction and acceptance, participants’ experiences appeared to be consistent with a recurrent or pendular model of adjustment.

However, it seemed that although clinical and academic understandings of adjustment had moved toward a more recurrent model, participants’ interpretations were generally based upon the assumptions of stage models (for example, there is a right and a wrong way to adjust). Although the researcher interpreted some of their experiences as “adjustment,” participants did not believe this term matched their own experiences and meanings of what “adjusting” (well) is.

It therefore seemed that there was a discrepancy between the perceptions of the participants and that of the researcher. Consequently, there did not seem to be a shared understanding of the term adjustment. Furthermore, it appeared that this key psychological concept (that has been extensively researched) was rejected or considered unhelpful by participants. This finding has significant implications for clinical practice and future research and will be discussed in chapter six.

## **5. Reflections on the research process**

The following chapter outlines my experiences of and reflections on the research process.

Further reflections on the methodological limitations of the present study will be presented in chapter 6.

### **5.1 Being a novel qualitative researcher**

Overall, the process of conducting qualitative research was a steep learning curve for me. At every stage of the process I felt I was “learning on the job” and noticed I was constantly questioning whether I was “doing it right.” I feel that my inexperience may have interfered with my initial interviewing style and meant that I required supervision to encourage me to become more interpretative in my analysis. However, I believe my constant doubt prompted me to be more aware of my decision making process and my influence over the analysis this therefore enhanced the quality of my research.

### **5.2 Talking to people who have a hearing loss**

When I was looking back through my diary, I was surprised that I had consistently mentioned my anxieties regarding communicating with participants.

**Extract 102:** Reflective journal, 08.12.07

Talking to deafened people makes you paranoid about how you are speaking. Am I speaking loudly enough, slowly enough, clearly enough? It makes you feel self-conscious; it's a bit embarrassing and is quite intimidating. Maybe hearing people shy away from speaking because they are worried they will get it wrong?

Although I was reasonably experienced at communicating with Deaf and deafened people, throughout the process I constantly questioned whether my communication skills were good

enough. I therefore wondered if other hearing people experienced these anxieties and whether they may have been a partial explanation for why participants felt others withdrew from them.

### **5.3 Dual role of researcher and trainee clinical psychologist**

Throughout the interview process I became extremely aware that my role of trainee clinical psychologist had a significant impact on my interview style. I felt my clinical psychology training meant that I was used to quickly developing rapport during interviews, conducting risk assessments and containing emotional distress. However, my familiarity with clinical interviews also meant that I struggled to “stop being a psychologist.”

**Extract 103:** Reflective journal, 29.02.08

I found it very difficult not to jump into the “helper” role and start giving advice. It’s difficult not to summarise, reflect back and attach a meaning. It’s hard not leading but being completely neutral and just curious.

I often found that I had consciously to refrain from trying to “look for problems” and propose a formulation. I also found it difficult not to offer help when a participant was obviously struggling with difficult emotions.

### **5.4 Emotional impact of the process**

Throughout the interviews participants described distressing experiences and expressed powerful (generally negative) emotions. This, inevitably, had an impact on me. I often found that participant narratives made me feel tremendously sad and often powerless.

Although, I discussed possible sources of support with participants following the interview, I generally felt that I would have liked to have offered them more help. At times I think I

found it difficult tolerating negative emotions because I knew that I would not be offering them the opportunity to work through these. In addition, I think the process of transcribing interviews and having to listen to accounts of distress over and over while at home, made the research often much more emotionally demanding than my clinical work.

In addition to negative emotions I often felt a sense of admiration at the way participants had coped with such difficult experiences. Overall, participants' narratives showed them to be inspiring and resilient individuals. However, in general participants did not seem to share my view and perceived themselves as to be adjusting less well.

## **5.5 Reactions of participants**

Throughout the process I was impressed by participants' willingness to share their stories.

**Extract 104:** Reflective journal, 13.02.08

I feel privileged people are telling me information they have never told anyone else before. I understand why people would share such information in therapy sessions: it's longer term and the person would have expectations that it might help. But telling a researcher who they will never see again? Is that easier? Maybe they feel it is very important to say the truth to a researcher? Maybe nobody has asked them before; nobody has taken an interest or has given them the opportunity?

I was surprised that people were prepared to discuss such distressing experiences so openly.

An unexpected outcome of the process was that most of the participants reported that they had received some therapeutic benefit (perhaps an opportunity to organise their experiences) from the interview.

**Extract 105:** Jenny, post-interview email, 06.03.08

Thanks for the email and the interview. What a laugh I had reading it. I can't believe what a blether I am. It made me laugh and cry, I could hardly believe it was me as well, being honest for the first time probably since I lost my hearing. Thanks for that.

Jenny's email seemed to highlight the lack of opportunity most of the participants had had to talk about their experiences. I therefore felt it highlighted a gap in service provision.

## **5.6 Data analysis**

As I stated in my reflective preface (chapter 3), I approached the analysis with the assumption that the experience of hearing loss has psychological implications. As a trainee clinical psychologist, I felt I brought to the analysis my knowledge of psychological concepts, mental health problems and some knowledge of current research on adjustment to life events.

Throughout the research process, I tried to be mindful of my prior knowledge and assumptions and endeavoured to ensure that themes emerged from participant narratives.

However, as I was explicitly attempting to explore the psychological processes involved in adjustment, my prior assumptions undoubtedly shaped the analysis. For example, my research focus prompted me to exclude three themes, regarding the physical issues and functional impairments associated with AHL, from further analyses. Furthermore, I believe that some of the terminology I used within the analysis might not have been introduced by someone who did not have a background in psychology. However, despite these issues, every care was taken to ensure that themes were grounded in the data and it did appear that AHL had profound psychological implications.

I found it interesting that participants and I seemed to have very different understandings of the concept of adjustment. It was therefore challenging to ensure I presented these different interpretations. This was particularly difficult when I felt participants were being overly critical and under-acknowledging their achievements and resilience. I therefore felt as if I was caught between wanting to tell readers about their accomplishments and knowing that this would not be an accurate representation of their perceptions. The clinical implications of the discrepancy in understandings of adjustment will be discussed in the subsequent chapter.

### **5.7 Impact of the research on my clinical work**

I found the experience of conducting a qualitative study had a positive impact on my clinical work. Listening to, transcribing and reflecting upon interviews encouraged me to reflect on my interview style. For example, I realised that I often asked a question and then gave participants some possible answers. Obviously, this limited participants' responses and was therefore not an ideal interview style. Becoming aware of this habit and trying not to do it, allowed me to be more client led in my clinical interviews.

## **6. Discussion**

### **6.1. Aims of the present study**

The present study aimed to explore individuals' experiences of the process of psychological adjustment to AHL. In addition, the present study attempted to explore what the concept of adjustment meant to people with AHL. Given, the dearth of research in this area, the present study aimed to explore how participants' experiences fitted with current models of adjustment. The research aims will now be discussed in relation to the present findings.

### **6.2 Summary of key findings**

Table 10 displays a summary of the key findings regarding individuals' experiences of the process of psychological adjustment to AHL. Each of the 9 super-ordinate themes and their corresponding sub-themes are described in detail in chapter 4. In addition, each theme has been discussed in relation to relevant literature. Given the number of findings it is impossible to discuss them all within this chapter. Consequently, the research aims will be used as a framework for discussion. In addition, findings that appear to have significant implications for clinical practice will also be discussed.

### **6.3 Participants' understandings of "adjustment"**

Table 10 summarises the key findings in relation to participants' understandings of the term "adjustment." As discussed in chapter 4, participants' understandings of adjustment appeared to be based on a stage model. The researcher hypothesised that participants' understandings could be represented by 5 assumptions (displayed in Table 11).

None of the participants believed they had “achieved adjustment.” Although the researcher believed many of the participants’ psychological and behavioural changes could be interpreted as “adjustment,” it was hypothesised that participants did not perceive it as such because they did not think their experiences fitted with the assumptions. It therefore seemed participants understood the concept of “adjustment” very differently from the researcher.

**Table 10:** Summary of the key findings relating to each of the nine themes

Theme	Key findings
1. A hidden disability	<p>Participants felt their family, friends and the general public did not understand the massive impact of AHL</p> <p>Participants believed misunderstandings arose because deafness was a “hidden disability”</p> <p>Participants’ assumptions regarding other people’s perceptions seemed to prompt them to question if they were making a “big deal about nothing”</p> <p>Having a “hidden disability” seemed to result in participants experiencing anxiety that social interactions would lead to embarrassment or others making erroneous perceptions</p>
2. Suddenly it all changes	<p>Sudden hearing loss seemed to be experienced as a unexpected and traumatic loss</p> <p>Participants with a progressive AHL did not seem to experience it as a traumatic loss</p> <p>Participants suggested sudden AHL resulted in them feeling overwhelmed and unable to cope</p> <p>Following sudden AHL most participants experienced depressed mood and some considered suicide</p> <p>Participants with both sudden and gradual losses questioned why hearing loss had happened to them</p> <p>Sudden hearing loss was considered in relation to cognitive theories of trauma</p>
3. Identity and loss	<p>All participants described experiencing a loss of their identity following AHL</p> <p>Loss of identity appeared to be related to participants inability to “do” and engage in their usual social roles</p> <p>Loss of identity seemed to have a negative impact on participants self-esteem</p> <p>Some participants described losing their imagined future and future self</p> <p>Most participants experienced a loss of agency in their lives</p>

	<p>Participants experiences of loss ( identity, future and agency) were found to be consistent with previous research regarding psychological adjustment to chronic illness and disability</p>
4. Negotiating Identity	<p>In response to losing their identity most participants engaged in a process of identity negotiation or reconstruction</p> <p>Negotiating identity was interpreted as the key psychological process involved in adjustment to AHL</p> <p>Participants' experiences of identity negotiation were represented as a continuum of 4 sub-themes</p> <p>It was suggested participants tested out their former and possible new identities by moving back and forward along the continuum</p> <p>Meeting other deafened people and establishing new and valued roles seemed to be important in identity re-construction</p> <p>Participants' experiences of identity negotiation appeared to be consistent with a pendular model of the reconstruction of self and the recurrent model of adjustment</p>
5. Relationships with others	<p>Most participants described changes in the roles performed by them and others</p> <p>Participants reported increased social withdrawal and anxiety</p> <p>Most participants believe other people withdrew from them because of their hearing loss</p> <p>Changes in roles and relationships appeared to have a significant impact on participants' self-esteem and identity</p> <p>Participants' experiences were consistent with previous research</p>
6. Roles in relation to hearing loss	<p>Following AHL participants appeared to simultaneously assume a number of often conflicting roles</p> <p>Participants' accounts seemed to reflect a tension between the roles of agent and recipient.</p> <p>In relation to help seeking, participants appeared to experience a tension between "I'm the one who has to change" and "there's nobody there to help me"</p> <p>In relation to services and support, participants often perceived themselves as being both "lucky" and "let down"</p>
7. Disclosure	<p>Participants' decisions regarding disclosure appeared to be related to acceptance and their perceptions of self-identity</p> <p>Participants' attitudes and experiences of disclosure appeared to be a important determinant in how they interacted with others</p> <p>Participants' experiences were represented as a continuum of three sub-themes along which participants could travel back and forth</p> <p>Accounts of disclosure appeared to be consistent with previous research on AHL</p>
8. Acceptance	<p>All participants raised and discussed the process of acceptance</p> <p>Acceptance appeared to be related to an individual's current identity status</p>

	<p>Participants' reflections were represented as a continuum of acceptance related beliefs and experiences</p> <p>Most participants felt acceptance was a difficult but vital process in minimising psychological distress</p> <p>Acceptance appeared to be a complex multi-faceted process rather than a dichotomous construct. This was consistent a small number of qualitative studies</p> <p>Participants with a gradual hearing loss felt acceptance was not a "one-off task" but a constant process</p> <p>Participants seemed to perceive acceptance as an important concept that was different from adjustment</p>
9. Adjustment	<p>Only one participant introduced the concept of adjustment during their interview. In 8 interviews the concept was introduced by the researcher</p> <p>There appeared to be a discrepancy between how the participants and the researcher perceived adjustment</p> <p>Some participants were unfamiliar with the term but most seemed to view "adjustment" as a simple, non-psychological process</p> <p>The majority of participants seemed to believe there was a "right" or "ideal" way to "adjust" and this seemed similar to stage models of adjustment</p> <p>In general, participants engaged in negative comparisons between their own experiences and the "ideal adjustment" (e.g. that they "did not do it very well")</p> <p>Although the researcher believed that all participants had managed some level of "adjustment," participants did not interpret their experiences as such.</p> <p>Participants interpreted their responses to AHL as a process of survival that came naturally. The researcher felt participant interpretations regarding "adjustment" were inconsistent with the rest of their narratives</p> <p>The researcher hypothesised participants' understandings of adjustment could be represented by 5 assumptions.</p>

**Table 11:** Participants' hypothesised assumptions regarding "adjustment"

<b>Assumption 1</b>	Adjustment should be simple
<b>Assumption 2</b>	Adjustment is something you choose to do
<b>Assumption 3</b>	When you do it right, adjustment is easy
<b>Assumption 4</b>	It is courageous people that adjust
<b>Assumption 5</b>	Adjustment is something you either do well or do badly

The researcher's assumptions regarding "adjustment" were based on academic and clinical literature. She understood "adjustment" as the process of psychological, interpersonal and

behavioural change in response to AHL. Although, it was unlikely her assumptions were representative of those held by all “professionals”, it was hypothesised that her interpretation was at least consistent with those presented in current literature.

It seemed that a concept which had been the focus of considerable research did not share the same meaning for participants. This suggested that when researching “adjustment” it cannot always be assumed that participants share the same understanding as the researcher.

Although study may be limited in terms of its generalisability to the wider AHL population, this finding seemed to have implications in terms of how research is transferred to clinical practice. For example, it seemed a professional would need to be cautious about how they used research containing the term “adjustment” within their clinical sessions. Further implications for clinical practice will be discussed in a subsequent section.

#### **6.4 Models of acceptance and “adjustment”**

As discussed in chapter 4, it appeared that participants viewed acceptance as an important and relevant concept. Given the issues surrounding “adjustment”, it was felt that it would be more appropriate (and consistent with participants’ accounts) to discuss models of acceptance. Although traditionally models have generally focused on adjustment, it seemed current models were also relevant to the process of acceptance.

Participants’ experiences seemed to support Woodcock and Aguayo’s (2000) model of deafened adjustment and their assertion that AHL is experienced as a threat to self-identity.

As described by Woodcock and Aguayo, identity loss appeared to be one of the key

psychological consequences of AHL. Furthermore, it seemed participants' experiences of negotiating their identity was an important task in terms of managing to accept AHL.

Across participants, descriptions of experiences that matched each of Woodcock and Aguayo's seven stages of identity development were found. Table 12 presents each of Woodcock and Aguayo's seven stages and indicates how themes from the present study corresponded.

**Table 12:** Comparisons between Woodcock and Aguayo's model of deafened adjustment and findings from the present study

<b>Woodcock and Aguayo Stage</b>	<b>Corresponding themes from the present study</b>
Identity confusion	Theme 2: "I don't know what to do" Theme 2: "My life is over" Theme 3: Loss of identity Theme 4: "I'm not deaf" Theme 8: "I don't want to accept it"
Identity comparison	Theme 2: Searching for meaning Theme 4: "not one thing or the other"
Identity concession	Theme 7: "I try to hide it"
Identity recognition	Theme 4: Identity re-construction Theme 7: "I tell people"
Deaf activism	Theme 4: Identity re-construction (engaging in volunteering)
Depression	Theme 2: "My life is over"
Identity synthesis	Theme 4: Integrating deafness into who I am Theme 8: Managing acceptance

As displayed in Table 12, there appeared to be considerable overlap between the findings of the present study and the model proposed by Woodcock and Aguayo (2000). However, participant narratives from the present study, did not cluster into themes that map directly on to the seven stages presented by Woodcock and Aguayo. For example, Woodcock and Aguayo described depression as the final stage prior to identity synthesis and conceived this as a marker of true acceptance. Within the present study, participants generally experienced depression as an almost immediate reaction to AHL and its associated losses. For participants, depression seemed to be a factor that hindered identity development rather than

promoted it. Furthermore, as presented above some of the stages were supported by the present study more than others (such as Deaf activism and Identity concession where only support by one sub-theme). Woodcock and Aguayo's model in combination with the findings from the present study suggest that identity is a crucial concept in terms of psychological adjustment to AHL. However, given the lack of empirical research presented by Woodcock and Aguayo and the limited generalisability of the present study's findings, it seems further research is required to explore issues of identity loss and identity reconstruction in AHL.

Stage models, such as that proposed by Luey (1980) did not seem to adequately represent participants' experiences. Consistent with research on other disabilities, stage models offered a linear, uni-directional description of acceptance that appeared to be too simplistic to capture the complex experiences of participants (Silver and Wortman, 1989). It therefore seemed that a recurrent model of "adjustment" and acceptance was more consistent with the data.

As described in chapter 1, the recurrent model proposed that unexpected life events challenge an individual's existing schemas (Newsome and Kendall, 1996). The recurrent model therefore suggested that "adjustment" and acceptance were processes of developing, revising, modifying and re-structuring schematic representations of themselves and the world (Kendall and Buys, 1998). Inherent in the recurrent model was the assumption that "adjustment" and acceptance were dual directional processes. As described in chapter 4, participants' experiences seemed to be consistent with a continuum of acceptance related beliefs and experiences (along which they moved back and forth). Furthermore, acceptance appeared to

be a multi-dimensional construct that incorporated different facets. Participant narratives suggested that it was possible for individuals to accept one part of their AHL but not others. It was therefore hypothesised that the construct of acceptance was composed of many facets, each representing a continuum of beliefs and experiences.

## **6.5 Factors related to acceptance**

Participant narratives revealed a number of factors which appeared to be related to their movement back and forth along the continuum of acceptance. Each factor will now be discussed.

### **6.5.1 Type of onset**

As discussed in chapter 4, it appeared that the onset (sudden or progressive) of AHL had a significant impact on participants' experience of acceptance. It appeared that individuals with sudden AHL experienced onset as a traumatic loss. Although those with progressive AHL also experienced psychological distress, they did not seem to experience this loss as a traumatic, unpredicted event. Some participants with progressive AHL felt acceptance was particularly difficult because of the constant deterioration in their hearing. Constant deterioration meant individuals felt that they were "chasing a moving set of goal posts" (Tom, 636). In terms of the continuum model, it seemed individuals with progressive AHL were continually battling to move toward "acceptance" but were pushed back, along the continuum, with every drop in hearing loss. After every deterioration, individuals would have to begin to accept a new set of functional limitations. Despite these differences both

groups of participants experienced similar issues in relation to identity and interactions with others.

### **6.5.2 Duration of living with hearing loss**

Stage models generally assume that acceptance occurs over time (Kübler-Ross, 1969).

Participants' narratives did seem to suggest that time facilitated acceptance. However, participant experiences did not suggest that the length of time living with AHL was always the most important variable associated with acceptance. In the present study, it seemed that a longer duration of living with AHL did not necessarily mean that a participant would have achieved a greater level of acceptance than someone who had had an AHL for a shorter period of time. For example, Steven said that his AHL did not significantly impact on his life for the first thirty years. He said that he did not experience the consequences of AHL (described in the present study) until thirty years after onset. Although Steven had been living with AHL for forty-three years, he experienced similar issues to John who had only been deaf for three. It therefore seemed the relationship between time and level of acceptance was complex and that given the small sample size, the present study could not provide a sufficiently detailed explanation of the association between the two variables. It is therefore recommended that further research explores the relationship between time and level of acceptance and whether the findings of the present study are generalisable to the wider AHL population.

### **6.5.3 Mental health problems**

Three participants reported that they had experienced clinical depression. A further participant admitted that she had experienced suicidal ideation and others appeared to describe experiences consistent with anxiety difficulties. Although it was not always explicitly stated, it seemed that in this study, experiencing depression or anxiety interfered with a participants' ability to accept their AHL. This was consistent with research relating to chronic illness that suggested depressed people demonstrate illness-specific negative biases that are not evident in patients with the same illness who are not depressed (Sharpe and Curran, 2006).

### **6.5.5 Identity negotiation**

Across participants identity negotiation appeared to be a core psychological process related to the acceptance of AHL. All participants described experiences that could be interpreted as identity negotiation. It appeared that the process of identity reconstruction was consistent with the pendular model proposed by Yoshida (1993). Participants' experiences suggested that as an individual began to develop a new identity as a deafened person, they moved along the continuum towards acceptance. For example, it was hypothesised that viewing oneself as deafened was an important factor in whether an individual disclosed their deafness (theme 7) and also in how they interpreted their reliance on hearing aids (theme 8). Furthermore, both individuals (Ben and Ian) who appeared to have integrated deafness into their identities also generally seemed to have accepted their AHL.

As with all facets of acceptance, individuals could move back and forth between identity states. However, meeting other deafened people, engaging in meaningful activities and establishing new valued roles appeared to help individuals to develop alternative identities.

## 6.6 Generalisability of findings

Professionals reading qualitative research often have concerns regarding about the generalisability of research that is based on small sample sizes (Mays, 1995). Like other qualitative methods, IPA is an idiographic approach. Unlike nomothetic approaches, IPA studies do not tend to make claims regarding generalisability<sup>11</sup>. In contrast to quantitative research, qualitative samples are rarely drawn from a representative sample of the population of interest and consequently are not statistically generalisable. However, Smith and colleagues (1999) proposed that, if done well, IPA studies should be viewed as having theoretical rather than empirical generalisability. Qualitative studies should be theoretically generalisable, in that the ideas developed should have some relevance beyond the actual participants in the study (Green, 1999). Theoretical generalisability involved the reader making links between IPA findings, their own personal and professional experience and claims in the existent literature. Theoretical generalisability therefore invites the reader to decide whether findings are generalisable out with the sample. Green (1999) recommends two questions that readers can ask themselves to gauge how useful the research is for them:

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<sup>11</sup> The word 'generalisability' is defined as the degree to which the findings can be generalized from the study sample to the entire population (Polit & Hungler, 1991).

- Has this research report made me think differently about my practice, or the motivations of my patients or the problems they may face in completing treatment regimes?
- If this report is about a different client group, or a different community, are the general ideas relevant to the community within which I work?

While theoretical generalisability is perhaps a useful concept for professionals who are familiar with the population of interest, it seems that it may be difficult for a reader who has no previous experience to judge whether the study is generalisable in this way. It therefore seems that both the empirical and theoretical generalisability of qualitative research methods is somewhat limited.

The researcher does not suggest the present study's findings are generalisable to the experiences of all people with AHL. However, exploring the experiences of nine individuals provided rich experiential accounts of AHL. The findings from the cross-analysis of these accounts seem to have some implications for clinical practice.

## **6.7 Implications for clinical practice**

### **6.7.1 Implications for services**

Findings from the present study suggested that AHL had significant psychological consequences. Hearing loss seemed to affect core aspects of participants' identities and changed the dynamics of their interpersonal relationships. Hearing loss resulted in

participants feeling as if they had lost who they were. Perhaps not surprisingly, more than half the sample reported experiencing some level of depression or anxiety. However, it seemed that only one participant had been referred to mental health services for psychological assessment and treatment. These findings appeared to be consistent with recent research that indicated deafened people rarely felt their psychological needs were met (RNID, 2004). It seemed that this study further highlighted the need for professionals and services to consider the psychological needs of AHL. There are currently no specialist mental health services for deaf or deafened people in Scotland. Furthermore, professionals in mainstream services are often unaware of how to communicate with deaf and deafened people. It is therefore hoped that the government's commitment<sup>12</sup> to provide mental health services for deaf and deafened people includes psychological support for those dealing with AHL and is replicated in Scotland (NIMHE, 2005).

Table 13 presents some recommendations for services. Some were suggested by participants during their interviews and others were recommended by the researcher. For example, all participants felt the service they had received from Ear, Nose and Throat (ENT) and Audiology was unsatisfactory. Participants suggested that staff should be given training in deaf awareness and communication tactics, Participants also highlighted that professionals gave no advice regarding (and did not appear to be aware of) appropriate support services. The majority therefore suggested professionals should be given training regarding the available support services and also in how to signpost individuals appropriately.

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<sup>12</sup> This refers to a commitment made by the Department of Health and only applies to England and Wales.

A number of participants explained that ENT and Audiology services would be greatly improved if they employed individuals with an AHL as peer support workers. Participants believed that talking to a person with AHL who understood their difficulties, was able to give advice, discuss the emotional impact of AHL and act as a positive role model would help to decrease the negative emotions experiences at the time individuals were diagnosed.

Evidence from data analysis suggested that ENT and Audiology services needed to consider the psychological impact of AHL. For example, it appeared that professionals would benefit from training on how to appropriately discuss emotional distress and how to communicate diagnoses in a sensitive manner. Given the high prevalence of mental health problem found in this and previous studies it seemed that services should perhaps consider routinely screening for psychological distress using self-report measures.

### **6.7.2 Recommendations for professionals working with people with AHL**

Despite limited generalisability, it is worthwhile considering the possible implications for clinical practice of the present study's findings regarding the concept of "adjustment." First, professionals should not assume that individuals with AHL share their understanding of "adjustment." Professionals should therefore ask people what their understanding of the term is prior to discussing it with them.

If an individual believes there is a "right" way to adjust and holds some of the assumptions described above, they might consequently view psychological distress as a symbol of "bad

adjustment.” Individuals might therefore be reluctant to share their experiences because of fears that professionals will think they are adjusting “badly.” Furthermore, participant narratives suggested that people with AHL frequently believe that other people perceive

**Table 13:** Possible Recommendations for Clinical Practice

<b>Finding</b>	<b>Recommendation for Clinical Practice</b>
Most participants were unhappy with the services they received from ENT and Audiology	<p>Participants suggested that where possible, follow-up appointments should be with a consistent named member of staff</p> <p>Participants suggested staff should be trained in deafened awareness and communication tactics</p> <p>Professionals should receive training in how to “break bad news” and also how to normalise individuals’ emotional distress</p> <p>Professionals should always try to sign-post individuals to appropriate support services such as social work, voluntary services, support groups or lip-reading classes</p>
Participant experiences and available literature suggest there is a high prevalence of depression and anxiety among individuals with AHL	<p>GPs, ENT* and Audiology departments should consider routinely screening for psychological distress using self-report measures</p> <p>Appropriate self-help information should be given to people with AHL</p> <p>Individuals experiencing mental health problems should be given the opportunity of accessing psychological support and/or therapy</p>
Most participants believed meeting other deafened people help them to accept their hearing loss and develop a new identity	ENT and Audiology departments should consider employing and training peer support workers (deafened people) to provide advice, information, emotional support and normalisation. Peer support workers could also act as positive role models for newly deafened adults
Many participants believed engaging in voluntary work or employment helped them develop new and valued roles. This appeared to have a positive impact on identity development and acceptance	Professionals should encourage individuals to engage in meaningful activities (which are manageable following AHL)
Participants experienced difficulties in inter-personal functioning as a result of hearing loss	Support should be offered to families of individuals with AHL. Family or couple therapy may be required.

\* Ear Nose and Throat

deafness as a “minor inconvenience.” Consequently, individuals might be hesitant to share their distress with hearing professionals because of fears they might be negatively evaluated.

Professionals should try to refrain from using stage models of adjustment and be mindful that their use might prompt individuals to engage in negative self-evaluations. Professionals’ clinical practice should be informed by the recurrent model of acceptance and adjustment. It is suggested that professionals should therefore assume that individuals will move back and forth along a continuum and be aware that this does not necessarily represent “maladjustment.”

Above all, professionals should provide information and education to individuals about common reactions (such as identity loss and loss of role) to AHL. Individuals should be encouraged to discuss their distress and professionals should aim to normalise this.

## **6.8 Methodological limitations**

### **6.8.1 Design limitations**

Participants’ approximate duration of living with AHL ranged from 18 months to 43 years. This meant that when discussing onset, participants were reflecting on experiences that might have occurred many years ago. The retrospective nature of the study therefore meant it was not possible to argue definitively that participants’ accounts reflected accurately the full reality of their experiences at the time when they first lost their hearing. It is possible that participants might have forgotten important aspects of their prior experience or that their

process of recollection had been biased by subsequent events. It therefore would have been useful to have recruited a wider range of participants (in terms of duration since onset) including some individuals who had just lost their hearing. However, research indicates that there is generally a period of eight to twenty years between the time that an individual first notices hearing difficulties and when help is sought (Carson, 2005). It therefore seemed unlikely that such participants could have been recruited using similar methods of recruitment.

The study's cross-sectional design meant causal relationships between themes could not be established. In addition, a number of participants suggested that the interview had occurred at a particularly good or bad time in their lives and that their narrative might not have been representative or how they felt at other times.

**Extract 106:** Laura, 620-623

...you're probably catching me on quite a good day, if you'd interviewed me about a year ago I probably would have been a bit less confident, a bit less sure of the future, you know, because I've had over the past year, had experiences which have built up my confidence as well.

Furthermore, some participants felt that it would have been interesting to conduct interviews over a number of years to get a more accurate representation of their process of acceptance and adjustment.

**Extract 107:** Tom, 126-127

I was thinking it might have been interesting for you had interviewed me before and after my implant.

It is therefore recommended that future research addresses these concerns and considers conducting longitudinal studies using multiple interviews over a number of years.

### **6.8.2 Sampling limitations**

It is worthwhile noting that the present study may not have recruited a truly representative sample of people with AHL. Although three sources were used, an individual was only recruited if they had made some contact with social work or voluntary services.

Beattie (1981) found that 65% of a sample of adults with AHL were unwilling to join a local hard of hearing club, while Kyle and Wood (1983) reported that only 9% of their sample had experienced contact with agencies specifically for hearing impaired people (such as RNID or local organisations). Hallam and colleagues (2006) also found that many people with AHL had difficulty accessing social work service support.

These findings indicate that people who access voluntary organisations, social groups and social work services may not be representative of the majority of people with AHL. This study therefore only recruited participants who had been diagnosed with a hearing problem, who had acknowledged that they required some support and had also sought help. The sample did not include people who denied or did not seek help for their AHL. This meant that the sample only contained people who had already managed some level of acceptance and adjustment and who were also willing to discuss their experiences. It therefore seemed that the present study's findings may not have been generalisable to all people with AHL.

### **6.8.3 Limitations of IPA**

It is possible that the use of IPA limited the exploration of theme 9 (“adjustment.”) In accordance with the principles of IPA, each transcript was analysed individually after all the interviews were complete (Smith, 1996). Consequently, the researcher did not have the opportunity to follow up this unexpected and interesting finding. In terms of this theme, it might have been beneficial to use a grounded theory approach. Grounded theory would have allowed information on participants’ understandings of “adjustment” to be carried forward and then explored in subsequent interviews (Strauss and Corbin, 1998). This would have provided a more refined and enriched framework for understanding this important finding (Charmaz, 2006). Although it seemed IPA was still an appropriate choice of methodology for this novel area of research, further studies should consider using grounded theory to develop a more detailed understanding of people’s perceptions regarding the concept of adjustment in relation to AHL.

### **6.9 Recommendations for future research**

It seemed the most important recommendation for future research related to the concept of “adjustment.” The findings of the present study seemed to suggest that participants understood “adjustment” as something very different from acceptance. In addition, participants believed there was a “right” way to “adjust” and perceive it as a simple, non-psychological process. Given the plethora of research regarding adjustment it seems important that future qualitative research explores how this concept is experienced and understood by the people whose lives it is describing. Future research should aim to uncover whether people’s assumptions regarding “adjustment” are consistent with those hypothesised above. In addition, research should explore the differences between the concepts of

acceptance and “adjustment.” Research should be carried out across a range of disabilities and chronic illnesses.

As mentioned in the preceding section, future research regarding acceptance and “adjustment” to AHL, should consider using longitudinal designs conducting multiple interviews over a number of months or years. In addition, studies should try to meet the challenging task of recruiting participants who do not access support services and also those who have just begun to experience AHL.

In terms of service based research, it is recommended that ENT and Audiology departments design, implement and evaluate pilot projects which establish whether employing peer support workers, conducting routine screening for psychological distress and providing communication training for staff would be useful service developments.

It is also possible that the findings of the present study could be used to inform the development of quantitative measures of acceptance or adjustment to AHL. At present there does not appear to be a questionnaire that measures acceptance or adjustment to AHL. However, given the high prevalence of psychological distress associated with AHL, it seems probable that the use of a measure that assessed how an individual was adapting to AHL would be extremely useful to services (as it would enable them to identify individuals that required additional support).

If more time had been available, it would have been worthwhile for the researcher to use the findings of the present study (and of previous research) as a starting point for the development of a questionnaire that measured acceptance and adjustment to AHL. Although

it seems no such questionnaire for AHL currently exists, questionnaires measuring similar dimensions for other chronic illnesses and disabilities (such as the Adjustment to Chronic Skin Diseases Questionnaire [Stangier et al, 2003] and the Psychological Adjustment to Illness Scale [Derogatis, 1986]) have been successfully developed. It seems that often the use of qualitative methodologies (such as semi-structured interviews or focus groups) is deemed a necessary precursor to the development of questionnaire items (Jack, 2006; Newman, 2006). It therefore seems that using the findings of the present study in this way would ensure they contributed, in some way, to the evidence base. Furthermore, using the present study's findings as the basis of questionnaire development would provide an opportunity for them to be tested across a wider population of individuals with AHL. The development of a quantitative measure would therefore could go some way to addressing the problem of the limited generalisability of qualitative methods and would provide evidence regarding the relevance of the present study's findings to the wider AHL population.

## **6.10 Conclusions and future directions**

The present study aimed to explore individuals' experiences of the process of psychological adjustment to AHL. Findings suggested that AHL has a profound impact on a participant's sense of identity and also changed the dynamics of their interpersonal world. These changes appeared to be accompanied by significant psychological distress. Overall, participants felt their psychological needs were not met by services and that they were consequently "left" on their "own."

The process of acceptance and "adjustment" appeared to be complex and dual-direction. Participants' experiences seemed to be consistent with the recurrent model proposed by Newsome and Kendall (1996). The psychological process of identity negotiation appeared to be an important factor in how individuals' experienced acceptance and "adjustment." It was therefore recommended that services recognise the key role of psychological factors in AHL and attempt to meet individuals' needs according.

One of the most important findings related to participants' beliefs and assumptions regarding "adjustment." Although this study may have limited generalisability, it suggests that perhaps clinicians should not always assume that individuals share their understanding of particular concepts. It demonstrated that clinicians should endeavour to let their interventions be guided by people's own terms that match their unique experiences. The present study therefore highlighted the important role of qualitative research in developing rich and detailed understandings of the complex processes involved in people's psychosocial worlds.

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## **8. List of Appendices**

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## Appendix 2: Interview Schedule



### Interview Schedule

**Can you tell me what level of hearing loss you have?**

Prompt:

- Practical terms i.e. what can you hear and not hear
- Audiological terms i.e. db, category of hearing loss

**Can you give me a brief history of your hearing loss from when it started until now?**

Themes /Prompts:

- Thoughts and feelings at each stage of the journey
- When did you first notice your hearing loss?
- Was it gradual or sudden?
- When did you seek help?
- How did your life change?
- What help were you offered?
- Hearing technology?
- Where are you now with your hearing loss?
- Perceived impact on others?

**What does your hearing loss mean to you?**

- Themes/Prompts:
- How do you feel about your hearing loss?
- What has it meant for your life?
- What do you think about your hearing loss?
- Perceived impact on others?



**What does the concept of adjustment to hearing loss mean to you?**

- Themes/Prompts:
- What do you think about adjustment?
- Do you think you have adjusted?
- What factors are important in adjustment?
- Do you ever achieve adjustment?

**How do you think your hearing loss has impacted on other people in your life?**

- Family
- Partner
- Friends

**Throughout your experience of hearing loss what has helped you?**

- Themes/Prompts:
- Professional help
- Social support

**What help would you have liked to have received but didn't?**

**Is there anything important, which we have not already discussed, which you think is important to mention?**

**General Prompts:**

- Can you tell me more about that?
- Has that changed?
- What does that mean to you?
- Can you explain that a little more?
- Can you help me understand that?

**END OF INTERVIEW – GO OVER WHAT HAPPENS NOW WITH THE DATA**



## Appendix 3: Participant Information Sheet for LINK Centre Participants

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
TD1 1PF

Tel  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



### Participant Information Sheet

**Study:** A qualitative study of psychological adjustment to acquired hearing loss

I would like to invite you to take part in a research study. Before you decide you should read the following information.

#### **What is the purpose of the study?**

There is strong informal evidence that acquired hearing loss can have a huge impact on an individual's daily life. Unfortunately, there has been little academic research exploring how adults adjust psychologically to it. This study aims to investigate how people adjust and cope with acquired hearing loss by interviewing people who have experienced it.

#### **Why have I been invited?**

I am inviting people who have acquired a moderate, moderate-severe, severe or profound hearing impairment in adulthood to participate. You have been invited because you have had previous contact with the LINK Centre.

#### **What will I have to do?**

If you would like to participate, you will be asked to meet with me and answer some questions on your experiences of hearing loss. The interview will take about one to two hours. The interview will take place in an appropriate setting of your choice. The interview will be recorded.

When you come for the interview, you will be given a copy of some of the questions you may be asked. You will then be asked to decide if you would still like to take part. If you would like to take part, I will ask you to name a professional you would be happy for them to contact, if they were concerned about your mental health or well-being. You will also be asked to sign a consent form to show you have agreed to take part.

#### **What will happen to my interview recording?**

I will listen to the recording and transcribe it on to a computer. Once the interview has been transcribed the interviewer will send you a written copy of the interview. You will be asked to confirm if the written copy is an accurate account of the interview. If you are unhappy with the interview you can withdraw it at any time. If the written copy is accurate, the researcher will add it to other interview transcripts.



### **Appendix 3: Participant Information Sheet for LINK Centre Participants**

They will then use computer software to look for themes across all the interviews. After I have been completed the interview recording will be destroyed.

#### **Will my answers be confidential?**

All the information discussed in the interview will be kept confidential. However, if I am concerned about your mental health or well-being I may contact your named professional. I will not do this without discussing it with you first.

So that I can send you a copy of your interview, I will label your interview transcript with your initials. However, once you have confirmed the written account of the interview, the recording and information on the computer will be anonymised. The research report will discuss themes across all the interviews and will not include any information that would identify individual participants.

#### **Do I have to take part?**

It is up to you to decide whether to take part. You do not have to take part. If you do not want to, your future care and legal rights will not be affected. If you would be unhappy with me contacting a named professional you should not participate.

If you decide to participate and change your mind later you can contact me at any time and withdraw your interview.

If you have any questions about this information please contact me.

#### **If I would like to take part what I should do?**

If you would like to take part please contact me using the contact details below. Alternatively, you can ask Linda to pass on your details to me and I will contact you.

Researcher: Suzie Black  
Trainee Clinical Psychologist  
Text:  
Email:

If you would like to receive a summary of the results from this study please tell me at your interview or contact them using the details above.

If you would like some information on mental health related issues such as depression, anxiety or bereavement you should contact Jenny Hastings on 01896 668 831 or [jenny.hastings@borders.scot.nhs.uk](mailto:jenny.hastings@borders.scot.nhs.uk) for free self-help information.

Thank you for your time it is much appreciated.

## **Appendix 4: Invitation Email to LINK Centre Outreach Volunteers**

Hi,

My name is Suzie Black and I am a trainee clinical psychologist studying at Edinburgh University. I am currently carrying out research into people's personal experiences of acquired hearing loss and am looking for volunteers to take part in the research. Although, there is strong informal evidence of the impact of hearing loss on people's lives there is very little academic research in this area. I am hoping that this study would give clinical psychologists, counsellors and other health professionals a better insight into acquired hearing loss and encourage them to design appropriate services.

**IF YOU ARE INTERESTED IN THE RESEARCH READ ON! IF NOT, THANKYOU FOR TAKING THE TIME TO READ THIS EMAIL.**

**If I take part what will I have to do?**

I will ask you to meet with me and take part in a one-off interview asking about your experiences of acquired hearing loss. If you would require communication support during the interview let me know and I will make every effort to provide this.

**What will happen during the interview?**

During the interview I will be really interested to find out about your personal experience of hearing loss. I will have a list of a few questions that I would like to ask but they are only a guide. It is up to you how long the interview lasts and how much you want to discuss with me. The interview is confidential and I will not discuss anything you say with anyone else.

Before we start the interview I will give you a paper copy of the questions so that you know what I will be asking. I will record the interview so that I have a record of what we discussed.

**What will happen after the interview?**

After the interview I will transcribe the recording on to a computer. I will then send you a copy of the transcript, ask you to confirm it is an accurate account of our interview and check that you agree to it being used in the research. After you have checked the transcript, I will remove all identifying information from it and make sure it is completely anonymous.

Once I have finished my interviews I will go through the transcripts and look for common themes across all the interviews. I will then write a report on what I have found. The report will not include your name or any other information that could identify you.

**If you are interested in taking part or would like to ask any questions about the research, please contact me by email: or text:**

Alternatively, you can tell Linda you are interested in the research and she will please on your contact details to me.

THANK YOU FOR YOUR TIME.

## Appendix 5: Staff Information Sheet

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
TD1 1PF

Tel  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



### Staff Information Sheet

**Study:** A qualitative study of psychological adjustment to acquired hearing loss

#### **What is the purpose of the study?**

There is strong informal evidence that acquired hearing loss can have a huge impact on an individual's daily life. Unfortunately, there has been little academic research exploring how young and middle aged adults adjust psychologically to acquired hearing loss. This study aims to investigate how people adjust and cope with acquired hearing loss by interviewing people who have experienced it.

#### **Inclusion criteria**

I would like to recruit people who have a moderate, moderate-severe, severe or profound hearing impairment (hearing threshold of 41 decibels and over) acquired in adulthood.

#### **Exclusion criteria**

People who meet the criteria below are excluded from the study:

- People who do not have a hearing impairment
- People who have had a hearing impairment since childhood
- People who have an age related hearing impairment
- People with a mild hearing impairment (hearing threshold of 26 to 40 decibels)

#### **What will clients be asked to do?**

Participants will be asked to meet with me and answer some questions on their experiences of hearing loss. The interview will take about one to two hours. The interview will take place in an appropriate setting of the participant's choice. The interview will be recorded.



**What will I have to do?**

I am hoping that you will help me recruit participants by asking any of your clients (who meet the inclusion criteria) if they would be interested in participating in the study. I would ask that you give your client a copy of the participant information sheet. If they are interested in participating they may ask you to pass on their details to me. Once I have been given the client's contact details I will be able to contact your client directly.

**Will I be informed of the any information from the interviews?**

I will endeavour to keep all information obtained during the interviews confidential. Consequently, you may not be informed of the information discussed during interviews with your client.

However, prior to the interview, your client will be asked to specify a named professional. The named professional is somebody that the client would be happy for me to contact if I am concerned about the client's mental health or well-being. If you are a client's named professional you may be contacted if I am concerned about your client.

The research report will discuss themes across all the interviews and will not include any information that would identify individual participants. When the research is complete, you will be provided with a copy of the final research report.

If you have any questions, please do not hesitate to contact me using the contact detail below.

Best wishes,

Suzie Black  
Trainee Clinical Psychologist

Thank you for your time.

## Appendix 6: Invitation Letter Sent by Social Worker

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
TD1 1PF

Tel:  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



06 February 2008

Dear

I am a trainee clinical psychologist who is currently conducting research into people's experiences of acquired hearing loss. I am writing to you because Myra Ward, Social Worker, thought you may be interested in participating in my research.

### **Why am I conducting this study and what is it about?**

Unfortunately, there is very little psychological research into people's experiences of acquired hearing loss. This means that the needs of people, with hearing loss, are often not appropriately met. Therefore, I thought it would be useful to conduct a study exploring people's experience of acquired hearing loss over time, what people think about the idea of adjusting to hearing loss and what they feel is important in helping them cope. I am hoping that the study will give clinical psychologists and other professionals a better insight into acquired hearing loss and encourage them to design appropriate services.

### **If I take part what would I have to do?**

If you would like to participate in the study I will ask you to meet with me and take part in a one-off interview asking about your experiences of acquired hearing loss. The interview would be really informal, not too long and I would only ask you questions you would be happy to answer! If you would require communication support during the interview let me know and I will make every effort to provide this.

If you think you might be interested in participating in the research have a read of the attached information sheet which describes the study in more detail. If you decide you would be happy for me to interview you or have any questions about the research please contact me by email: or text:

Thanks very much for your time.

Yours sincerely,

Suzie Black  
Trainee Clinical Psychologist

## Appendix 7: Participant Information Sheet Sent to Social Work Clients

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
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Tel  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



### Participant Information Sheet

**Study:** A qualitative study of psychological adjustment to acquired hearing loss

I would like to invite you to take part in a research study. Before you decide you should read the following information.

#### **What is the purpose of the study?**

There is strong informal evidence that acquired hearing loss can have a huge impact on an individual's daily life. Unfortunately, there has been little academic research exploring how adults adjust psychologically to it. This study aims to investigate how people adjust and cope with acquired hearing loss by interviewing people who have experienced it.

#### **Why have I been invited?**

I am inviting people who have acquired a moderate, moderate-severe, severe or profound hearing impairment in adulthood to participate. You have been invited because you have had previous contact with Myra Ward, Social Worker.

#### **What will I have to do?**

If you would like to participate, you will be asked to meet with me and answer some questions on your experiences of hearing loss. The interview will take about one to two hours. The interview will take place in an appropriate setting of your choice. The interview will be recorded.

When you come for the interview, you will be given a copy of some of the questions you may be asked. You will then be asked to decide if you would still like to take part. If you would like to take part, I will ask you to name a professional you would be happy for them to contact, if they were concerned about your mental health or well-being. You will also be asked to sign a consent form to show you have agreed to take part.

#### **What will happen to my interview recording?**

I will listen to the recording and transcribe it on to a computer. Once the interview has been transcribed the interviewer will send you a written copy of the interview. You will be asked to confirm if the written copy is an accurate account of the interview. If you are unhappy with the interview you can withdraw it at any time. If the written copy is accurate, I will add it to other interview transcripts. They will then

## **Appendix 7: Participant Information Sheet Sent to Social Work Clients**

use computer software to look for themes across all the interviews. After the research has been completed the interview recording will be destroyed.

### **Will my answers be confidential?**

All the information discussed in the interview will be kept confidential. However, if I am concerned about your mental health or well-being I may contact your named professional. I will not do this without discussing it with you first.

So that they can send you a copy of your interview, the researcher will label your interview transcript with your initials. However, once you have confirmed the written account of the interview, the recording and information on the computer will be anonymised. The research report will discuss themes across all the interviews and will not include any information that would identify individual participants.

### **Do I have to take part?**

It is up to you to decide whether to take part. You do not have to take part. If you do not want to, your future care and legal rights will not be affected. If you would be unhappy with me contacting a named professional you should not participate.

If you decide to participate and change your mind later you can contact me at any time and withdraw your interview.

If you have any questions about this information please contact me.

### **If I would like to take part what I should do?**

If you would like to take part please contact me using the contact details below. Alternatively, you can ask Myra to pass on your details to me and I will contact you.

Researcher: Suzie Black  
Trainee Clinical Psychologist  
Text:  
Email:

If you would like to receive a summary of the results from this study please tell me at your interview or contact them using the details above.

If you would like some information on mental health related issues such as depression, anxiety or bereavement you should contact Jenny Hastings on 01896 668 831 or [jenny.hastings@borders.scot.nhs.uk](mailto:jenny.hastings@borders.scot.nhs.uk) for free self-help information.

Thank you for your time it is much appreciated.

## **Appendix 8: Invitation Email to Social Group Members**

Hi,

How are you? I'm emailing because I was wondering if you could help me with my university thesis. I have chosen to do my thesis on people's experience of hearing loss and I am looking for volunteers to let me interview them about this topic.

I was wondering if you would be prepared to meet with me for a one-off interview about your experience of hearing loss, the interview could be really informal, wouldn't be too long and I would only ask you questions you would be happy to answer! I have written some more detailed information about the interviews and attached it below. If you wouldn't mind being interviewed email me (EMAIL GIVEN) or text me (NUMBER GIVEN) back and we could organise a time and a place. Don't worry if you are not keen to be interviewed. I will understand if you are too busy to take part or if you would feel uncomfortable talking about your hearing loss. Please don't feel any pressure to agree! I am recruiting participants from a variety of different sources so it's not just from the group.

Thanks for reading the email, hopefully see you at the sign language on the 22<sup>nd</sup> of Feb.

Suzie

### **INTERVIEW INFORMATION**

#### **If I take part what will I have to do?**

I will ask you to meet with me and take part in a one-off interview asking about your experiences of acquired hearing loss. The interview can take place a place and time of your choice.

#### **What will happen during the interview?**

During the interview I will be really interested to find out about your personal experience of hearing loss. I will have a list of a few questions that I would like to ask but they are only a guide. It is up to you how long the interview lasts and how much you want to discuss with me. The interview is confidential and I will not discuss anything you say with anyone else.

#### **What will happen after the interview?**

After the interview I will transcribe the recording on to a computer. I will then send you a copy of the transcript, ask you to confirm it is an accurate account of our interview and check that you agree to it being used in the research. After you have checked the transcript, I will remove all identifying information from it and make sure it is completely anonymous.

Once I have finished my interviews I will go through the transcripts and look for common themes across all the interviews. I will then write a report on what I have found. The report will not include your name or any other information that could identify you.

**If you are interested in taking part or would like to ask any questions about the research, please contact me by email or text**

## **Appendix 9: Communication Tactics Used During Interviews**

The following communication tactics were used to promote effective communication with participants:

- Ensuring I had the participant's attention before speaking
- Looking directly at the participant and maintaining eye contact
- Making sure my face or mouth were not obstructed while I was talking
- Ensuring I did not turn away while speaking
- Making sure the light was on my face
- Trying to minimise background noise
- Making sure the participants had their hearing aids switched on
- Speaking slowly and clearly
- Sitting at the same level as the participants (to promote ease of lip-reading)
- Ensuring I did not shout or exaggerate my lip movements
- Using non-verbal gestures (such as nodding and facial expressions) rather than verbal active listening strategies such as "uh huh", "ok" etc.
- Using non-verbal gestures to enhance meaning and to help compensate for inability to hear tone of voice
- Rephrasing rather than repeating a statement or question if the participant did not understand
- Giving participants the opportunity to have a break during the interview if required

Adapted from: Hearing Concern (2006). *Communication with Deaf and Hard of Hearing Patients: A guide for health professionals*. Hearing Concern: London.

## Appendix 10: Interview Guide Given to Participants Prior to Interview



### Rough Interview Guide

The aim of this interview is to gain a deeper understanding of your experience of acquired hearing loss. The interview will be informal and I am happy for you to ask me any questions throughout it. I am interested in learning about your **own personal experience** of hearing loss. There are no right or wrong answers to any of the questions I will ask. I have written below some of the questions I am interested in but these are only a guide! During the interview I want to be flexible and give you the opportunity to discuss what you think is important. This means we might not cover all the questions below. The interview will probably take about an hour.

Can you tell me what level of hearing loss you have?

Can you give me a brief history of your hearing loss from when it started until now?

What does your hearing loss mean to you?

What does the concept of adjustment to hearing loss mean to you?

How do you think your hearing loss has impacted on other people in your life?

Throughout your experience of hearing loss what has helped you?

What help would you have liked to have received but didn't?

Is there anything, which we have not already discussed, which you think is important to mention?



## Appendix 11: Participant Consent Form

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
TD1 1PF

Tel  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



### Consent Form

**Study:** A qualitative study of psychological adjustment to acquired hearing loss

Please initial  
each statement

- I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask any questions
- I understand that my participation is voluntary and that I am free to withdraw at any time. I understand I can withdraw without giving any reason and without my medical care or legal rights being affected
- I understand that the researcher may contact my named professional if they are concerned about my mental health or well-being
- I understand the interview will be recorded
- I agree to take part in the above study

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



## Appendix 12: Named Professional Form

**NHS Borders**

**Psychological Services**

12/14 Roxburgh Street  
GALASHIELS  
Selkirkshire  
TD1 1PF

Tel  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



### Named Professional Form

If the researcher is concerned about my mental health or well-being I give them permission for them to contact:

Name: \_\_\_\_\_

Profession: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_



## Appendix 13: Descriptions of Audiological Categories Given to Participants



Please decide which category best describes your level of hearing loss.

Category	Description
Mild	You have some difficulty following speech, particularly in noisy situations. A hearing aid not always helpful to you.
Moderate	You have difficulty following speech without a hearing aid. You use a hearing aid most of the time.
Severe	You have severe difficulty following speech, even with a hearing aid. You use a hearing aid all the time.
Profound	Hearing aids do not help you distinguish speech. You generally have to rely on lip reading to understand speech.

## Appendix 14: Transcription Notation

The following features of talk were transcribed. This is a selection of notation the conventions presented in Antaki, Billig, Edwards and Potter (2003)<sup>1</sup>.

- Speakers: **P** was used to denote words spoken by the participant and **I** denoted that spoken by the interviewer.
- Pauses: numbers in parenthesis indicate elapsed time in second (2) or a dot in parenthesis indicates a tiny (less than 1 second) but noticeable pause (.)
- Intonation: ( . , ? ! ) are used as they are in current text to indicate the speakers intonation.
  - ? indicates a raising inflection
  - ! indicates an animated tone
  - . indicates a natural pause
  - , indicates a breathing “comma-like” pause
- Omitted text: [ ] within an extract square brackets are used to indicate text has been omitted. A line or more of omitted extract, the omitted lines are indicated within square brackets e.g. [lines 10-12 suppressed].
- Continuing speech: ... is used to indicate an extract is part of continuing speech.
- Descriptions of behaviour or non-speech sounds: (( )) when describing sounds that add but are not part of “proper” speech double parenthesis are used e.g. ((laughter)).
- Descriptions of events: [[ ]] when describing events during the interview double square brackets are used e.g. [[gets up to answer the door]].
- Identifying features: These are substituted by a description within parentheses e.g. (name of family member).
- Inaudible sections: ( ) empty brackets are used when a word or sentence is inaudible (because of overlap or noise).
- Unclear sections: when there are doubts about what a word or section is, parentheses indicate the transcriber’s possible hearing (best guess) of that word or section.
- Other words: there are a variety of sounds in talk (eh, erm, uhuh) which are notated as close as possible to the sound that is heard on the recording.

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<sup>1</sup> Cited in Coelho, C. (2005). Constructing Parapsychology: A Discourse Analysis of Accounts of Experimental Parapsychologists. Unpublished PhD Thesis: University of Edinburgh.



## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface for an interview transcript titled "Interview with Participant 1". The main window shows a dialogue between a participant (P) and an interviewer (I). The text is color-coded with various colors (red, yellow, green, purple, blue, orange) corresponding to different codes. On the right side, a "Coding Density" bar shows the distribution of these codes across the text. The status bar at the bottom indicates "Linked Nodes: 205 References: 343 Read-Only Line: 391 Column: 9".

**Interview Transcript:**

**P:** Erm, but, (.) I don't know if it's just I would be depressed anyway and it's something to blame it on, you know, I don't know, em, but its really the last, since the operation failed in sort of May, June 2006 I haven't really been the same person

**I:** Uh huh

**P:** as I was before, before it was just, you know, just going down slowly and I was accepting it, you know, there was a lot of things that I got annoyed about that I couldn't hear or whatever, em, you know, I won't hear the phone, but I a mean, my husband now, but he wasn't my husband then, he would answer the phone, you know it wasn't, I didn't find it a BIG deal, I mean, it was a problem but not, it wasn't life changing but now I don't now I find it hard, I find it very hard.

**I:** And why are you finding it harder than in past?

**P:** I really think, I mean, its really since my operation failed in May 2006 and the fact that, you know, I have been waiting, waiting, waiting,

**I:** Uh huh

**P:** on the national health for all that time, em, and if if I hadn't have gone privately I wouldn't have even been able to get a job, because, I couldn't have coped at all in a work situation, just wouldn't have been possible, em.

**I:** Did you have to leave your work before the operation?

**P:** No, em, I was actually, when I got the first operation, many years ago, I was in the lab and then I was just had a small part-time job, eh, teaching English but if was kinda privately

**Coding Density:**

- something to blame it on
- I don't know, uncertain about why depressed
- but don't know if I would be depressed anyway
- paraverbal, pause
- narrative P1, working it out
- loss of identity
- Identity and loss
- lots of things I would get annoyed about
- my husband would do the things I couldn't
- it was a problem but it wasn't life changing
- I didn't find it a BIG deal
- before it was just going down slowly
- I could cope before then, I was accepting it
- but now I find it very hard
- I have been waiting, waiting, waiting
- If I hadn't gone private I wouldn't

## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface. The main window shows an interview transcript with the following text:

**I:** And how did that sort of, make you think about yourself, did it have any... ?

**P:** I, I felt very, I felt unless really, and just (2)of no value in life and I think I did feel very suicidal and very depressed and that's when the doctor said, you know you need to, I didn't what to start taking tablets and things but he said there wasn't really, you know, I was just so down, erm, but now you know, I have days where I'm down but not as down as low as you can go, if you know what I mean.

**I:** So how have you managed to, sort of, get yourself back up really?

**P:** Well I think, just with buying this hearing aid, you know, that I mean when I'm, when I have it out I really couldn't cope at all em, but you know, buying this hearing aid, my husband and I decided, right, just go privately and get it erm, at least, you know, I still struggle but compared to not having the hearing aid

**I:** Yeah

**P:** and being totally deaf in my right ear, em, you know what I find really hard, if I've got the cold or something, that you know that, with most people it goes into their throat or their ears, it always goes into my ears, I suppose because its a weakness and even with hearing aids I can't hear a thing and if that happened I just would need to be off work and just explain that I couldn't hear.

**I:** Yeah

**P:** Eh, so I keep thinking oh try not, I hope I don't get the cold, and you know, just little things like you never bothered about whether you got the cold before, I know it would just have such a big impact because I wouldn't, I wouldn't hear. Erm, but I mean I feel sorry

On the right side of the interface, a 'Coding Density' chart is visible. It consists of a vertical axis labeled 'Coding Density' and several horizontal bars of different colors extending to the right. The bars represent the density of codes applied to specific segments of the transcript. The colors and their corresponding text labels are:

- Red: paraverbal, pause
- Yellow: incomplete statements
- Green: of no value in life
- Orange: now, days when I'm down but not as low as you can go
- Purple: I still struggle but much better
- Light blue: without hearing aids I really couldn't cope at all
- Dark blue: I keep thinking to myself, what if
- Light green: I feel
- Dark green: very suicidal
- Light purple: doctor said I need to take anti-depressants
- Dark purple: I was really, totally depressed, my life is over

The bottom status bar shows: Linked Nodes: 206 References: 343 Read-Only Line: 508 Column: 0. The Windows taskbar at the bottom shows the Start button, taskbar icons for 'Nvivo screen shots.d...', 'My Documents', 'thesis data.nvp - NVivo', and 'Interview with Partici...', along with system tray icons and the time 22:16.

## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface. The main window is titled "Interview with Participant 1" and contains a transcript of an interview. The transcript is as follows:

**P:** Eh, so I keep thinking oh try not, I hope I don't get the cold, and you know, just little things like you never bothered about whether you got the cold before, I know it would just have such a big impact because I wouldn't, I wouldn't hear. Erm, but I mean I feel sorry for my husband, but I suppose he's used to it now, you know.

**I:** Hmmm. Why do you feel sorry for him?

**P:** Well, I feel, its harder for him, you know, cause he's got to keep repeating everything all the time and you know, and especially when I go to bed and my hearing aids are out, I really can't hear anything he says, you know, and when he even, I mean, I know I could get one of these alarms that shakes and things like that but I don't hear the alarm and like my husband wakes me up and things like that, you know and I just feel, I just feel, I suppose I'm sure he would prefer somebody that did hear him

**I:** Hmmm

**P:** Than somebody that doesn't, erm. But then I suppose if it was him, eh, then I would do my best to help, help him.

**I:** Mmhhmm mmmhhmm

**P:** But, he has been supportive and good to me but I, I suppose I've still got this worry in the back of my head (1) I mean I'm pleased to have this new hearing aid but it's not, no hearing aid is perfect but eh because my right ear is totally dead, if, if my left ear does start to go down any more, what, what will I be able to do? I, I know its terrible, but I just keep trying not to think about it, cause I don't really want to think about it cause, you know, I don't know what you would do.

To the right of the transcript is a "Coding Density" visualization. This visualization shows various codes applied to the text, represented by colored bars and labels. The codes include:

- I keep thinking to myself, what if
- I feel sorry for my husband
- narrative, repetition
- I suppose he's used to it now
- he has to wake me up in the morning
- sometimes I really can't hear anything he says
- I'm sure he would prefer someone that could hear him
- harder for him has to keep repeating things
- but it was him, I would help him
- he has been supportive
- but I've still got this worry in th
- narrative P1, working it out
- just keep trying r
- if my left ear goes do
- without hearing aids I rea
- cause I don't

The bottom of the window shows a status bar with the following information: Linked Nodes: 207 References: 346 Read-Only Line: 547 Column: 7. The Windows taskbar at the bottom shows the Start button, several open applications (Nvivo screen shots, My Documents, thesis data.nvp - NVivo, Interview with Partici...), and the system clock showing 22:25.

## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface. The main window is titled "Interview with Participant 1" and contains a transcript of an interview. The transcript is as follows:

**P:** Maybe I'm not adjusting very well, cause I don't know if that means you have to accept that you've got a hearing loss

**I:** Hmmmm

**P:** and try to do what you can to, you can't really improve it, apart from hearing aids and things but and again I suppose you could go to lip reading but, don't know I still feel I'm at the sort of, don't want to accept it stage and, and depressed about it

**I:** Mmmhmm

**P:** and feeling sorry for myself and I don't seem to have got out that stage since the operation was unsuccessful and I, I just feel, even the way the way that your treatment, I mean, I know the national health are over stretched and everything but I mean I got the operation in May, saw someone in November, the man that did the operation and it really was just like oh, tough luck, its unsuccessful

**I:** Yeah

**P:** And then you were just forgotten about and then you're waiting in this cue to get a hearing aid and I just feel terrible to have to wait all that time

**I:** Uh huh, yeah

**P:** And I feel, you know, its just really upsetting and even to have to go and pay all that money, you know, privately to get one I keep thinking, you know I really shouldn't have to have had to do that in some ways but then I think oh well, I'm still waiting, if I hadn't of

Below the transcript, a "Coding Density" visualization is shown. It consists of a vertical bar on the left labeled "Coding Density" and a series of colored horizontal bars extending to the right, representing the density of codes applied to different parts of the transcript. The codes and their corresponding colors are:

- depressed about it (pink)
- feel I am at don't want to accept it stage (pink)
- haven't got out that stage since operation (green)
- feeling sorry for myself (orange)
- I'm not adjusting very well (purple)
- adjusting, try to do what you can (red)
- don't know if adjusting means you have to accept your hearing loss (purple)
- I know they are over stretched (orange)
- not treated well by NHS (red)
- oh tough luck, its unsuccessful (purple)
- waiting for a cue to get a hearing aid (orange)
- terrible to have to wait all the time (blue)
- just forgotten about (purple)
- its just really up (green)
- keep think (yellow)
- having to go an (blue)
- perhaps (yellow)

The bottom status bar shows: Linked | Nodes: 204 | References: 338 | Read-Only | Line: 651 | Column: 0. The Windows taskbar at the bottom shows the Start button and several open applications: Document1 - Microsof..., My Documents, thesis data.nvp - NWi..., and Interview with Partici... The system clock shows 21:32.

## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface for a file named "Interview with Participant 1". The main window shows a transcript of an interview with the following text:

**P:** and that, but I don't know, I don't really think I have made the adjustment, perhaps, apart from going privately and getting the hearing aids (2) I just kind of want to be normal and I don't want to have a hearing loss, just like I don't really want to be depressed but I can't seem to (3) I can't seem to shake it if you know what I mean?

**I:** Uh huh, Uh huh.

**P:** Em

**I:** Do you think it's ever really possible to adjust, do you think it is?

**P:** I think some people, you know they've got very strong personalities and eh, you know its like some people you see that have had illness or something and they feel sorry for themselves and you know, you can see that their just not happy and yet other people have had quite terrible things happen to them and they seem to, to be able to cope with it and get on with their life,

**I:** Hmmmm

**P:** So, I think it is hard with hearing (2) cause it is a loss,

**I:** Uh huh

**P:** I mean it's a bit like, I suppose when someone dies

**I:** Yeah

**P:** you've got to, you know you've got to accept its happened and then and then go through

On the right side of the interface, a "Coding Density" chart is visible. It consists of vertical bars of various colors (purple, red, green, yellow) that represent the density of different codes applied to the text. The codes are labeled as follows:

- paraverbal, pause (purple bar)
- narrative P1, working it out (red bar)
- perhaps getting the hearing aids privately (green bar)
- I don't know, not sure about the concept (green bar)
- I'm not adjusting very well (green bar)
- I don't want to have a hearing loss (purple bar)
- adjustment depends on your personality (blue bar)
- have to go through the stage where y (yellow bar)

The bottom status bar shows "Linked Nodes: 205 References: 341 Read-Only Line: 687 Column: 0". The Windows taskbar at the bottom includes the Start button, several open applications (Nvivo screen shots, My Documents, thesis data.nvp - NW..., Interview with Partici...), and the system clock showing 21:45.

## Appendix 15: Example Coding: Six Screen Shots from NVivo

The screenshot displays the NVivo software interface. The main window is titled "Interview with Participant 1" and contains a transcript of an interview. The transcript is as follows:

**P:** I mean it's a bit like, I suppose when someone dies

**I:** Yeah

**P:** you've got to, you know you've got to accept its happened and then and then go through the pain and I, I think I'm kinda at the first stages of that em, and then you have to go through the stage that you have to sort of say to people that you can't hear,

**I:** Mmhmm

**P:** em, and like everyday, you know, you go to the shop to buy something and that and you don't hear what their saying and you know, it just seems to come up all the time, em, and I suppose its something as well like, initially people don't know that you've got a hearing problem, unless they can see a hearing aid or something em, whereas someones blind or something you can see straight away and I think people treat you as if you're stupid, em, when you've got a hearing loss,

**I:** Yeah

**P:** they don't think initially she's got hearing loss, they think she's stupid. So, but yeah I do think if you've got the right frame of mind and everything, you, you can adjust and I think, I suppose you've no option but to adjust, cause its something, I mean my hearing isn't going to get any better, I mean that's for sure, unless some new technology or something comes along, em, I just have to hope that it doesn't get worse too quickly,

**I:** Mmhmm, Mmmhmm

To the right of the transcript is a "Coding Density" chart. The chart shows various codes applied to the text, represented by colored bars. The codes and their corresponding text are:

- Yellow: have to go through the stage where you say I can't hear
- Purple: I need to accept it
- Pink: feel I am at don't want to accept it stage
- Blue: comes up all the time
- Green: its everyday
- Orange: someone who is blind can see it straight away
- Red: have to hope it do
- Light Green: initially don't think she has hearing
- Dark Green: initially people don't know you've got a hearing problem
- Light Purple: people treat you as if you're stupid
- Light Green: no option but to adjust
- Light Purple: adjustment depends on your person
- Orange: its not going to get any bet

The bottom of the screen shows the Windows taskbar with the Start button and several open applications: "Nvivo screen shots.d...", "My Documents", "thesis data.nvp - NW...", and "Interview with Partici...". The system clock shows 21:52.

## **Appendix 16: Example Extract from NVivo Memo**

### **Reflections after interview 31.01.08**

sadness wanted to help. felt sorry for Lynn. depression, loss, self-esteem, sense of worthlessness, feelings that some how she is at fault for not adjusting , feeling sorry for herself, while others do well. idea that it is factors within the person that adjust and if you don't it is a weakness.

being let down

loss theme - self, activities, work, social life, mood, future

worry- about future, everyday social situations

### **Reflections after transcribing 03.02.08**

Without this hearing aid I really couldn't cope at all. Heavy reliance on hearing aids, what does that mean for the self? So conscious that you depend on something, does it mean you are weak? Deficient?

### **First level of coding - 31.05.08**

a lot of uncertainty, has to live with not knowing if one day she will be completely deaf, worries about the future a lot and nobody can say whether she should or not.

having hearing loss in the family meant, it wasn't as bad. Had seen her mum and gran cope and lead normal lives so had a role model, new people with hearing loss already. Contrast from P11 cause she thought having a family history made it worse. Family used to it, already used the strategies so they could communicate with her ok.

Critical point - may 2006, before then it wasn't so bad, I could cope but after that can't?

constant battle to get the equipment needed, waiting for a long time and then having to push people. writing letters, getting GP to do the same, over and over.

I just felt I couldn't do anything - echo of P2's transcript. Extremity of the situation, shows that people feel as if they cannot do anything at all, isn't strictly true but it is how they feel and how they interpret the situation.

seems that for most people with gradual hearing loss, there was a time when it became important, didn't notice straight away, gradually changed but then critical point when it became a problem and began to affect their lives

I've been quite lucky, similar to P2, interpret situation as being quite lucky but actually they sought the help themselves, asked for it and got it, not really luck!

indication that mum and sister seemed to have coped ok, but I struggle, all got hearing loss so is it something wrong with me? Am I weak, something wrong with me? Why do I struggle and they don't seem to?

seems important that she keeps saying I don't know, she doesn't know why depressed in a way, ambivalence about whether it is the hearing loss or whether it is just her.

frustration at NHS, had to do something herself, had to pay money and go privately. If hadn't of done that wouldn't have been able to cope. Let down by the NHS.

didn't think it was severe enough to say it was a disability but have no hearing at all in one ear. Element of thinking it is her that has the problem, she should be able to do these things, it is her fault she is failing.

question of whether she has a disability could relate to concept of identity, she isn't sure whether she sees herself as disabled or if she should describe herself as disabled.

similar to P2 - feeling useless, of no worth or value because couldn't do.

feels a burden on her partner, feel like he would prefer someone else, that he didn't have to do everything for, she says she still has this worry but doesn't say what it is, does she think he might get fed up and leave her?

everyday something upsets me about my hearing - similar to P8 said that its constant, everyday you wake up thinking it will be ok but then something happens, constant, can't get away from it.

I should be glad, I should think I am lucky, comparisons to others less fortunate, similar to P8, he said thinking or meeting other people worse off than yourself helps you adjust. Lots of shoulds, feeling self, should think this but maybe don't think it, is that helpful?

adjustment, difficult concept, most people don't seem sure about it, not thought about it, or don't know what to think.

hearing loss as an invisible disability, makes it harder, have to tell people, people think you are stupid, forget.

said a bit about no option but to adjust cause its not going to get better, similar to survival theme for P2 and P8, have to do it, not much choice, but at the same time she said she doesn't think she is doing it.

Living with uncertainty, only things he is certain about is that her hearing loss is not going to get any better.

idea that there is maybe a right way to do things, I don't know.....etc not sure if she should be doing certain things, thinks the things she does are probably not right and making her worse. I should push myself etc

even though have to talk about it everyday, think about it everyday, come across things, problems everyday, still don't accept it, strange-not what you would think (?)

operation being unsuccessful, shock, never expected it not to work, expectations shattered. had worked previously and supposed to be better now.

regret about having the operation cause it failed and actually took away some of the hearing she had, didn't think it wouldn't work and that is why it is so hard to adjust too. Does she think she should have thought about it, does she think she has made the wrong decision?

Through out interview idea of stages of acceptance and adjustment.

disclosure of failure of operation, similar to P2's disclosure of diagnosis

real emphasis on its people's personalities that affects how they deal with things, comparison with sister, mother, others she has met

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 1: Summary of the Analysis of Ben's Transcript**

Theme	Sub-theme	Quote	Page	Lines
In the beginning	Depression	It was very ,very difficult, very difficult thing, there's times that you even felt like suicidal	2	46-47
	Loss of future	but I felt she was better with somebody else because I knew I was gonna be in for problems so I gave it up, I broke up wi' (name). I didnae want to but ken I did.	7	246-247
	Loss of confidence	It was very, very difficult and I lost a lot of confidence myself and my esteem sorte went way down	2	43-44
	Social Isolation	You can't hear the sounds, you can't make the words out, you can't hear people speaking, you can't have a conversation [ ] it makes it a lonely isolating disability	10	394-396
	Others didn't understand	A lot of them didn't understand or want anything to do wi' it. Eh, they couldnae understand why you couldnae hear them and a lot of them were mair or less laughing behind yer back...	4	137-139
Acceptance	Negotiating identity	...I'd classify myself as disabled yes without a doubt. I'd classify any disabled person, eh any person as disabled if they're deaf.	8	295-296
	Reliance on hearing aids	Once the hearing aid comes off, that's me completely out and eh, the only thing I try and fall back on is lip reading	1	8-9
	Tolerating uncertainty	Some people have said to me, what will you do if the dog had to eh, get retired or ill health or die. I say, "well I'll cross that bridge when I come tae it."	13	513-514
Adjustment	I wouldn't have it any other way	I wouldn't have it any other way, no now. I'm a better person now than I was then definitely...	13 8	523 285-286
	Hearing dog	I would never have done all that if it wasnae from him coming into ma life and giving me the confidence because he was a stray, he was found on the street and it was just like, he came into my life as if he said "Well, I've tum my life around why ye no turn yours, why ye no do something to help yersel'?"	3	76-79
	Increasing confidence	It made things different, it made a wee bit of difference and then when I got the qualifications in word processing my confidence lifted.	3	90-92
	Establishing valued roles	A lot of pleasure, especially when I go to the schools. I get a really great pleasure out of doing the schools because I feel its very vital, very vital to catch the young children, at a young age, so that they are able to understand no just about deafness, about any disability so that they are able to understand about disability on the whole	11	486-489
	Learning new skills	And eh, nowadays I'm even going to try and learn sign language, eh, I'm hoping to go to ...	5	166-168
	People need help to adjust	You can adjust to hearing loss, if you're willing to adjust tae it, if you get help to adjust to it. People I feel will no adjust to it themselves, they will definitely no adjust to it themselves.	9	349-353

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 2: Summary of the Analysis of David's Transcript**

Theme	Sub-theme	Quote	Page	Lines
Identity and Loss	I am different	I don't know if I am a better or worse person but I'm different.	8	264-265
	Loss of confidence	I've lost the techniques [ ] when you go into a crowd of people you there's a certain amount of acting and bravado cause otherwise it wouldn't even happen and all that confidence has gone completely	8	268-270
	Loss of self-worth	... wasted forty years of skills, knowledge, success in business, utter waste...	7	258-259
	My world has suddenly shrunk	...we don't go out, we don't go on holiday, [ ] so my world has suddenly shrunk quite dramatically and drastically	4	116-119
	Loss of independence	I just feel like I'm a liability, to just to my wife but to myself and maybe to others. I need my wife with me if I go anywhere	4	121-122
I am alone with this	I was expecting answers	So I feel annoyed, I was expecting answers to the problem from Audiology (1) but I'm afraid I just feel um they're very amateurish,...	2	56-57
	There's nobody to help me	...I'm still out there swimming on my own, I mean I'm going round in circles for all I know, although I've seen dry land in the (name of organisation) so I'm heading over there ((laughter)) and there's nobody there to help me, there's no rescue boat there.	10	350-353
	I feel I'm not welcome	So, you do feel (3) you're not welcome, not, you're not welcome not for negative reasons really just that you're an inconvenience, difficult to talk to.	7	247-248
This is my fault not theirs	I can't and don't blame others	I can't blame people and I don't blame people, they have to live their normal life, speak normally	5	169-170
	I'm the one who has to change	I'm the one that has to change, I have to find ways and means not them.	5	177-178
	I'm constantly battling it	I've never been, all my life I don't accept, eh, illness, change anything like that, anything that seems defeatist I am a battler, I fight it, I hate it and so it makes it more difficult for me	6	223-225
Acceptance	Constantly accepting	So, it wasn't like one day I was ok, the next day I was totally deaf, I think if you could have accepted that, that would have been it, when its slow progression you seem to be constantly accepting the fact that its getting worse, um, and for a wee while you don't notice it and it, you need other people to tell you,	3	96-99
	I have to accept	I have to accept it otherwise its happy farm or something stupid and I'm no way going down that route so yes, you just have to accept that even though I don't like it, I have to accept it.	6	228-230
	I can't go back	I can't go back to the things I was doing then so that's fine, I must find something new	9	307-308
	Disclosure	I don't mind, I think at one time I saw it as a weakness but long ago that disappeared, but I find it doesn't matter I even have a little badge, brown deaf that says "I am deaf"	5	162-164
Adjustment	Establishing valued roles	I've become an (name of organisation) volunteer, so I'm not just trying to get use of it, I'm trying to get into it and involved with it, helping other people who are worse than me,	8	276-278

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 3: Summary of the Analysis of Ian's Transcript**

Theme	Sub-theme	Quote	Page	Lines
In the beginning	Paradox of deafness	I mean it is a difficult thing to have because people are not aware of it em, you know, people say if the guy's got a hearing aid then we'll need to speak up a bit but if you don't have any hearing aid and you're deaf then there's nothing, I mean you don't have this sign that says "deaf, speak up" but a blind person will usually walk with a stick and people will help you across this, that and the other, you know this sort of thing, it's a visible thing whereas,	11	404-409
	Identity and loss	But as it becomes worse than that then you start to become isolated, you do, your personality changes and em, I know that for a fact, I was very out going gregarious person I think in the past but the, I began to like, want to go out less and less.	4	124-145
				4
	No explanation	Its neither here nor there knowing or whatever, I think at the beginning I thought well, I wish they ...could have done something else but they're pretty much resigned to the fact that they can't so, I just get on with it	4	116-119
Acceptance	I can't change it	...I think eh, you obviously come to a resignation that its never gonna get any better	17	659-660
	I am deaf and I have a disability	I'm deaf, I'm disabled, without a doubt.	11	433
	Reliance on hearing aids	I'm very conscious of it, [ ] I think if it packs in then I have a problem, [ ] but yeah, I'm really aware of it.	12	471-473
	Disclosure	I mean I just eh, I just say to folk right away, so I say "I'm deaf what did you say?" and then say "no, I'm still not getting that"	3	253-255
	Accepting compromise	...I miss some stuff I know that but I just grab the minutes after the meeting and I check to see what it was...	9	322-323
	Tolerating uncertainty	...just keeping my fingers crossed that it does n't deteriorate eh, anymore or if it does not a great deal, em, but presumably I can get you know, stronger hearing aids, you know, you can always turn the volume up.	16	620-623
	Accepting other people	...I've just thought, well, you know, I've said before, I've raised it at meetings, I've raised it at several meetings [ ], they're not able to do it em, so fair enough, you know I won't hold it against them, that's just the way they are and I'll get by.	10	383-386
Adjustment	Taking an active role	I ended up on a group that were preparing a publication for the Borders, em, about hearing loss about what to do and who to see [lines 506-512 suppressed] so I like to champion the thing now rather than keep it a secret.	13	504-514

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 4: Summary of the Analysis of John's Transcript**

Theme	Sub-theme	Quote	Page	Lines
Suddenly everything changes	My life is over	I was kinda stuck in my car in the middle of nowhere, really, really em, really, really depressed cause I couldn't see any end to it, I couldn't see any way forward.	4	129-131
	Searching for meaning	I had nae confidence at all, I'd lost everything at the beginning, I loss everything em, you're sitting greeting about, couldnae believe it, couldnae believe why has it happened to me? What's inside my head?	11	395-397
	You don't adjust, you survive	...but ye must if you want to survive, you don't adjust, you don't survive, em (.) and it's a fact.	10	370-371
Identity and Loss	I'm not the man I used to be	I'm just no the guy I used to be, I've definitely no got the confidence.	12	420-421
	Loss of future	I've got grave concerns for the future I worry about it all the time...	10	340-341
	Loss of control	I don't want to be totally reliant on tablets but I am cause if I stop taking them I'd be quite depressed.	7	257-258
Role in relation to hearing loss	Let down by the system	The system, there isn't anything in place, as I was saying before, for somebody like me, waking up in the morning deaf, there isn't anything in the system to allow for that, if I'd woke up in the morning with a heart attack I would have been dealt with right away.	14	505-508
	I've had to get a grip o' myself	I'd sit in front of the mirror and talk to my self, right, "what you gonna dae about this? How are you going to handle this?" ... "you gotta get oot this house, you've gotta go out there and face everything, that's what you have to do." But there isn't really anybody out there that can make you do that, the only person that can make you do that is yourself.	16 17	572-573 578-581
	Seeking and accepting help	I have to, I think I'm kinda fighting back nowadays more than what I did before so I'm fighting back and I didnae really want to get myself into a position where I'm dependent on other people. ...it does help to talk like, em, it does help to talk...	15 16	530-532 554
Acceptance	I can't change it	"you've just got this hearing problem John, deal with it."	12	414
Adjustment	Getting it back together	I see people who are a lot worse of than me like. That makes you adapt	11	387
		I actually teach the people on the other side of the counter what they need to know about they're hearing loop system and how to use it and how to address people like me.	8	284-286

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 5: Summary of Analysis of Jenny's transcript**

Theme	Sub-theme	Quote	Page	Lines
Suddenly everything changes	Expectation of cure	I think I found that hard that somebody wasn't gonna come along and go "I'll tell you what we'll do, we'll just put your hears back to what they were" and they werenae. Probably for a long time I maybe thought somebody could do that.	3	93-96
	Searching for meaning	I was just mad, I was just mad at [ ], I didn't know, I think part of it was they couldn't explain why it'd happened to me either, they couldn't say this has happen.	10	378-380
	I'm not putting up with this	I didn't accept it straight away I was like, I'm no having, I'm no putting up with that, there's gotta be something else that can be done, whatever, and there wasnae.	11	388-390
Identity and Loss	It changed me as a person	I think I changed as a person and if you know, I wasn't, and that's taken a long time as well, I've changed, its changed me and I think that was the hardest bit I was never goin be that person again.	3	100-102
	Loss of future	...not being as free before not being as sort of just relaxed, you go into a situation now and it doesn't matter what situation, you don't think about, "I'm not gonna be able to hear this, I'm not gonna be able to hear that" its just a unconscious thing you just, you're just tense and that all the time whatever situation you go to...	3	111-115
Relationships with others	Impact on family life	I feel sorry for my husband cause you know, he seems, its like he's doing more.	5	171-172
Negotiating Identity	Not one thing or the other	...cause I'm kinda not one thing or the other and that makes it more difficult.	2	64-65
	Going back to the person I was	... I get into a car and I'll play it quite loud and it hurts and it hurts and I think I don't care, I don't care [ ] Oh dear, that's the person I was...	5	190-193
	Am I disabled?	Some people would say "you've not got a disability blah, blah," and my friends and family actually forget that there's anything wrong with me [lines 262-264 suppressed] I would say I have but eh, everybody's perception of it is different...	7	259-265
	Developing a new identity	...realising that I wasn't that person and things had changed and saying "right ok, its changed and I've got more friends that are a bit more like me and I can do other things...	10	362-364
Ambivalence about disclosure	I don't know why I don't tell	I don't know why I don't want to tell folk, its not that I don't want to...	9	303
	They don't realise the impact but I don't want sympathy	maybe I don't want people to feel sorry for me not that they will (1) they don't realise the impact it's got on your life, if you just say "I'm hard of hearing"...	9	304
	Trying to predict reactions	I probably would have said to her "look, you know, it's this and that kinda carry on," she probably would have been like "oh right" cause that's what you get.	9	310-311
	I should/need to tell people	I probably would have said to her "look, you know, it's this and that kinda carry on," she probably would have been like "oh right" cause that's what you get.	9	305-307
Acceptance	I can't change it	With work, yeah I couldn't not I think whereas before [ ] there wasn't so much of this eh (.) well owning up to it, yeah I have to, I'd have to this time probably...	7	249-251
	You just get on with it	when these things happen they do change you and you can't, you can't go back, I can't, I can't undo what's happened, I can't, I can't change it.	11	417-418
		I suppose you don't notice after a while, well you do, you just get on with it, what can I do?	6	209-210

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 6: Summary of Analysis of Laura's transcript**

Theme	Sub-theme	Quote	Page	Lines
Suddenly everything changes	I don't know what to do	I was really pretty thrown into it, so I didn't have any coping strategies or communication skills.	6	216-217
	My life is over	it was like somebody stabbing me through the heart when I thought about this, my life stretching ahead of me.	7	290-292
	Searching for meaning	...how does this happen? How does this happen and they don't have any answers for you?	4	124-125
	Survival	I don't know what else to do, eh, it was very much a sort of survival thing because my head was reeling...	4	137-139
Identity and Loss	I lost who I was	I kinda felt I lost who I was. Em, and that's partly to do with how you define yourself in what you do.	9	353-354
	Spectating on your own life	It's just like you are spectating on your own life, its like you're in a glass tank cause you can see everything you just can't touch it, you're kind of locked in this place and everything is flying about by your eyes and you just can't reach out and get it.	9	362-367
Ambivalence of role	Agent versus recipient	I knew I had to do something. I couldn't just sit there...	4	126-127
		I have to credit a lot of people that were put in my path, you know, for helping me.	11	451-452
	Fortunate versus let down	I was lucky enough to have the (voluntary organisation) rehabilitation course the week after. So, that was fantastic timing, that was really good, em, because (name) from (voluntary organisation) was just, she was an absolute god-send at the time. It could have saved some of my hearing, possibly, but I wasn't given it until after I was completely ((Laughter)) deafened, so, kinda pointless.	5 3	197-200 112-114
Getting back to who I am	Acceptance and compromise	Obviously, I would prefer to have natural hearing, cause I still can't listen to music but um, I think it was probably the best result that I could have got.	7	275-277
	Working out who I am	So, I went from hearing to deafened to kind of somewhere, what do I call myself now?	10	393-394
	Getting my life back	Some days, I don't want to see people, em, but its easier in the long run if you do go out and put yourself in the situation where it might be difficult because you feel like you've achieved something.	11	430-432

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 7: Summary of Analysis of Lynn's transcript**

Theme	Sub-theme	Quote	Page	Lines
Suddenly everything changes	My expectations were shattered	I suppose, really deep down I never for a minute thought the operation would be unsuccessful.	17	522-523
	My life is over	I really was, really totally depressed, I mean I just felt that I wouldn't be able to do the things that I could do before.	10	300-301
	Maybe I did the wrong thing?	...maybe I was naïve but I just didn't think of it at the time...	18	556
Identity and loss	Loss of identity	I haven't really been the same person as I was before...	8	238-239
	Loss of self-worth	I felt very, I felt unless really, and just (3) of no value in life.	11	320
	Loss of confidence	I mean I've not got the confidence, I've not, em, I feel, I feel sort of stupid and not listened to as well, and I wasn't ever really confident before but I, I certainly I've lost confidence.	16	510-512
	Loss of future	I'm beginning to just worry about losing my job, and things, you know, I'm beginning to get very worried, erm, and I suppose a bit worried about what the future holds.	7	194-197
	Loss of control	that's the problem they can't, they can't say how long or (2) you know, like, it could be years, it could stay at this level	4	91-92
Roles in relation to hearing loss	I feel let down	I do feel really let down by the people that did the operation.	20	637
Relationships with others	I feel like a burden	I mean I feel sorry for my husband, [ ] I feel, its harder for him...	11	339-342
Acceptance	I don't want to accept it	just kind of want to be normal and I don't want to have a hearing loss, just like I don't really want to be depressed...	15	449-451
	I need to accept it	Cause I need to stop feeling sorry for myself.	19	604
	Negotiating identity	I didn't feel it was severe enough so that I could put on application forms that I had a disability...	9	268-269
Adjustment	I'm not adjusting very well	...don't know I still feel I'm at the sort of, don't want to accept it stage and, and depressed about it...	14	428
	Adjustment as an ideal	...mean it's a bit like, I suppose when someone dies [ ] you've got to accept its happened and then [ ] go through the pain and I think I'm kinda at the first stages of that em, and then you have to go through the stage that you have to sort of say to people that you can't hear...	15	463-467
	It depends on personality	...maybe for some people and it depends what your personality is like, some people just accept what's happened and get on with their lives.	15	445-446
	My family adjusted, why can't I	...its not something mum suffered from, or my elder sister but I seem to (2) struggle.	8	226-228

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 8: Summary of Analysis of Steven's transcript**

Theme	Sub-theme	Quote	Page	Lines
Identity and Loss	Loss of Identity	I think I'm a gregarious individual and I enjoy people and interacting and I enjoy humour, I enjoy making people laugh if I can and so on. All of this kind of thing but has now got to the stage where sometimes I'm just more comfortable if I am on my own. Not that I really want to be but its easier.	2	58-62
	Loss of confidence	an instrument that um, I've been accustomed to using all my life and now it has become very stressful I really get uptight when I have to answer a phone call or I have to make a phone call because I've no confidence...	2	51-54
	Loss of control	...they don't ask me to do X work as in the past and they don't put me on committees anymore and so forth. It's not that I've asked them to do that, they just, you know, people become aware of what your limitations are...	9	343-346
Relationships with others	Avoidance and social withdrawal	...always trying to be the life and soul of the party so to speak and now here you are at this stage in life and sometimes feeling a bit more comfortable and a bit more relaxed if you're on your own	12	427-429
	Taking control of interactions	I think its sometimes you become more loquacious and garrulous because it a way of coping, because its more difficult, not that I am unwilling to listen [ ] but in a social context where there's banter and eh, conversation then I think its easier for you, if you're doing the speaking...	2	64-69
	Others withdraw from you	...he didn't say to me but he said to my wife on one occasion, he says "och I don't bother to speak to Steven anymore cause he doesnae hear what yer saying." I thought that was a wee bit unkind	9	328-331
	Lucky others put up with me	...so on and that seems to endear me to people and they're prepared to put up with the hearing loss.	5	152-153
	Do they still love me?	You have to watch you don't become paranoid you know but you, you begin to wonder if, at times, you begin to wonder if em, if the people around you, particularly those closest too you, em, no longer find you very congenial or attractive. You begin to wonder if they still love you.	7	237-240
	Feeling at fault	I think sometimes my wife feels that I don't do enough to help myself, I don't feel that but she obviously does. I think sometimes you're left feeling guilty as though you're blame worthy because of this hearing loss and really you can't, its not the kind of thing that you can blame somebody for but that's the kind of feelings that can arise	14	514-518
Keeping a sense of meaning	...it probably helps to, (.) maintain my sense of self and dignity to some event because I have all this going on and being invited over to the states and so on to X and so forth is probably an enormous help because it feels that you still have some value, you still have something to contribute to other people and their well-being and so forth.	9	346-350	

## Appendix 17: Summary Tables of Individual Case Analyses

**Table 9: Summary of Analysis of Tom's transcript**

Theme	Sub-theme	Quote	Page	Lines
Loss	Depression	I think I was terribly depressed at that point, I, you know, I really should have been, I should have sought help for it and I should have been treated and I possibly should have been on medication cause I was very, very down and that lasted for quite a long time	11	470-473
	Loss of confidence	people aren't trying to be unpleasant but its you know, it erodes your confidence, makes you feel terrible	4	163-164
	Loss of future	...at my age you want to be doing um, some sort of managerial type work instead of purely hands on technical stuff so its limited my career prospects.	2	73-74
Relationships with others	Others didn't understand	where people made jokes about my hearing, that was when I was terribly sensitive about it and it was just, it was a disaster.	14	561-562
	Social withdrawal	...in terms of friends, I (.) tended to isolate myself from friends so I've distanced myself from all my friends and (.) they've let that happen, but really I've wanted it to happen so I don't hold it against any of my friends...	10	393-396
	Fear of being dependent	I didn't want to be dependent on one person, like having a girlfriend that does everything for you does all your, you know, does all your hearing for you.	12	488-489
Role in relation to hearing loss	Lucky versus let down	I think I could argue that the NHS let me down by not providing suitable counselling or support... In a lot of ways I see myself as being quite lucky...	16	663-664
			16	680
Acceptance	Negotiating identity	I used to be very self conscious about it and I would go out my way to describe myself as something that wasn't deaf, I didn't use the word deaf so hard of hearing or you know mildly deaf or em, partially deaf, all these things didn't offend me much but you know, I kind of avoided using them.	7	296-300
	Disclosure	...and then after a while you get to the point were you just can't avoid, cause its so obvious and then you get to the point were you really need to tell people in order to function.	8	300-302
Adjustment	Ambivalence	Its difficult to say that, I mean in (1) its difficult to answer that briefly in (2)some ways its been a tremendous um, problem to me that I haven't dealt with very well and its affected me a lot socially and emotionally [ ] In other respects I think I've dealt with it very well and I've had more or less a normal life...	9	379-383
	Constantly adjusting	...it's been difficult for me because my hearing is constantly going down and every time that I have actually made some level of adjustment to how my hearing was at the time, it only lasted for a few months or a year or two and then I've had to adjust to yet another set of problems and so its been chasing a set of moving goal posts which I've never been able to catch up.	15	633-637
	I should have adjusted better	I kind of blamed myself in a way for not dealing with it better but in some ways its been very difficult and um, I shouldn't blame myself but you know, its part my, the way I see myself is that I should have done better, I shouldn't have let it get me down but it did get me down and I should probably have recognised how much it gets me down.	15	637-641
	Adjustment to implant	I seem to be adjusting to it quite well, for quiet sounds its surprisingly good, when its louder sounds, I'm not adjusting to it so well, its obviously going to take a bit of time.	25	1047-1049

**Appendix 17: Summary Tables of Individual Case Analyses**

## Appendix 18: Tables Displaying Additional Themes

**Table 1: Themes relevant to each participant**

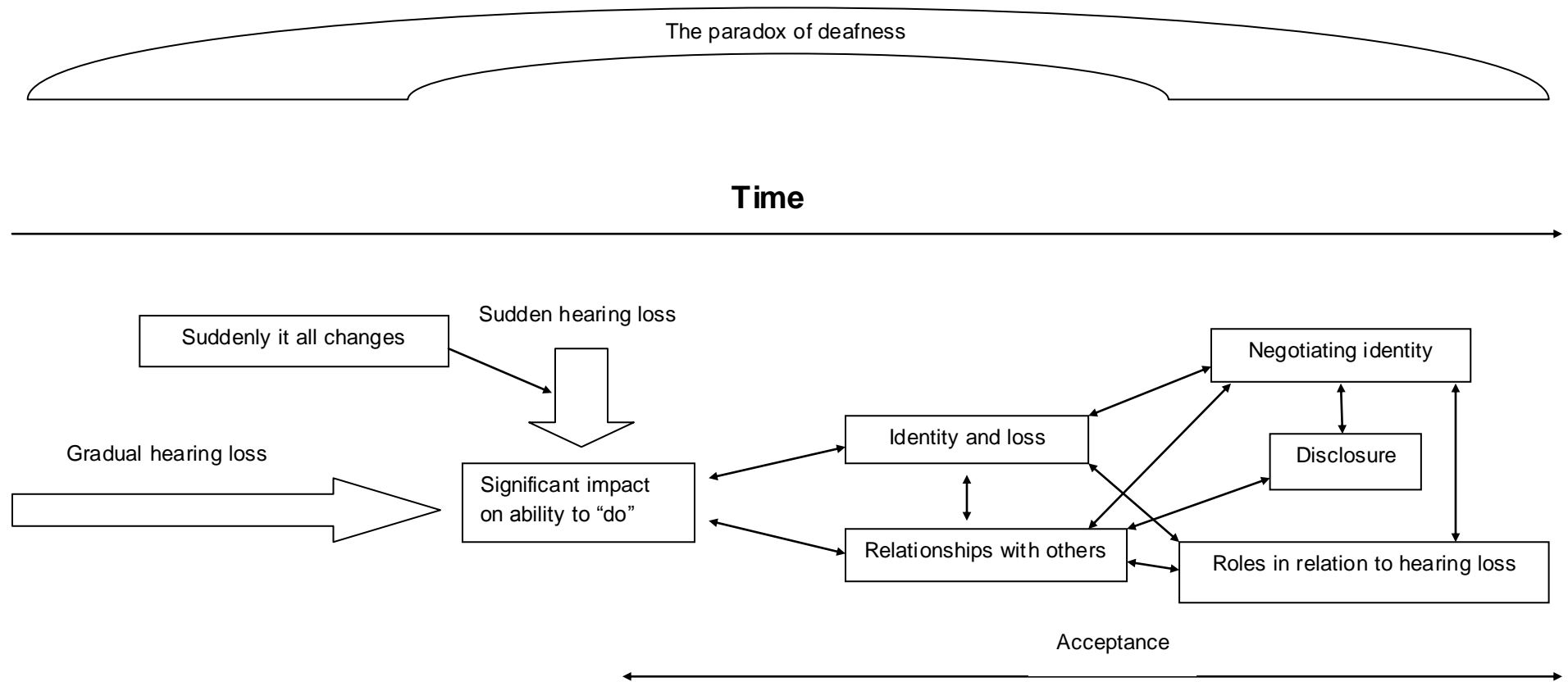
Theme	Sub-theme	Ben	David	Ian	Jenny	John	Laura	Lynn	Steven	Tom
Losing my hearing	Physical sensations				✓	✓	✓	✓		
	How I noticed	✓	✓	✓	✓	✓	✓	✓	✓	✓
I can't do the things I used to		✓	✓	✓	✓	✓	✓	✓	✓	✓
Associated physical problems				✓	✓	✓		✓		

**Table 2: Example quotes describing 3 themes**

Theme	Sub-theme	Quote	Participant	Page	Lines
Losing my hearing	Physical sensations	...there was like just a sorta popping sound in my right ear [ ], after that I could hear just nothing at all and it was, do you know, I was putting something in the microwave and you know when you're like, the package meals and you do that ((motioned piercing)) and I just like poked it with the knife and I just heard this pop and it was ringing for ages and ages and then just nothing.	Laura	2	47-51
	How I noticed	I don't know if I realised that I had a hearing loss, but my sister is a nursing sister and she was staying with me and she said "I think your hearing's not so good" and she did a test and it was she who discovered it.	Jenny	1	13-15
I can't do the things I used to		I can't always make out what's being said and particularly listening to a public speaker or if I'm in a room with a number of people and there's interaction...	Steven	1	15-17
		I played the trumpet at school [ ] and tried to get into an orchestra but I just couldn't do it and I like skiing and I like wind surfing and I like swimming but I can't anymore.	Tom	13	533-535
Associated physical problems		..one of the problems I have [ ], I suffer, always have done with eh, mucus and that makes the hearing much, much worse...	Ian	3	74-76
		I get constant tinnitus, I get two different types of tinnitus, in here I've got a tune playing and in here I've got an engine rolling all the time...	John	4	138-141

**Appendix 18: Tables Displaying Additional Themes**

## Appendix 19: Interactions Between 8 Super-Ordinate Themes



The above diagram attempts to explain the interactions between 8 of the super-ordinate themes. Theme 9, 'Adjustment' has not been included in the diagram because it was not a term introduced by participants. The diagram depicts the two types of onset of hearing loss (sudden and gradual). While gradual hearing loss deteriorates over a period of time, sudden hearing loss happens quickly over a period of minutes or days. In sudden hearing loss "suddenly everything changes," they experience an unexpected and unpredicted hearing loss that completely changes their life. Although, the two types of onset approach hearing loss through different time scales, the important factor (that leads to "Identity and loss" and "Relationships with others") for both onsets, appears to be a significant impact on an individuals to "do." It appears that if an individual perceives hearing loss as preventing them from "doing," they begin to experience loss of identity and changes in their relationships with others. The two themes of "Identity and loss" and "Relationships with others" interact (for example, if an individual believes others withdraw from them this may have a negative impact on their self-esteem, self-concept and consequently their identity.) The psychological distress caused by both these themes may in turn have a negative impact on individuals' ability to go out and "do." Changes in identity and relationships led to the process of negotiating identity (a key psychological process in acceptance.) Negotiating identity also has a significant impact on the roles individuals take into relation to their hearing loss and also in their decisions to disclose to others. The process of acceptance is presented by a double headed arrow indicating that individuals can move back and forth along the continuums of these themes. There is no limit to the amount of times they do this. As depicted all the themes interact in a dual-directional manner.