EXPERIENCES OF ACQUIRING HEARING LOSS: LESSONS FOR REHABILITATION.

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Volume 1
Abstract

Acquired hearing impairment affects one in six people in the United Kingdom. The process of becoming hearing impaired and seeking help is different for each individual and consequently very little is known about their personal experience of this journey. The aim of this thesis was to explore the essence of the experience of acquiring hearing impairment from the individual’s perspective, in order to better understand and meet the needs of clients seeking aural rehabilitation.

Data was generated in the Phenomenological tradition using unstructured interviews and analysed using a constant comparison method drawn from Grounded Theory. Participants were recruited from the UK and the USA. Individual participant’s experience ranged from those who had not yet approached services, to those who had worn hearing aid/s for several years. Data is comprised of 24 recorded interviews, reflective journals, field notes and memos. Each interview, journal, field note and memo was coded and analysed to identify a core category. The results produced categories that identified stages the individual experiences when acquiring hearing impairment, and a core category, “Preserving the social identity” emerged.

Most of the data was generated from interviews and focus groups but additionally a comprehensive audiological assessment was carried out with ten of the participants in order to compare their perception of their hearing before and after assessment. The assessment included taking a detailed medical and social history, performing otoscopy, pure tone audiometry, tympanometry, speech testing and the random gap detection test.

This thesis adds to the body of knowledge about the personal experience of acquiring hearing impairment within the framework of Social Identity Theory. It proposes a theory of how individuals experience and adapt to changes in their social identity, and proposes that rehabilitation needs to be available at a much earlier stage than hearing aid fitting. It must also be multifaceted and multidisciplinary in order to meet the needs of the individual and their significant others at various stages in their journey. Finally it identifies an unmet need within Audiology provision and suggestions are made for service development and further areas of research.

Keywords
Hearing Impairment, Counselling, Aural Rehabilitation, Service Provision, Phenomenology, Grounded Theory, Social Identity Theory.
Acknowledgements.

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Friends and family have always been my main support, not only during the period of this study but throughout my life, and I would like to thank my brother Paul, and my friends Mechelle and Helen for being there for me. My gratitude and love go to my husband Peter, who has walked every step of this journey with me, and to my boys Sam, Ben and Bracken.

This work is dedicated to my parents John and Elizabeth Taggart who always told me that if I believed in myself anything was possible.

Finally I would like to thank the late Stuart Gatehouse for inspiring me with his efforts to further the profession of Audiology. He often said, “Audiologists should not be in the business of fitting hearing aids.” He was right; we can do so much more.
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Introduction to the thesis.

1.1 Background to the thesis

1.1.1 Introduction.
The aims of my research were to explore the experience of acquiring hearing impairment from the individual’s perspective, and to develop a model in order to better understand and meet the needs of individuals seeking aural rehabilitation. I believe this thesis adds to the body of knowledge about the personal experience of acquiring hearing impairment and participation in aural rehabilitation. One in six people in Britain suffer from a degree of hearing impairment. Despite this, it is estimated that only a small proportion of those who could benefit from aural rehabilitation actually seek help (AOHL 2012). In the last 30 years many researchers have explored possible causes for this reluctance to access services. Several reasons have been suggested, ranging from concern about stigma to technical and aesthetic limitations of hearing aids.

1.1.2 Current provision of Audiology services.
In Britain, aural rehabilitation generally consists of provision of amplification via personal hearing aids, with few additional services. Following the Public Health Institute, Scotland (PHIS) report (Jan 2003) a resultant modernisation project attempted to introduce a generic client journey which would be adopted by all Audiology centres. This included: a full audiometric assessment, development and implementation of an individual management plan that covered all aspects of aural rehabilitation; provision of digital hearing aids fitted and verified by objective means; and structured ongoing reviews to provide support and monitor outcomes.

The project has not been completely successful in implementing this full patient journey. Lack of resources and training has prevented universal implementation throughout Scotland. Disagreement between professionals as to the effectiveness of objective verification measures such as Real Ear Measurements (REM), systems that allow the Audiologist to view the response of the hearing aid while in situ and fine tune the response to account for ear canal acoustics, has led to a decrease in the use of this as
a verification tool. A lack of clinical trials on newer measures such as Visible Speech Mapping (VSM), a similar procedure to REM, that shows responses to speech signals, has prevented widespread adoption of this technique. More recently the debate has centred on whether using data logging facilities on hearing aids, where the hearing aid records hours of use in different environments, is a legitimate means of assessing successful fittings. At present there is no consensus as to the most effective audiological assessment and verification process and service varies throughout the country.

1.1.3 Emergence of current provision.
In the last 40 years clinicians have experienced many changes in the provision of services. In the 1970s the range of hearing aids available to clients was limited. They were analogue aids, primarily body worn, that provided amplification but very poor sound quality. Audiologists could therefore provide very little help by means of technology, and our time was dedicated to persuading the patient to wear the hearing aids and offering advice on additional hearing tactics.

In the 1980s post aural (behind the ear) hearing aids were more common in the NHS. Although these were more acceptable cosmetically, they were still analogue aids with limited processing ability and were often rejected or used sporadically. However, the expectations of many professionals had changed. The improvements in hearing aid technology had resulted in a widespread belief that the hearing aids would now be worn more and consequently the aids were expected to play a greater part in the rehabilitation process. Many clinicians now expected to spend less time on communication tactics, and concentrate resources on reducing the waiting lists that had resulted from the introduction of the more aesthetically pleasing post aural aids. The focus of aural rehabilitation was beginning to move from therapy to technology.

In the 1990s in the ear (ITE) hearing aids became available in the National Health Service as did programmable hearing aids and, towards the end of the 1990s, digital hearing aids. Now, in theory, the technology covered all areas of concern. Digital programming allegedly addressed the common complaints of poor sound quality and difficulty hearing in background noise, and the ITE addressed cosmetic concerns.
Unfortunately digital ITE aids were only made available as part of the modernisation project for England and were removed following a National Institute for Clinical Excellence (NICE) report, (2007) that concluded that they were not cost effective because of the high maintenance required. This recommendation was taken into account in planning the later modernisation project for Scotland and ITE aids were not provided. This meant that clients who wished to obtain smaller hearing aids still had to make a choice between NHS and private provision, and may have been one of the reasons why people did not access NHS services.

In the private sector, high specification digital ITE and CIC (completely in the canal) aids have been widely available for many years. Hearing Aid Dispensers do, however, report having clients who still experience dissatisfaction. In recent years the private sector has reported a move away from ITE aids back to post aurial hearing aids. The main reason for this is to provide a more sustainable service. ITE and CIC aids tend to need more maintenance and the client is either without their aids for several days while they are being cleaned or repaired, or has to purchase spare hearing aids which are costly.

1.1.4 Rationale for study.
If client satisfaction and adherence were solely reliant on the sound quality and acceptability of hearing aids then it would be expected that outcomes in the public and private sectors would be similar. This is not the case. Clients who purchase aids tend to have higher expectations, but better outcomes. This would suggest that a good outcome is not dependent on amplification alone. On average a Registered Hearing Aid Dispenser spends 3-5 hours with a new client over a series of visits which often take place in the client’s home. In contrast, in NHS audiology departments contact time is being reduced in a bid to reduce waiting times. First appointments can be as short as thirty to sixty minutes, with the hearing aid being fitted at this first appointment and follow up being conducted by phone. This has led to some clinicians expressing concern about the implications for rehabilitation if amplification alone does not meet all the client’s needs and contact time is reduced in the early stages of rehabilitation.
As an Audiologist, working in NHS audiology clinics from 1975-2005, I regularly saw clients who had been re-referred because they were unhappy with their hearing aids. They often expressed concern about not being listened to or having been offered limited choices. This lack of involvement in the decision making process frequently formed the basis of their complaint. In 1993, as part of a BSc (Hons) in Health Studies, I completed a study that looked at patients’ perception of hearing aid fitting. In this study some clients were given a hearing aid chosen by the Audiologist, and others were given the opportunity to participate in the hearing aid selection process. Participants were allowed to choose from three hearing aids based on the appearance of the hearing aids alone. In fact all the hearing aids had the same technical specification, but there were minor variations in the design. The study showed that the subjects who were involved in the decision making process were more satisfied with their aids and were wearing them more consistently than those who had been given no choice.

In order to address the concerns of unsatisfied clients in the clinical setting, I provided Counselling sessions to allow them to explore the issues they had raised. I became aware that talking about their fears and anger about not being heard helped them to move on and deal with their hearing impairment. I saw this as a potential means of increasing adherence and satisfaction with rehabilitation. As a Humanistic Counsellor, I believe that each individual is the expert in their own life and it is essential to allow them to be at the centre of the rehabilitation process. To the best of my knowledge, however, there is no conclusive evidence in the literature to demonstrate that this would be a cost effective method of significantly improving outcomes in aural rehabilitation.

1.1.5 Providing patient centred services.

In Audiology, as in most areas of health, reference is often made to person centred services. This is an important concern for the Scottish government and is addressed in its report, 2020 Vision for Health Care (Scottish Government 2011). As a Counsellor, I see this as providing a service which is based on the needs of the individual according to their perception. To ensure a truly person centred service, clinicians first need to know what the clients believe they need and the management plan should then be based on these needs. This may mean that a generic patient journey cannot be used for every individual and amplification alone may not meet the patients’ needs. We may
require a range of services including Counselling, lip-reading, communication tactics, relaxation and assertiveness training. Realistically, there may be insufficient resources to provide such a range of services; consequently there is a need to justify the provision of each of these services, and to consider whether these services are acceptable to the client.

The first stage in designing a person centred rehabilitation programme is to explore the needs of the clients from their perspectives. Drawing on my experience as an Audiologist, I feel there are several issues that need to be considered.

- What does it feel like to experience acquired hearing impairment?
- Why do patients delay seeking help? Is it denial? Or do patients experience their hearing impairment differently from their family members? If the patient is not aware of any difficulties, do they have the hearing problem, or does their family?
- When do patients move from becoming aware of hearing difficulties to feeling they need to seek help? Are there specific events that facilitate this change? Is it counterproductive to offer amplification and rehabilitation before they have reached this stage?
- What do patients feel they need from services? How do we reconcile their needs with finite resources? Is there a way to determine common requirements and establish whether these requirements are culturally determined or common across populations? If requirements are similar across populations, do outcomes vary when different rehabilitation programmes are used, and is this related to the services provided, or to individual characteristics such as attitude or beliefs?
- How do we measure the effectiveness of a person centred programme? Can we do this by objective verification via REM and VSM or do we need to use more subjective methods such as client satisfaction questionnaires or, indeed, in depth interviews? Do objective measurements correlate with clients' perception of a successful outcome?
1.1.6 The patient journey.

Audiologists refer to the assessment and management process as the patient journey. By this they mean the steps taken when a patient is referred to Audiology services, i.e. a process that takes the client through initial assessment and testing to fitting, verification and review. This is designed to ensure that standards of care are consistent and measurable throughout the services and as such is a standardised generic journey. The individual however faces another journey, the journey that takes them from being a person who “hears normally” to a person who has acquired hearing impairment. While some stages of the journey will be common to all, each individual journey will be unique and will almost certainly have an impact on any therapeutic relationship based on person centred principles.

1.1.7 Research aims.

This study is constructed on the principles of Phenomenology and Grounded Theory therefore it is not appropriate to state specific aims for research at the outset (this is discussed further in Chapter 3). However, the main aim of this study is to explore the individual experience of acquiring hearing impairment in order to develop our understanding of what it means to become hearing impaired. I will explore how individuals feel Audiologists can interact effectively to facilitate rehabilitation. I will also investigate whether the individual’s self-evaluation of their hearing impairment correlates with objective audiological assessment in order to identify whether a particular level of hearing loss could indicate when an individual is likely to identify with having a hearing impairment.

1.1.8 Overview of the thesis.

As this study has drawn on the principles of Phenomenology and Grounded Theory, it is structured in the manner of qualitative research. In Chapter 2, the existing literature regarding hearing impairment and aural rehabilitation is critiqued. This review concentrates on the impact and consequences of hearing impairment. In order to understand the phenomenon of acquired hearing impairment fully, the reader needs some knowledge of the pathophysiology of hearing impairment and its impact on rehabilitation. As the purpose of my study is to explore the lived experience of acquiring hearing impairment, the pathophysiology is not discussed in depth, however, Plack (2005) is recommended for further reading. In keeping with the principles of
Phenomenology and Grounded Theory, the literature is presented in two stages. (The rationale for this is discussed in more detail in chapter 3). The second stage of the literature review is provided in Chapter 7.

In Chapters 3 and 4, I provide my rationale for my choice of Phenomenological and Grounded Theory methodology, and a description of the method used. Chapter 5 presents the findings from the data, and in chapters 6 and 7 I present the components of the emergent theory. A description of the complete model is then given and the chapter ends by discussing the model within the extant literature. In Chapter 8 I share my reflections on the research process, and finally Chapter 9 indicates areas for further research resulting from the theory and draws final conclusions.

1.2 The author’s voice and terminology

Many qualitative papers are written in the first person, and this is what I have chosen to do. My decision is based on the principles of Phenomenology and Constructive Grounded Theory, i.e. that the researcher’s own experience and insight form part of the theory and it is therefore more appropriate to discuss the theory in these terms. Individuals with hearing impairment are labelled differently depending on the setting. NHS staff often refer to individuals as patients, private practitioners as clients, and hearing aid manufacturers as end users. My personal choice would be to identify each as an individual and I have used this throughout the text; however there are occasions when it seemed more appropriate contextually to use the terms client or patient.

A timeline for this study is provided on page 8
### Figure 1 Timeline for the study

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2 Initial literature review

2.1 Introduction
As previously noted, in keeping with Phenomenological and Grounded Theory methodology my literature review was undertaken in two stages. The first stage was to explore the area of interest in order to define a specific area of enquiry, by identifying the existing literature on the topic and gaps in the current knowledge. Consequently the first stage of the literature review includes papers published up until the end of 2003. At this point the first stage ended. The second stage of my literature review was carried out during the analysis of the data once the themes began to emerge, and presents literature directly related to the emerging themes. The first stage of the literature review is outlined in this chapter.

2.2 Developing the question
Reflecting on the topic of acquired hearing impairment, I considered several questions:

- Why are people reluctant to seek help?
- Why do people fail to have successful outcomes from rehabilitation?
- How do people experience hearing impairment and rehabilitation?

These seemed to be interrelated; if individuals are reluctant to seek help or do not have positive outcomes from rehabilitation, it is essential that the professionals are aware of the reasons for non-engagement in order to develop services that are relevant to potential users. In order to do this, we need information about the individual’s experience of hearing impairment and aural rehabilitation. A PEO chart (Population, Exposure, and Outcome) was completed to help develop the area of interest further. This is shown in table 2.1. overleaf.
Table 2.1 PEO Chart for literature review

<table>
<thead>
<tr>
<th>Population</th>
<th>Older adults (Over 50 and under 85 years of age.) with acquired hearing loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exposure</td>
<td>Aural rehabilitation</td>
</tr>
<tr>
<td>Outcome of themes</td>
<td>Lived experience of hearing impairment and rehabilitation.</td>
</tr>
</tbody>
</table>

The population under study was older adults (between the age of 50 and 85 years). This age range was chosen because the likelihood of acquiring hearing loss increases sharply after 50 years of age (AOHL 2012) and after the age of 80-85 there are more likely to be additional hearing difficulties associated with age which make the hearing impairment more complex (Glyde et al. 2011, Dillon 2012). Therefore those between the ages of 50 and 85 years are most representative of the population that may consider rehabilitation services for the first time. Using the PEO the following research question was identified;

“How do older adults experience acquired hearing impairment and aural rehabilitation.”

Prior to carrying out a full literature search I undertook a scoping exercise to establish whether there had been any reviews of aural rehabilitation in the period 1996-2003 using the Cochrane Library Website (Cochrane Library) No Cochrane reviews were found and therefore a literature search was carried out.

2.3 Search strategy

2.3.1 Search terms

The purpose of this review was to assimilate current knowledge about the individual experience of acquiring hearing impairment and using rehabilitative services. The following search terms were used with Boolean terms *or* *and* *and*

1. Adults.
2. Acquired hearing loss.
3. Acquired hearing impairment.
4. 2 and 3.
5. Aural rehabilitation.
6. Auditory rehabilitation.
7. 5 and 6.
8. Lived experience.
10. Experience.
11. 8, 9 and 10.
12. 1, 4, 7 and 11.

2.3.2 Resources used for the literature search.
The electronic sources used are listed in Table 2.2. The search was restricted to the period 1996-2003, the rationale being that digital hearing aids were not widely available in the UK until after 1996, and there were major changes in service delivery associated with the introduction of these aids. The history of rehabilitation stretches from the years following the Second World War, but current methods of rehabilitation were of particular interest, and consequently the search was restricted to this time frame in order to keep the research current. In addition to the electronic search, a hand search of British, American and Scandinavian journals (Table 2.3) was undertaken.

**Table 2.2. Electronic databases searched**

<table>
<thead>
<tr>
<th>Databases</th>
<th>Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>(1996-2003)</td>
</tr>
<tr>
<td>ProQuest psychology journals</td>
<td>(1996-2003)</td>
</tr>
<tr>
<td>Communications and media complete</td>
<td>(1996-2003)</td>
</tr>
</tbody>
</table>

**Table 2.3. Journals searched**

<table>
<thead>
<tr>
<th>Journals</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Journal of Audiology (BJA)</td>
</tr>
<tr>
<td>International Journal of Audiology (IJA)</td>
</tr>
<tr>
<td>Journal of the American Academy of Audiology (JAAA)</td>
</tr>
</tbody>
</table>
Table 2.4 Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult participants. (Age group 50-85 years.)</td>
<td>Age group under 50 years of age or over 85 years of age.</td>
</tr>
<tr>
<td>Qualitative and quantitative papers.</td>
<td>Editorials.</td>
</tr>
<tr>
<td>Case studies.</td>
<td>Papers pre 1996.</td>
</tr>
<tr>
<td>Reviews.</td>
<td>Foreign language papers.</td>
</tr>
</tbody>
</table>

2.3.3 Results from search of databases
A summary of the results from the literature search are shown in table 2.5. I could find no papers specifically exploring the lived experience of acquired hearing impairment and rehabilitation from the electronic search. In view of this, all papers identified in searches prior to the inclusion of the search term “lived experience” were reviewed and 48 papers were considered relevant. A summary of these papers is shown in table 2.5. overleaf.
<table>
<thead>
<tr>
<th>Abstract number</th>
<th>Primary author, year of publication and journal</th>
<th>Title</th>
<th>Theme</th>
<th>Notes on Method/Content</th>
<th>Limitations and remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hetu (1996) Scand Audiol.</td>
<td>The stigma attached to hearing impairment.</td>
<td>The role of stigma and self-identity in rehabilitation.</td>
<td>Discussion paper. Based on an earlier qualitative study, (structured interviews) looking at the impact of deafness on self and others. Discusses social identity and Goffman's concept of stigma and &quot;normalizing.&quot;</td>
<td>Very little detail given about the earlier study. E.g. number of participants etc not given, however the paper is based on a small selection of responses obtained in the earlier paper and does not report results.</td>
</tr>
<tr>
<td>2</td>
<td>Preminger (2003) JAAA.</td>
<td>Should significant others be encouraged to join adult group Audioligic rehabilitation classes?</td>
<td>Benefits for the hearing impaired individual and significant others (SO).</td>
<td>All participants attended classes, 13 with SO, 12 alone. Group interviews (with SO) and handicap questionnaires (HHIE) completed by participants.</td>
<td>25 adults and SO selected, not all randomly assigned in order to accommodate personal commitments. This may affect the outcome as these allowances may not be possible in clinics.</td>
</tr>
<tr>
<td>3</td>
<td>Kricos and Holmes (1986) JAAA</td>
<td>Efficacy of audiological rehabilitation for older adults.</td>
<td>Evaluating auditory training and other methods of rehabilitation in older adults.</td>
<td>78 adults divided into 3 groups.</td>
<td>This was carried out in the USA. It may not be transferable to the UK.</td>
</tr>
<tr>
<td></td>
<td>Study</td>
<td>Title</td>
<td>Methodology</td>
<td>Outcome</td>
<td>Conclusion</td>
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<tr>
<td>4</td>
<td>Beynon et al (1997) BJA</td>
<td>A randomized controlled trial of the efficacy of a communication course for the first time hearing aid user.</td>
<td>Compares HA only and HA plus communication training.</td>
<td>RCT 26 in treatment group, 27 in control group.</td>
<td>Small numbers for RCT. This was the only RCT looking at this topic.</td>
</tr>
<tr>
<td>5</td>
<td>Danermark (1998) Scand Audiol</td>
<td>Hearing impairment, emotion and audiological rehabilitation; a sociological perspective.</td>
<td>Sociological approach to hearing loss.</td>
<td>Discussion paper.</td>
<td>Suggests emotional problems should be given more consideration in rehabilitation. Emotions are generated from interpersonal communications. Refers to Goffman's fear of losing face. Emotional reactions related to expectations and shame is one of the most important emotions and draws attention to the fact that the bond is broken. Feelings of solidarity produce a positive energy. Failure in interactions reduce energy - contribute</td>
</tr>
<tr>
<td></td>
<td>Authors and Year</td>
<td>Title</td>
<td>Keywords</td>
<td>Methodology</td>
<td>Summary</td>
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<tr>
<td>8</td>
<td>Erler and Garstecki (2002a) American Journal of Audiology</td>
<td>Hearing loss and hearing related stigma: perceptions of women with age normal hearing.</td>
<td>Stage of life and belief systems in relation to stigma.</td>
<td>191 participants in 3 age groups.</td>
<td>Identified level of awareness/impact of stigma in three age groups.</td>
</tr>
<tr>
<td>14</td>
<td>Brooks (1996) British journal of audiology</td>
<td>The time course of adaptation to hearing aid use.</td>
<td>Acclimatization and use.</td>
<td>Hearing aid use monitored in the first year and then contacted 10 years later. Measured battery use and questionnaire.</td>
<td>72 first time users</td>
</tr>
<tr>
<td></td>
<td>Author(s)</td>
<td>Year</td>
<td>Title</td>
<td>Research Design</td>
<td>Estimation Method</td>
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</table>

American study, all from one region.
<table>
<thead>
<tr>
<th>Study</th>
<th>Title and Year</th>
<th>Methodology</th>
<th>Findings</th>
<th>Sample Size and Characteristics</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td>Hallberg and Carlson (1991) JARA.</td>
<td>Hearing impairment, coping, and Family dynamics.</td>
<td>Coping.</td>
<td>12 individuals 40-60 years. 10 hearing aid wearers.</td>
<td>Grounded theory.</td>
</tr>
<tr>
<td>#</td>
<td>Authors and Year</td>
<td>Title/Context</td>
<td>Main Findings</td>
<td>Study Details</td>
<td>Critique</td>
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<tr>
<td>31</td>
<td>Hurnes et al (2003) IJA</td>
<td>Examination of difference between</td>
<td>Stats on hearing aid uptake.</td>
<td>50 participants. Matched groups 50</td>
<td>Looked at uptake and successful and unsuccessful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>successful and unsuccessful elderly hearing aid candidates, matched for age hearing loss and gender.</td>
<td>control. Between group comparisons.</td>
<td>hearing aid candidates in matched groups.</td>
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<tr>
<td>34</td>
<td>Blood and Blood (1999) Journal of Communication Disorders.</td>
<td>Effects of acknowledging a hearing loss on social interactions.</td>
<td>Determine subjects' preferences for interaction and perceptions of hearing loss.</td>
<td>80 undergraduate students aged 18-21. Stimulus was two males similar in age etc.</td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>Karlsson and Rosenhall (1998). Scandinavian Audiology.</td>
<td>Aural rehabilitation in the elderly. Supply of hearing aids related to measured need and self-assessed hearing problems.</td>
<td>Correlation between self-assessment and audiological testing. Estimation of when rehabilitation is required.</td>
<td>615 participants in 3 groups depending on age, (70.75.88.) 70 year olds 12 % with HA. 75 year olds 14% with HA. 88 year old 32% with hearing aids 70% of hearing aids Age groups are older than this study. ? Analogue or Digital aids.</td>
<td></td>
</tr>
<tr>
<td>Users were 65 years of age or older and Unmet need for AR in the 70-75 age groups.</td>
<td>Some suggestions for improving general group settings but inconclusive evidence for making changes.</td>
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<tr>
<td>Discusses the gender differences and impact on rehabilitation.</td>
<td>Men tend to have higher frequency hearing losses and women more loss in the low frequencies. Cardiovascular disease is more linked to hearing loss in women than men. Estrogen therapy may help to hearing but not significantly. Women are more likely to report problems in friendly settings whereas men are more likely to bluff. Women assign greater importance to communication and depression and have greater stress.</td>
<td></td>
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<tr>
<td>JARA (Heller, 2001)</td>
<td>36</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Israelite and Jennings (1995) JARA.</td>
<td>Participants' perspective on group aural rehabilitation. A qualitative enquiry.</td>
<td>Reports themes from 4 participants. View about a specific rehab class.</td>
<td>Argues that quantitative methods cannot pinpoint changes in real life. Gives justification for using quantitative methods; 4 adults aged 28-78. All long term hearing aid users. Group AR gave them a sense of belonging and being honest. Provided information and role models. Facilitators should not expect cause and effect relationships between topics and how and when people learn.</td>
<td>Did not reach saturation in some categories and therefore more research needs to be done to inform this area.</td>
</tr>
<tr>
<td>38</td>
<td>Erdman and Demorest (1998). JSLHR.</td>
<td>Adjustment to hearing loss I: Description of a heterogeneous population.</td>
<td>Providing normative data for adjustment to hearing loss.</td>
<td>Move to obtain help is not estimated by audiological data alone but by perceived disability and handicap.</td>
<td>Participants did not know they were taking part in research. Gender pattern not representative of...</td>
</tr>
<tr>
<td>Multi-centre research programme</td>
<td>Using CHP in relation to demographic and employment trends</td>
<td></td>
<td></td>
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<tr>
<td>--------------------------------</td>
<td>---------------------------------------------------------</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual sites</td>
<td>Educational levels varied, and there were significantly different use and subjective analysis used.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison between centres and aggregate sources 1,000 participants</td>
<td>Adult education class focused on change in performance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation of a particular type of ACP class designed to develop communication skills and change.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching coping strategies to aural rehabilitation.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Alvahamson (1981)</td>
<td>JARA.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
|   | Brewer (2001)  
JARA | Consideration in measuring effectiveness of group audiological rehabilitation classes. | Evaluation of a specific rehab programme looking at skills training, communication strategies and informational counselling. | 8-10 week programme  
15-16 hours contact over a 2-3 month period.  
35 participants aged 29-89 mean age 73  
25 females and 10 males.  
Range of hearing loss  
19 wearing hearing aids  
Participants paid for the course.  
No significant others chose to attend  
Minimal change to HHIA scores although participation raised awareness of difficulties.  
Changes were more specific to the individual rather than the group overall. | 25 females and 20 males- how were these distributed or were they all one group, not clear.  
Outcome measure does not seem adequate.  
Perhaps it is not possible to evaluate reduction in handicap across a group. It may be better to look at satisfaction and self-report of improvement. |
|---|---|---|---|---|---|
|   | Bryant and Roberts (1992)  
JARA | Bibliotherapy. An adjunct to audiological counselling. | Evaluation of bibliotherapy in relation to Audiology. | Helps provide information, understand universality, insight, | Adjunct to counselling-problematic for UK services at present. |
<table>
<thead>
<tr>
<th></th>
<th>Authors and Year</th>
<th>Description</th>
<th>Participants</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>Jennings and Head (1994) JARA</td>
<td>Development of an ecologic audiological rehabilitation program in a home-for-the-elderly</td>
<td>Development of an ecologically based rehabilitation programme in a nursing home. 30 residents aged 60-94. 4 males and 36 females. State of the art provision within the home.</td>
<td>Residents were known to each other in the community before moving to the home. One of the inclusion criteria was that a registered nurse stated the participant would benefit from the course. How did they assess this? Residents forgot to come to the sessions but found the drop in sessions very useful. Use of ALD had big impact.</td>
</tr>
<tr>
<td>43</td>
<td>Lesner and Klingler (2001) JARA</td>
<td>Assessment of the effectiveness of an adult audiological program using knowledge-based</td>
<td>2 groups. One fitted with hearing aid, the other with hearing aid and group information sessions. Used SADL as</td>
<td>Knowledge about hearing aids is not a particularly good measure of how individuals perform day to day.</td>
</tr>
<tr>
<td>47</td>
<td>Dahl (1998) Scand Aud.</td>
<td>Self-reported need of information counselling and education: Needs</td>
<td>User's opinion on counselling.</td>
<td>102 hearing aid users: Only 10-20 felt they needed further counselling in those</td>
</tr>
<tr>
<td>48</td>
<td>Thibodeau and Cokely (2003) JARA</td>
<td>Maximising auditory rehabilitation for clients, students and faculty through an intensive training programme.</td>
<td>A description of the residential course runs at the Callier institute.</td>
<td>Real life activities in rehabilitation.</td>
</tr>
</tbody>
</table>
2.3.4 Themes identified in initial literature review.

Many of the papers identified in the electronic search were discussion or critical review papers. There were very few papers reporting empirical data. Of the initial 48 papers only 3 (7.69%) were qualitative, including 1 Grounded Theory and 1 Phenomenological study, suggesting there is a paucity of qualitative literature in this area. In order to ensure a comprehensive literature review had been carried out, a hand search of journals was also undertaken. These papers, and those subsequently found in an extended hand search of journals, from 1975-2003, focused primarily on psychosocial aspects of deafness, rehabilitation and hearing aid use. Using a mind map these papers were sorted into themes as shown below;

- Impact of Hearing Impairment on the individual.
  - Emotional responses to hearing impairment.
  - Attitude to impairment.
  - Impact on relationships.
  - Communication breakdown and socialising.
  - Life stage and self – image.
  - Quality of life.
  - Gender issues.

- Impact of hearing impairment on society
  - Work implications.
  - Economic implications.

- Rehabilitation
  - Short overview of rehabilitation.
  - Technological solutions.
  - Reluctance to seek help.
  - Stigma and hearing aid use.

These will be discussed further in the next section. However, in order to prepare the reader for the range of terminology, I have given a short description of common terms used to describe hearing loss and deafness. I have also outlined the WHO definitions of disability with respect to hearing impairment.
There can be some confusion over the terminology used to describe hearing impairment. Many of these terms are interchangeable in every day conversations, but it is generally accepted that the term Deaf with a capital D refers to those individuals who align with the Deaf community, its culture and language. Other terms are hard of hearing, hearing impaired, hearing loss, and deafness. The significance of the term used and its meaning for the audience varies greatly and will be discussed in more detail later in the thesis, but for consistency the term hearing impairment is used throughout the text.

A second area of debate is whether or not acquired hearing impairment is in fact viewed as a disability by those who experience it. This will be explored in the thesis. The World Health Organisation (WHO) has defined disability in terms of impairment of bodily functions or structure, activity limitation and participation restrictions. As such acquired hearing impairment would fit into the category of disability; therefore this term will be used throughout the thesis.

2.3.5 Impact of Hearing impairment on the individual

Acquired hearing impairment interferes with more than communication. In an interview in 1955, Helen Keller is attributed with saying;

“Blindness cuts you off from things; deafness cuts you off from people”.

Developing hearing impairment at any stage of life can have an impact on both the individual with hearing difficulties and those who come into contact with them. The hearing impairment itself may cause communication problems, but the repercussions can reach much further leading to isolation, loss of confidence and low self esteem.

Ventry and Weinstein (1983) stated that while all physical disability has a great impact on both the psychological and social spheres of the individual, hearing disabilities is a communication disorder that is normally hidden and therefore deserves exceptional note.

2.3.6 Emotional responses to hearing impairment

Danermark (1998) suggested that one of the more serious impacts of acquired hearing impairment was the emotional problems it may cause. These emotions are elicited in
interpersonal communication with individuals experiencing hearing impairment. It had previously been argued by Danermark (1998) that one of the most important emotions felt is shame, and Goffman (1963) also described a fear of losing face. Certainly one of the outcomes of unsuccessful communications is that there is a risk of the hearing impairment becoming obvious, and individuals will often fear this happening. Often individuals talk about being exhausted trying to keep their difficulties secret, but Danermark suggested another reason for this fatigue. He cited Collin's (Danermark 1998) description of communications as rituals, and suggests that solidarity in relationships produce a positive energy, however this energy is reduced when these interactions fail and negative energy is created. Since hearing impairment leads to threats in the established bonds of relationships, it can be assumed that hearing impairment leads to negative emotions and therefore a negative valuation of the self, inducing shame as described by Goffman (1963).

As hearing impairment often affects the individual's ability to meet others expectations in interactions, it is not uncommon for the individual to withdraw from situations (Hallberg 1999). It may be difficult for individuals to talk about these problems, and in fact men may be less likely to talk about difficulties in interactions. This is something that is not often fully explored in the clinical setting. Danermark believed that emotional problems should be given a higher priority in rehabilitation (Danermark 1998). This has implications for managing hearing impairment. He believed that acceptance is the first stage of moving towards successful rehabilitation. Using coping strategies rather than disclosing difficulties may be a way of repairing communication breakdown, but will cause fatigue and negative emotions. Whereas Jennings et al (2013) suggested that individuals who are able to discuss their difficulties and suggest specific repair strategies received positive feelings from communication partners. Blood and Blood (1999) found similar results. In a study with 80 participants, all undergraduate students, aged 18-21 years (mean age 19 years); they randomly assigned participants to two groups and asked them to watch video recordings of two hearing impaired students. In differing conditions, one disclosed their hearing impairment, the other did not. Sixty of the eighty students said they would prefer to work with the person who revealed their disability. Positive responses were recorded by 93% and included comments that this person was perceived as open and honest, able to deal with problems, and talk about
his difficulties. Of the twenty students who selected the student who did not reveal his hearing impairment, 60% had no rationale for their choice, other than they felt the person reminded them of someone else or they liked the look of the person. Prior to the experiment, in an attempt to standardise the reactions to the students, a separate group of students who did not participate in the experiment were asked to rate each of the hearing impaired individuals in terms of attractiveness, and scored them similarly. However these were not the students who made the judgment so the results could be contaminated by personal preference, or by transference (Dryden and Reeves 2014). In any case, the authors suggest that those individuals who have reached acceptance of their hearing impairment should share this information and repair strategies with communication partners, in order to improve relationships. However, these students were from a different age group than the participants in this study and to the best of my knowledge there have not been similar studies with the 50-85 age group.

2.3.7 Attitude to impairment

The commonly used descriptive phrase, hearing loss, has negative connotations implying the individual has lost something that is part of them. Most studies concentrate on the negative aspects of hearing loss, and strive to find ways in which this loss can be compensated. There are however several studies that have looked at positive aspects of hearing loss. Stephens and Kerr (2003) described anecdotal accounts of positive situations gathered from patients over the years. Perhaps the most well-known positive experience is the account in Captain Corelli’s Mandolin by de Berniere (1998), in which Doctor Iannus is exhorted by Stamatis to replace the object the doctor had removed from his ear as the hearing impairment it caused helped him cope with his wife’s nagging. The removal of the hearing impairment had in fact made his life unbearable. Similar comments are often made by clients in an attempt to bring some humour into the clinic room and could perhaps in these circumstances be seen as an ego defence (Dryden and Reeves 2014) rather than a positive aspect. In a paper by Stephens’ and Kerr’s (2003) six factors emerged; cognitive changes in self-perception, using hearing loss to self-advantage, successful communication behaviours, resignation, the effect on communication and technical facilitators of communication. The study however did not find any relationship between positive experiences and other measures. The one positive factor relating to the impact of hearing impairment on life was using the hearing
loss to self-advantage, but it could be argued that this is another defence mechanism employed to enable the individual to withdraw from social situations and, depending on whether it is viewed from the perspective of the client or the Audiologist, could be deemed a maladaptive coping strategy rather than a positive aspect.

Many clients report problems at home with TV and conversation which lead them to seek out help with their hearing problem. In many cases their spouse or children have insisted that help be sought in order to reduce the stress and friction at home. Where clients have felt pressurised into coming for help there can be difficulty in coming to terms with the hearing impairment and this can affect hearing aid use. An estimated 10.4% of the adult population in the UK could benefit from a hearing aid but are unwilling to use them, and one in three hearing aids prescribed by the National Health Service is hardly ever used (AOHL 2012).

Smedley and Schow (1990) explored the reasons for frustration with hearing aid use. Data was gathered using an open ended item from a questionnaire used in a previous study. This open ended item was worded, “Other comments I wish to make about my hearing aid(s)”. Two groups of clients were surveyed. The first group (N = 178) were fitted by Hearing Aid Dispensers, the second group (N = 312) by Clinical Audiologists. The authors report that half the subjects in both groups volunteered comments about their fitting. In the group fitted by Hearing Aid Dispensers, 66% of these comments were judged to be negative in nature, 10% to be positive and the rest informational, i.e. providing information about acclimatising to aids. In the group fitted by Audiologists similar proportions were found. 63% of the comments were negative, 19% positive and 17% informational. This would seem to indicate that there is no real difference between the methods of fitting used by particular professional groups. However this survey was carried out in the United States and training and fitting protocols may vary in other countries. Analysis of the data showed a considerable amount of repetition in the complaints. These related to (1) the effects of competing background noise (2) fitting comfort and mechanical problems (3) concerns that the hearing aid provided too little benefit; and (4) perception that the costs of the hearing aids, repairs and batteries etc. were excessive (Smedley and Schow 1990). This final concern may be less relevant in this country where, at present many people are fitted with NHS hearing aids which are
provided and serviced free of charge. The authors of this paper describe their clients as elderly, but no specific age range is given. It is therefore difficult to establish whether these results can be extrapolated to a wider hearing aid population, or are specific to a particular age group where other factors such as significantly reduced dexterity and/or reduced cognitive function affect use of prosthetic aids. Erber et al (1996) investigated the factors that affect the use of hearing aids in older people. This study concluded that non use of hearing aids was related to several factors, the authors proposed that:

- The communication benefit that a person derives from listening through a personal hearing aid is not necessarily the same as the communication benefit that the person derives from listening to "amplified sound".
- One cannot specify the communication benefit of a hearing aid without also considering the environment in which it was used.
- The benefit that a person derives from listening through a hearing aid often depends on the knowledge and experience of the communication partner whose speech is amplified.

In general, attitudes to hearing impairment and hearing aids play a part in influencing a patient’s attitude to rehabilitation. Attitudes and beliefs about hearing aids in particular appear to have an effect on the outcome. This will be explored further in the thesis.

2.3.8 Impact on relationships
Hetü et al (1993) reviewed the literature on the effect of acquired hearing impairment on intimate relationships. They found that the interactive coping strategies which evolved to cope with the hearing loss caused tension, irritation and frustration. They listed four converging forces;

(1) Lack of internal reference. When the hearing loss is progressive and symmetrical there is a lack of internal reference to judge the reduction in one’s hearing.
(2) Blame. Hearing impairment results in violation of implicit social rules such as talking with an inappropriate loudness, which leads to responses which suggest blame.
(3) Misunderstanding. Loss of frequency sensitivity makes the hearing capabilities dependent on the prevailing background noise and reverberation. This results in what appears to be incoherent behaviour.

(4) Stigma. The sense of blame combined with the presence of stigma combines to lower self-esteem.

Hetù et al, (1993) stated that the effects of acquired hearing impairment are far reaching, disrupting communication between the individual, his family, friends and colleagues, and affecting both leisure and work activity. I think it is important to note though that this is not the case for many individuals, who are more stoical about their hearing impairment, and are able to incorporate the hearing impairment into their lives with little difficulty. I have worked with many individuals who have been fitted with hearing aids, with very little additional rehabilitation, who have adapted easily to the changes in their means of communication. This assumption is of course based on the fact that these individuals report no problems, and return to the clinic only for minor maintenance appointments such as renewing batteries. There would be value in exploring their feelings about their experiences in order to check out these assumptions. At present I am unable to find any studies which have looked at this.

The impact of hearing impairment on significant others has been documented in the literature by Brooks et al (2001) and providing amplification appears to reduce the negative effects of hearing impairment for both the client and the significant other. With regards to aural rehabilitation in general, Preminger (2003) found that the greatest reduction in handicap was measured for subjects who attended group aural rehabilitation classes with their significant other. The paper does not however discuss whether the significant other felt their relative was able to be more independent as a result of their attendance or whether progress at the classes affected their relationship.

It is clear from the literature that hearing impairment impacts on all aspects of life and aural rehabilitation programmes must address these issues. Noble (1996) outlined a psychosocial approach to hearing impairment, which addresses issues concerning the individual characteristics of the person with impaired hearing, the circumstances the
person must cope with and the circumstances of others with whom the client lives, works or otherwise spends time.

In summary, in our phonocentric society where the primary means of communication is oral/aural, individuals with hearing impairment can be greatly disadvantaged, perhaps more so than individuals who have been born Deaf and identify with Deaf culture. Individuals with impaired hearing may feel displaced. How they are perceived by their peers may change, and prejudice and misunderstanding may cause them to withdraw from some activities.

2.3.9 Communication breakdown and socialising.
Communication depends not only on the ability to hear but also on the ability to listen and to process sound. As previously discussed, a popular misconception is that an acquired hearing impairment means that sounds are merely quieter but this is not the case. The majority of individuals attending Audiology departments have presbyacusis or noise induced deafness. Since these are sensorineural losses the cochlear damage causes more than reduced audibility; it also causes processing difficulties and a degraded signal (Dillon 2012). The effort taken to contribute to a conversation, may lead to irritability and tiredness, and the individual may begin to withdraw from tiring situations such as family gatherings, or outings with friends. This can lead to isolation and loneliness, and may impact on relationships and significant others.

2.3.10 Life stage and self – image.
Hearing impairment can occur at any age, but, as described above, it becomes more common in adults aged 50 years and over. It is important to consider how hearing impairment may interact with typical lifestyle changes. Erikson’s (1994) theory of development outlined events which take place at various times in life. While some of these stages relate to childhood development, the final two stages relate to the adult aged fifty years and older. Loss of hearing may have an impact on how the adult experiences these life events. Stage VII occurs around the ages of 25 to 50 years. Erikson described this stage as generativity versus stagnation. In this stage the individual focuses his energy on his own children and his contribution to society, e.g. the workforce. The adult with acquired hearing impairment may begin to feel isolated from his family. Social events may become more difficult and he may feel detached.
from significant others in his life. He may perceive that his hearing impairment has hindered his career and he may not have reached his full potential, either because others have prevented this or because his hearing impairment has resulted in a loss of confidence which had prevented him from participating in his own development.

Stage VIII occurs from 50 years onwards. Erickson named this stage integrity versus despair. In this stage individuals look back on their life with either a sense of accomplishment or feelings of despair. This stage can have a very profound effect on people’s lives. A sense of satisfaction can help the individual come to terms with the end of their lives, whereas an individual who feels they have not accomplished all they would wish can experience a deep depression in their later years. Where someone believes hearing impairment has contributed to their lack of accomplishment, there may be a loss of self-esteem, leading to depression, and a long term impact on quality of life. In the final stages of life, communication is important not only for the individual with hearing impairment but also for their family and significant others. Hearing impairment can have a profound impact on this very important life stage and could potentially influence the family’s ability to come to terms with the bereavement.

Chen (1994) looked at the relationship between hearing impairment, self-esteem and loneliness using a descriptive correlation design involving 88 elderly participants. Data was collected using the Hearing Handicap Inventory for the Elderly (HHIE), a demographic data form, the UCLA Loneliness scale and the Rosenberg Global Self Esteem Score. All four instruments were self-reporting, as was the evaluation of hearing impairment. The rationale for this was that unless participants perceived they had a hearing impairment, there would be no self-report of difficulties in relation to this. The results suggested hearing handicap rather than hearing loss i.e. not the measured level of hearing loss but the degree to which the individual feels they are handicapped by the loss, had a significant correlation with loneliness. Furthermore, a higher level of hearing handicap led to a greater degree of loneliness. In this study there was also an association between increased hearing handicap and lower self-esteem in adults, and increased loneliness leading to lower self-esteem. This correlation was also described by Mulrow (1990) who reported that hearing impairment is associated with important adverse effects on the quality of life as reported by elderly individuals. Moreover these
effects are perceived by the individuals as severe handicaps even in individuals when there is only a mild to moderate degree of hearing loss present.

Many elderly people feel different because of a hearing impairment. Schow (1977) suggested that hearing impaired subjects rated their health worse than those with normal hearing. They were less likely to venture out without help and stayed closer to home than those who could hear. Hearing impaired subjects are more likely to say that they do not get out enough and feel they have fewer friends than they had before they experienced hearing loss. They are less likely to be assessed as having a relationship in which they make an active contribution and are more likely to be rated as depressed (Hinchcliffe 1997). Hinchcliffe believed that clients were more likely to feel different;

- Depending on the severity of the deafness.
- When the onset of defective hearing occurred before retirement age.
- Where there was a feeling that the hearing defect matters.
- Where they described themselves as a lonely person.
- Where they were depressed.
- Where there was a feeling that having a hearing defect was bothersome.
- Where there was a feeling that people get irritable with one because of defective hearing.
- Where there is a feeling that people mistake the hearing defect for absentmindedness.

He also concluded that where younger adults experience hearing impairment they retain negative feelings through into their retirement, this may contribute to the feelings Erikson described where there is lack of fulfilment. Further, he suggested that the degree of hearing loss assessed by objective methods is the least significant of all the determinants of the handicap, a conclusion also reached by Alberti (1984); Ventry and Weinstein (1983); Surr (1978); Kaptyen (1977); and Schow (1977)

2.3.11 Quality of life.
Joore (2002) carried out a prospective intervention study in the Netherlands in 2002. He recruited 80 participants aged 18 years and over, 31% of the participants were
under 65 years of age with an average hearing loss of 35dB HL or more in the better ear. In this present study 33% of the participants were under the age of 65 and the mean age was 68 years. However the hearing levels of all the participants in this study were not available so it is not possible to provide information about the level of hearing loss in the present cohort. All the participants were fitted with hearing aids for the first time, 80% were given BTE aids and 60% were fitted bilaterally. Their findings were that, post fitting, participants were more inclined to instigate social visits, although they did not instigate visits with new contacts. It may be they were more comfortable keeping conversations to those they already knew, but perhaps not confident enough to approach new people. With the exception of a moderate change in the feelings domain, there were no other statistically significant changes in quality of life in the study.

2.3.12 Gender issues
As stated previously, it has been reported that males find it more difficult to discuss difficulties than females (Helfer 2001). This may have an impact on rehabilitation. It may be that we need different methods of rehabilitation to accommodate these differences. In addition to the personal impact of hearing impairment, the impact on the significant others and society in general also needs to be explored.

2.4 Impact of hearing impairment on society

2.4.1 Work implications.
Markides (1979) outlined employment difficulties arising from hearing impairment, and explained that hearing impairment in adult life imposes limitations on the hearing impaired person in terms of employment and career limitations, with hearing impaired people being automatically limited to a smaller range of suitable job choices. Despite advances in technology and support services such as Access to Work, a government scheme that supplies funding for hearing aids and assistive devices to enable individuals to perform their work duties. In the 30 years since Markides’ report was written, many clients still describe stories of prejudice and lack of understanding at work which in turn leads to anxiety about the consequences of disclosing difficulties in hearing.
2.4.2 Economic implications.
There are two areas to be considered under the economic implications; firstly the cost to the economy in terms of impact on the workforce of uncorrected communication difficulties and secondly the cost to the NHS in terms of unused hearing aids. If hearing aid fittings are not successfully impacting on quality of life, it may be that public funding is not being used in the most effective way, and there may be other, more successful and cost effective means of assisting those with hearing impairment. At the present time there is no evidence in the literature evaluating this.

2.5 Aural Rehabilitation

2.5.1 Short overview of rehabilitation in relation to hearing impairment
It is clear from the literature that hearing impairment impacts on all aspects of life and aural rehabilitation programmes must address these issues. Noble (1996) outlined a psychosocial approach to hearing loss, which addressed issues concerning the individual characteristics of the person with impaired hearing, the circumstances the person must cope with, and the circumstances of others with whom the client lived worked or otherwise spent time. However this type of rehabilitation is not routinely offered at the present time.

Managing acquired hearing impairment is a complex issue. Amplification can help to improve the auditory signal but hearing aids do not compensate for loss of hearing to the same degree that eyeglasses can compensate for impaired vision, a concept many patients find difficult to grasp. While hearing aids can amplify soft incoming sounds before they reach the cochlea they cannot sharpen the peak of the travelling wave. Sabes and Sweetow (2007) concluded that personal amplification, in the form of either personal hearing aids or cochlear implants were unable to adequately provide comfortable communication in adverse conditions as they were unable to restore the accurate temporal and frequency resolution required.

2.5.2 Technological solutions
Technology does however, continue to play a leading part in aural rehabilitation and since the advent of digital technology, advances in signal processing have increased exponentially (Edwards 2007). Despite this, there is no clear evidence of improved
outcome measures in relation to this advancing technology. The role of hearing aids is discussed in more detail below. Listening is a task which requires a number of skills, including attention and intention to access and utilise acoustic information (Kiessling et al. 2003). In order to listen one must be able to hear auditory signals. In the case of the individual with hearing impairment this can only be achieved through amplification but hearing aids may deliver a degraded signal, making this task more difficult. Therefore clients cannot rely on amplification alone to provide adequate access to information in all listening conditions. There are however additional methods of rehabilitation available to those with hearing impairment.

In Britain the advent of the NHS in 1949 (Brooks 1981) allowed clients access to services that were free at the point of delivery. At present hearing aids are still free to all NHS clients, but this is not the case in other countries, where services vary considerably. Anecdotal evidence suggests that in parts of the United States there is only private provision for adults with the exception of war veterans, although children in full time education are able to access a specific range of models based on an assessment of need. In Australia hearing aids are provided by the government, while in South Africa there is no government provision. In developing countries such as Nigeria, centres are run exclusively by Ear Nose and Throat units which rarely have facilities for dispensing hearing aids, and hearing aids can generally only be provided to those with the means to buy them privately.

Until the introduction of electrical hearing aids, many hearing impaired people made use of ear trumpets; in fact these were still in use in many care of the elderly wards as recently as the 1980s. Brooks (1988) noted that the search for solutions to hearing loss has been recorded since earliest times, concluding that the only assistance many generations of people were able to rely on was to cup their hand behind their ear in order to funnel the sound into the canal while asking the speaker to raise his voice. A study by Barr-Hamilton (1983) showed that this action increased sensitivity by 15-20dB SPL in the mid frequencies while suppressing background noise. Perhaps this was an effective way of improving audibility in the absence of more sophisticated signal processing.
Although electrically powered hearing aids were available at the end of the nineteenth century they were not available for free distribution to the public until the 1940s (Brooks 1981). The technology has improved immensely since the introduction of these basic linear body worn aids. In the 1970s ear level aids were introduced. These were followed by the introduction of compression features and multi-channel hearing aids, and more recently by digital technology. The models now available on the NHS contracts are multi-channel compression aids which can be provided in both BTE (behind the ear) and ITE (in the ear) models. Hearing aids do not restore normal hearing. They provide amplification and process the incoming signal in order to assist the listener in difficult situations, for example listening to speech signals in background noise (Dillon 2012). Hearing aids cannot provide the additional components required to effectively process sound. They cannot, for example, address problems caused by central processing disorders, and are often particularly ineffective in clients who have suffered considerable brain damage after CVA.

Despite the availability of high specification hearing aids and rehabilitation programmes many clients still do not have good results from their hearing aid/s. Several factors have been investigated. These can be divided into audiological reasons such as; poor discrimination, atypical hearing loss and dead regions in the cochlea, and non audiological reasons such as; poor motivation, unrealistic expectations and lack of support. Many of the studies listed difficulty with background noise, poorly fitting ear moulds/aids and difficulty distinguishing speech. Age and expectations also feature as a significant factor. In earlier papers such as those detailed in table 2.6, physical difficulties appear to figure more prominently than in later studies where attitude and motivation appear more frequently. Hearing aids in the 1970s and 1980s were technically inferior to later models. It may be that problems with size and performance have been addressed to some degree as hearing aids improved and, as concerns with these aspects lessen, it is more evident that other factors play a significant part in compliance with hearing aid use. Expectations may also play a part; many clients expected more from digital technology than they had from analogue technology and this may have impacted on their motivation and attitude to the aids.
One of the central components of aural rehabilitation is amplification. Therefore adherence to hearing aid use can be a key indicator of successful rehabilitation. In light of this I decided to expand the literature review by using the same databases and journals as shown in table 2.2. and 2.3. to search using the terms hearing aids and compliance. For this search the dates were from 1978-2003 in order to look for trends in compliance over a period of time. 1978 was chosen as the lower limit of the range because this was when post aural aids became widely available in the NHS.

I found that a large body of literature exists looking specifically at the reasons for non-use of hearing aids. A selection of the papers and the reasons for non-compliance with hearing aid use are shown in the table 2.6. overleaf.
<table>
<thead>
<tr>
<th>AUTHOR</th>
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<td>Poor quality of sound.</td>
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<td>Complains of whistling.</td>
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<td>Excessive background noise.</td>
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<td>Ear mould uncomfortable.</td>
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<td>No benefit in one to one conversation.</td>
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<td>Poor handling skills.</td>
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<td>Calling attention to the handicap.</td>
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<td>Dispenser practices.</td>
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<td>Concern about amplified sound.</td>
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<td>Manipulation problems.</td>
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<td></td>
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<td>Lack of information.</td>
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<td>Brooks (1985)</td>
<td>1985</td>
<td>Inability to insert ear mould.</td>
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<td>Difficulty hearing in background noise.</td>
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<td>Lack of recognition of hearing impairment.</td>
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<td>Advanced age and poor health.</td>
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<td>Less than ideal match of aid to the loss of</td>
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<td>Author(s)</td>
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<td>Chung and Stephens (1986)</td>
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<td>Greater proportion of males will use bilateral aids.</td>
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<td>Greater use where there is an asymmetrical loss.</td>
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<td>Smedley and Schow (1990)</td>
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<td>Unable to hear in groups.</td>
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<td>Clarity.</td>
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<td>Feedback.</td>
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<td>Erber (1996)</td>
<td>1996</td>
<td>Communication benefit from listening though a hearing aid is not necessarily the same as listening to “amplified sound”.</td>
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<td>Personal reaction to hearing aid use.</td>
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<td>Personal conviction to succeed.</td>
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<td>Self-perceived value of effective communication.</td>
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<td>Availability of social support.</td>
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<td>Erler and Garstecki (2002b)</td>
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<td>Motivating factors.</td>
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As previously noted, amplification plays a large part in aural rehabilitation and so, in order to rehabilitate clients more effectively, the factors that may affect hearing aid use need to be examined closely. Identifying which, if any, of these factors have significant impact on the success of rehabilitation programmes will enable clinicians to facilitate changes in practice.

2.5.4 Impact of costs on aural rehabilitation.
Regardless of the structure for the purchase of hearing aids, aural rehabilitation in its widest sense is not funded and therefore not universally provided. One of the main reasons for non provision is cost. If a client buys a hearing aid privately he may expect that aural rehabilitation is provided for in the cost. This means the clinician must build the costs for that time into the purchase price of the hearing aid. This would impact on the clinician’s practice. One option would be to increase the price to cover the costs of providing additional rehabilitation, which in turn could potentially lead to fewer sales or a lower profit margin. The impact of this would be that the clinician would have to increase their workload to meet overheads, which in turn would limit the amount of time available for each client. Alternatively the audiologist would need to provide a separate rehabilitation programme at an additional cost which may not be acceptable to the client, or indeed within the client’s means.

In a situation where there is no direct cost to the client, e.g. NHS, the impact of provision of aural rehabilitation is still a consideration for the clinician. The introduction of digital technology led to increased demand for Audiology services. Clients’ expectations were heightened by media information about the benefits of digital technology. This increased demand which, coupled with the additional time taken to programme and verify the digital hearing aids, led to increased waiting lists. Further constraints by the government’s 18 week targets have put considerable pressure on Audiology departments, many of which are understaffed, to improve waiting times. Aural rehabilitation is labour intensive and providing individual programmes for all clients may have a detrimental effect on the services. One solution to this dilemma may be to provide group rehabilitation sessions. This would allow several clients to attend a formal class with a group of their peers and could help to develop bonds and provide peer support in the early stages of rehabilitation. In the UK group sessions for hearing
aid fittings have been used for several years primarily as a means of reducing waiting times. The object of the group fittings was to bring together first time hearing aid users and instruct them in the use of their hearing aids in a supportive environment. After the initial fitting by the Audiologist a group of 6-8 clients would take part in a group instruction session, usually led by the Audiologist who was assisted by an Assistant Technical Officer (ATO). Finally there would be a group discussion and question and answer session before clients went home to acclimatise for a period of weeks prior to any review.

Group fittings were more common prior to the introduction of digital technology and the new patient journey. My personal experience of providing group sessions was that analogue aids were limited in the adjustments that could be made and few clinics used objective measures to verify the fitting so the initial fitting session with one Audiologist could be done in 15 minutes on average. The new patient journey meant that fitting and verifying the aid took longer and unless the numbers of Audiologists were increased to programme each aid individually before the group fittings, the time taken to fit and verify the aid meant that it was no longer possible to set the aids within the same space of time. The success of group fittings depended on the uniformity of the group, i.e. where all clients had similar hearing loss and were given the same model of aid. The new client journey meant that each client may need individual settings and programmes in their hearing aid and this made uniform instructions impossible. It would seem reasonable to conclude that the individual needs of the client would limit the effectiveness of group rehabilitation programmes also, depending on the content of the session.

2.5.5 Types of aural rehabilitation programmes.

It is evident from previous discussions that aural rehabilitation has not been clearly defined. Many clinicians describe Aural Rehabilitation as hearing aid fitting and counselling; counselling in this context meaning giving information about hearing aids, i.e. technologically based. Others describe speech reading or discourse tracking as essential components of a rehabilitation programme. Aural rehabilitation may, in fact, be a range of techniques including information giving, counselling, technological solutions and training e.g. based on psychological models such as described by Hogan.
(2005). In 1994 the Journal of the American Speech and Hearing Society (ASHA) published a report produced by the Committee on Rehabilitative Audiology and adopted by the ASHA legislative council in 1983 entitled, “Definitions of and competencies for aural rehabilitation”. This sets out a comprehensive list of their recommended requirements of any programme and outlines the competencies required of those undertaking the tasks.

2.5.6 Sensory management
For the majority of individuals the first step, known as sensory management, is to try to correct the deficits in sensory signals. This can be provided through the use of hearing aids, radio microphone (wireless) systems and other assistive listening devices (ALD). Hearing aids are routinely provided by Audiology services throughout the UK. Wireless systems are provided for children primarily through education services, and ALD provision varies throughout the country. In some regions these are provided free of charge from a variety of sources such as occupational therapy and social work departments. In other regions there is no provision of ALD. In general wireless systems are not supplied to adults either in addition to or as an alternative to hearing aids. Instruction on the use of aids is integral to the hearing aid fitting and should therefore be provided by the Audiologist at the time of fitting and reinforced through a variety of mediums where necessary during subsequent reviews.

2.5.7 Perceptual training
Perceptual training aims to develop listening skills and improve discrimination and perception of speech to support the signal delivered through the hearing aids or other equipment. It involves techniques such as discourse tracking where the listener has to repeat a piece of text read by the therapist. Any unrecognised parts of the text are repeated using repair strategies where necessary until the whole passage is heard. The number of correct words for a given period of time is noted and used to monitor progress. The therapist can chose texts which vary in complexity to grade the task. However, Pichora-Fuller and Souza (2003) were critical of discourse tracking as it does not replicate naturalistic speech. It might therefore be limited in its contribution to auditory training. Additional computer based tasks are also available to develop lip reading skills. It would be anticipated that within a group of hearing impaired listeners there would be some variation in comprehension and ability and this task would not
therefore be suitable for group rehabilitation sessions. Some studies have questioned the effectiveness of some types of training when delivered in isolation (Kricos and Holmes 1996) and have identified the need for control groups in studies that document the effectiveness of audiological rehabilitation programmes (Kricos et al. 1992). Although other studies have emphasised the importance of communication for quality of life and suggest that the efficacy of these programmes be explored further (Hickson and Worrall 2003). A pilot study conducted by Danermark (2002) over a four week period held seven classes each lasting three hours with 13 participants, in which the patient was coached to gain insight and knowledge that they then shared with their communication partners. The findings from the pilot study suggested that rehabilitation programmes providing knowledge and insight in relation to communication behaviour coupled with counselling may be more effective.

2.5.8 Counselling

Counselling is a term that also needs to be defined in rehabilitation. This is an important topic in the context of this thesis and will be looked at in detail. Often hearing aid manufacturers will use the term "pre-fitting counselling", referring to the information and advice that is given before an aid is fitted. Counselling is also used to describe information giving or problem solving with regard to hearing aid use. It may be possible to provide information about hearing aids or discuss common problems in a group session but professional Counselling, by its nature, is a private and confidential practice specific to the individual's perspective and could not be delivered effectively in group sessions where there is not a common goal. It is important to distinguish between Counselling as a profession and counselling as an activity, i.e. someone giving information or using counselling skills, Counselling is a profession in its own right, bound by a code of ethics and scope of practice. This is referred to in the text as Counselling with an upper case "C". There are several schools or models of Counselling such as Psychodynamic Counselling, Humanistic Counselling, Cognitive Behavioural Therapy and Existential Counselling.

Psychodynamic Counselling was developed from psychoanalysis, drawing on the work of (Freud 2010) and the psychoanalytical movement, including Adler, Erikson and object relations theorists such as Melanie Klein. Many of the techniques used in
Psychodynamic Counselling that may be relevant to Audiology are based on Freud’s theories of development and the unconscious. The basis of this theory is that the psyche is governed by the id, the ego and the superego (Freud 2010). The id is frequently described as being instinctual and disorganised, seeking to avoid painful and unpleasant experiences. The ego grows from the id and is often seen as being the part of the psyche that deals with “common sense”. In other words it seeks to control the id’s desires in a way that allows for gratification while considering the long term consequences. The superego is the opposite of the id and acts as the “conscience”. This makes us act in a way that is socially acceptable within society’s norms. One analogy might be the experience of a young child at the checkout in a supermarket. The child sees a selection of sweets and attempts to eat them regardless of the fact that they have not been purchased. This causes a familiar scene where the child screams constantly until she gets the sweets (id). The mother may rescue most of the sweets from the child’s grasp and select one packet which she buys and then gives to the child (ego). However she may make it clear to the child either verbally or non-verbally that the behaviour is not acceptable and may even incur consequences (superego). This is a very simplistic explanation of a rather complicated process in which the ego strives to maintain a balanced psyche despite the events we face in everyday life. In some cases, however, traumatic events are difficult to deal with and the ego needs to employ strategies to help it cope with these difficulties (Dryden 1996). These strategies are known as ego defences.

Some ego defences such as repression, the process of dealing with distressing thoughts by placing them in the unconscious so that we forget them, and denial, where we deny the existence of a distressing issue, are well known. Others such as introjection, where we internalise others value systems or traits, and displacement, where we substitute one person for another, (e.g. where someone is angry with their work supervisor but takes their anger out on their partner), are less well known but may be relevant to audiological settings and can affect therapeutic relationships if undetected. Ego defences are used by everyone to a greater or lesser extent throughout their lives, but when these ego defences are used repeatedly as an alternative means of dealing with distressing circumstances they can lead to maladaptive coping strategies. Psychodynamic Counsellors seek to bring unconscious
processes to consciousness in order to help clients gain insight into these issues and so recognise and change unhelpful behaviours. There appear to have been no published studies specifically evaluating the use of Psychodynamic Counselling in acquired hearing impairment, so it is unclear at present whether using Psychodynamic Counselling to address ego defences as part of an aural rehabilitation programme would be beneficial.

Humanistic Counselling is an umbrella term for a range of therapies such as Gestalt and Transactional Analysis. The humanistic movement grew from Person Centred Counselling developed by Carl Rogers (1976). Rogers believed that human beings instinctively know what is best for them and that they strive constantly to meet their full potential even in the face of desperate circumstances. It has been argued that the existential movement grew out of this humanistic movement and Rogers’ theories do have aspects in common with the work of Victor Frankl in, “Man’s search for meaning” (Frankl 2008). Rogers believed that we are all born as “free spirits”, instinctively knowing what is best for us, but circumstances influence this free spirit and we adapt to meet our circumstances. For example, where someone experiences only conditional love, they may adapt behaviour to fit in and obtain positive responses.

To some extent we all have to adapt our behaviour to fit into society’s norms, but in extreme cases individuals’ behaviour can become so adaptive that they lose sight of their true self and develop what is known as an external locus of evaluation, relying on the opinions of others to make important decisions about their life. Again this is normal to some extent, as can be seen within a group of adolescent peers. While searching for our identity we seek to be like our peers and any deviation from the approved code of dress or conduct can cause distress for someone who is not secure in their own personality. Normally, given the right circumstances adults develop an internal locus of evaluation relying on their own judgement to make important choices. However if the individual has experienced criticism or ridicule in making their own choices they may not develop to this stage. This may affect the individual’s ability to adapt and take ownership of their hearing impairment independently. In Person Centred Counselling the goal is to help the individual develop an internal locus of evaluation and thus reach their full potential. Rogers believed that if a Counsellor was able to demonstrate three
core conditions (1996) and the client was able to experience these in a safe supportive environment they would grow as a person. The three core conditions are (Dryden and Reeves 2014);

Unconditional positive regard. This is the ability to accept the person as they are without judgement. Although the Counsellor may not agree with or condone the client’s behaviours or decisions they can accept the client without prejudice and work with the client in the here and now.

Congruence. This means being truthful with the client. It is essential that the client knows they can trust the Counsellor to give them honest answers to questions in order to explore issues safely. The client may feel they cannot discuss their feelings or issues with their family without being influenced or indeed ridiculed and they need a safe place in which to test out feelings.

Empathy. This means being able to see the situation as if you were the client. In other words being able to put aside your own views and understand how it feels from the client’s perspective.

A search of the literature did not identify any papers evaluating the use of various Counselling methods in clients with acquired hearing loss, but personal experience has shown that many of the critics of Person Centred Counselling feel that Rogers' theory is too simplistic. However, my own Counselling practice has shown that clients who are able to experience the core conditions feel supported and empowered to make profound changes in their lives. Any description of the three core conditions lacks the ability to convey the complexity of the process and the skills required to interact with another human being in such an intense way. As a Counsellor, I provided this service to clients within the Audiology setting, but experience demonstrated that it is difficult to take on the role of Audiologist, often a directive role based on technical knowledge and expertise, at the same time as the role of Person Centred Counsellor, a non directive role allowing the client to set the agenda. It may be more constructive to either provide dedicated facilities for counselling within the department or to ensure that the Audiologist does not play both roles with the same client.
Cognitive Behavioural Therapy (CBT) is perhaps one of the best known methods of Counselling, often used in psychology to treat addictions and phobias. It is used successfully in Audiology in the management of tinnitus and in vestibular rehabilitation. Many of the techniques employed, such as diaries and motivational interviewing, can be used to help patients make changes in their lives. The basis of Cognitive Behavioural Therapy is that thoughts can influence actions and by examining our thought processes and challenging unhelpful thoughts we can change our behaviour. Rational Emotive Behavioural Therapy (REBT) was developed by Albert Ellis (2005). Ellis believed that human beings had two goals in life; to stay alive and to pursue happiness. From Ellis’ perspective, rational referred to anything that helped them to attain these goals, and being rational meant being flexible, logical and consistent with reality. Whereas being irrational meant being rigid, illogical and inconsistent with reality. Ellis believed that human beings had a tendency toward irrationality and that they were not affected by events per se but by their interpretation of them. He developed the ABC model in which A represented the person’s inference from the event, B represented their beliefs and C represented the consequences, i.e. their behaviours. In other words, what the individual believes happened will affect their behaviour; therefore two people could experience the same scenario but have a completely different outcome. Person A could walk down the street and, seeing someone they know on the other side of the road, might call to the person and wave. If the person did not respond Person A might infer that they have not seen or heard him; if the person has his head down and there is a lot of traffic noise that would be a logical inference. Person A might even believe that the person has a hearing impairment and did not hear him call, and consequently might be amused by the incident or concerned for the other person, depending on the relationship. His behaviour might be to carry on walking and ignore the incident, raise his voice or cross the road to speak to the person. In the same scenario Person B might infer that the person is deliberately ignoring him because he has his head down and is not making eye contact. Person B might believe that the person is avoiding him or does not like him. This may be irrational, unless there is other evidence to support this, and may lead to Person B becoming anxious or angry without cause. Experience suggests that individuals with hearing impairment often have irrational thoughts about people laughing at them or excluding them from conversations, so it may be that some
of the techniques used in REBT may help clients explore irrational thoughts about hearing loss and its impact on their life.

Existential counselling methods such as Logotherapy (Frankl 2014) tend to deal with profound issues in an individual's life such as divorce, redundancy or death. These life changing events can cause the individual to question their purpose in life or their identity. Acquired hearing impairment can have an impact on the individual's self-concept, especially in the 50-60 year age group where the client may be settled into a career and have a vision of how their career will progress. This vision may be affected by a loss of hearing which may impact on their ability to do their job and interact with their colleagues. Clients may have to struggle with the fact that they are becoming more dependent either on technology or others to help them communicate and may not see themselves as they did. The struggle to reconstruct their self-image may cause additional stress.

It would appear that Counselling may have a lot to offer aural rehabilitation but there are some barriers to overcome. Counsellors need to be able to offer a safe place for clients to explore their issues, and to do this Counsellors work within a strict contract that sets out limitations for confidentiality and access. It is a unique relationship in which two people meet and share personal and often intimate discussions, then agree to part without further contact. This is not possible in the field of Audiology. A client with acquired hearing impairment will continue to have contact with the Audiology department throughout their life. Many of the problems the client will discuss with the Audiologist will relate to the hearing impairment and may be relevant to their rehabilitation. The Audiologist cannot offer the same degree of confidentiality as a Counsellor and therefore the client may not feel safe enough to divulge sensitive information and consequently problems may not be addressed.

2.5.9 The Audiologist in the role of Counsellor.

There may also be a conflict of interest in combining the roles of Audiologist and Counsellor. It is difficult to maintain boundaries when the professional takes on both roles. For example an Audiologist may feel it necessary to make recommendations to the client based on the audiological evaluation but this does not fit with the role of the
Humanistic Counsellor who allows the client to set their own agenda and make their own decisions. Although CBT, a more directive method of Counselling, may be within the remit of the Audiologist with specialist training, other types of Counselling may not be effective. Until relatively recently Audiologists training has been almost exclusively technologically based. Additional training in rehabilitation was provided by two universities in England, leading to a hearing therapy qualification. These courses no longer run and the profession of Hearing Therapy has been amalgamated with Audiological Scientists and Audiologists under the British Academy of Audiology. At this time, only one Masters Degree course in Rehabilitative Audiology is delivered by Queen Margaret University in Edinburgh. With the introduction of the BSc in Audiology in the UK, rehabilitation modules have become integrated into audiology training, but modules specifically designed to teach counselling skills are not yet part of all BSc programmes. Recently the government has decided to change the training of Audiologists and there is a possibility that this may lead to reduced training in rehabilitation.

In the United States, English (1999) evaluated an Audiology Counselling course run at the Central Michigan University. Fourteen third year Doctor of Audiology (AuD) students took part in a course designed to develop facilitative listening skills. Students were then required to answer four questions:

What are the psychosocial implications of hearing loss?
How can the Audiologist serve as a non-professional counsellor?
How can the Audiologist transfer theory, in this study a behaviouralist approach, a Humanist approach and a Rational Emotive Approach, to practice?
How can we evaluate our effectiveness in counselling?

The study contained only a small number of participants and there is no information about how their answers compared to students who had not completed the course. It would be interesting to see if other students naturally matured into this role without additional input as their experience of working with people increased. Since this information is not available it is not possible to draw definitive conclusions but the data suggested that students moved from a pre course approach which was predominantly technical to a more feeling approach in the post course evaluation. This would suggest
that while it may not be possible or indeed appropriate for Audiologists to be trained Counsellors, training in using counselling skills may be advantageous for Audiologist / client relationships. However, it is essential that Audiologists maintain clear boundaries and are aware of their limitations in using counselling skills in order to protect the client. They should also be aware of when it would be more appropriate to refer clients to Counsellors or Psychology departments for issues that are outwith their scope. An alternative method of delivering Counselling would be to have a trained Counsellor employed as part of the rehabilitation team. This would allow Counselling to be part of the process, but there are difficulties here also. There would be financial implications as additional resources would be required to provide this service. Some studies have looked at the effectiveness of Counselling and although there has been a suggestion that Counselling improves quality of life (Backenroth and Ahlner 2000) the evidence is not clear. In this study 30 individuals with moderate to severe loss, who were all experienced hearing aid users, took part in a rehabilitation programme involving Counselling interventions. Although the authors state that there were counselling interventions in the medical, psychological, educational, social and technical area, it is unclear which form the Counselling took. Data was obtained from in depth interviews and case studies were used to illustrate the findings. The case studies demonstrate a range in effectiveness. The first case, a female, had a very good outcome despite the fact that she had to be persuaded to participate. However this raises some concerns around ethical issues and whether the data is robust given that she had been persuaded to take part. She did gain a lot of insight, but it is interesting to note that she was herself employed as a Counsellor. It may be that she found it easier to participate in the counselling relationship and was able to explore her own feelings more easily, given her training. The other case studies were less convincing in terms of demonstrating a much better outcome following counselling. It appears that the main benefit expressed by participants was a better understanding of their deafness and its impact on their life. Whether this can be incorporated into an aural rehabilitation programme without individual Counselling sessions needs to be explored further.

Robertson (1999) discussed provision of Counselling for patients with hearing impairment in general terms rather than in relation to hearing loss. In this paper it was concluded that Counsellors were unprepared for the task of dealing with those who are
“hard of hearing”. In order to provide Counselling services that are supportive there would seem to be a need for additional deaf awareness training, an additional cost to the service. It would seem that although there may be some evidence to suggest that Counselling can improve quality of life further work needs to be done to establish whether it needs to be offered as part of the patient journey.

Regardless of whether aural rehabilitation is delivered on an individual basis or in a group setting, it is labour intensive and has implications for resources. Home based systems have been designed which allow the client to practice exercises in their own home (Sweetow and Sabes 2006). The advantage of these is that they can carry out the exercises at their own pace and at a time that suits them. This also frees clinic resources, but how is progress monitored? Are patients motivated to carry out the exercises on their own?

In summary, aural rehabilitation is multifaceted and provision is variable. There is some evidence that when used in conjunction with amplification, perceptual training can enhance communication skills. There are however implications for resources, particularly in the NHS where there are staff shortages. The solution may be to offer programmes that may be used at home, but this raises the question of adherence.

Adherence to aural rehabilitation, whether this refers to technological solutions such as hearing aid fitting, or comprehensive aural rehabilitation programme as described previously, has been the subject of debate for many years.

2.5.10 Reluctance to seek help

The primary means of addressing hearing impairment in the UK is the provision of hearing aids. Although these are freely available many people still wait for long periods of time before requesting amplification and many of those who do obtain hearing aids do not wear them consistently. In order to provide patients centred services the reasons for this delay, and subsequent underuse of hearing aids need to be explored and addressed.

2.5.11 Stigma

Scambler (1998) described stigma as any trait or disorder that marks an individual as significantly different from the “normal” people in a community. The presence of a
stigma would also lead to some form of sanction from within the community. It would seem that stigma still exists around deafness. Anecdotal evidence suggests that many clients still insist on wearing CIC (completely in the canal) models of hearing aid because they are less conspicuous, even when they know they are less effective for their hearing loss than other models. There is a perception that people are not tolerant towards those with hearing difficulties, and clients often report instances where they have been treated differently from their peers, or subjected to ridicule in public situations. Goffmann (1963) suggested that given the opportunity of hiding a stigmatising disorder most disabled people will try to do so in order to protect themselves from negative attitudes. For these reasons individuals may feel they will be penalised for their hearing impairment and may prefer not to make their difficulties known. This may partly explain why clients wait for so long before seeking help.

2.5.12 Health Behaviour and acquired hearing loss.
There is a paucity of literature on health behaviour and acquired hearing loss. However Noh (1994) looked at two theoretical models, the health belief model and the theory of reasoned action in relation to aural rehabilitation. The Health Belief model was developed to predict participation in health prevention or detection programmes and draws on cognitive theories of behaviour i.e. that behaviour is dependent on the value the individual places on the desired outcome and the belief that a particular behaviour will produce that desired outcome.

The second theory, the theory of reasoned action states that the most useful predictor of behaviour is the intention to engage or not engage in a particular action, which is in turn affected by personal attitudes and subjective and cultural norms. Noh (1994) stated that the individual is more likely to engage in the behaviour if it is viewed favourably and if others approve of the behaviour. This would suggest that engaging in the behaviour is more likely if the client has an external locus of evaluation. Noh (1994) suggested it might be more beneficial to emphasize the positive benefits of amplification rather than the negative aspects in order to increase use. He also suggested that social support may improve use, which concurs with the work of Getty and Hetu (1991). Emphasizing the positive aspects may be useful in motivational interviewing if the goal is to influence the client’s beliefs, but the effect of any negative beliefs that are not addressed needs to
be considered. If the client feels unable to express these beliefs it may not be possible to gain insight into negative feelings about hearing loss or rehabilitation which may be detrimental to the client.

2.6 Conclusion

It is clear from the literature that aural rehabilitation is a complex subject that has been subject to much debate. Many of the papers centre around the efficacy of various types of rehabilitation programmes, but as yet there is no evidence to suggest that one clearly defined programme is more effective, and it seems that the contents of programmes are dependent on individual preference and professional experience, rather than on the expectations of the participants. What is clear from the literature is that the research into aural rehabilitation is predominantly centred on evaluating the techniques and technologies available to the professional. There seems to be very little literature centred on the clients’ experiences or perceived needs.

In order to provide a truly person centred service the needs and perceptions of the client need to be explored in much greater depth. This is necessary in order to establish whether failure to access services or lack of adherence is a result of; technological limitations leading to dissatisfaction with amplification, lack of additional services that clients feel are a necessary adjunct to amplification, services which are deemed to be unnecessary or ineffective from the clients point of view, or indeed some other as yet unknown reason. There is a gap in the body of literature in that the clients’ perceptions about the experience of acquiring hearing loss have not been rigorously explored and documented.

This thesis will address this area of enquiry by analysing individuals’ thoughts and feelings about, and experiences of, acquiring hearing impairment in order to provide more detailed information of the needs of this client group. In order to explore this further it would seem essential to choose a research method that allows the client to express their thoughts and feelings about this journey. This would suggest that a qualitative method may be more suitable. There are a range of qualitative methods available, and these need to be considered individually in order to choose an approach and method that captures the relevant data in the most effective manner. In the next
chapter I will discuss the various methods of qualitative inquiry and my rationale for my choice of method.
3 Developing the methodological approach.

3.1 Introduction
Having defined the research area, it is essential that the most appropriate methodology is used to generate and analyse data. In this chapter I evaluate three research approaches with reference to the aims of this project; quantitative methods, qualitative methods and mixed methods. This is followed by my rationale for my choice of method. A brief overview of each of the three methods is given below.

3.2 Overview of research methods.

3.2.1 Quantitative approach.
For most of the twentieth century the predominant method of research was quantitative research because it could be undertaken in a controlled environment and could be replicated and generalised to a wider population. Driven by theory and current knowledge, it set out to test hypotheses against a specific theory; therefore data was gathered after a working hypothesis had been constructed (Smith.2003). Quantitative researchers use a process of deductive reasoning to develop theoretical hypotheses that can then be tested. Quantitative research tends to be more formally structured than qualitative research as it tends to follow the standardised procedure of; formulating a research question, generating a hypothesis, and finally, collecting and statistically analysing data leading to results and potentially new findings. This method is most associated with a positivist/post positivist paradigm where it is important that the research can measure variables and uncover truth (Teddie and Tashakkori 2009). The nature of quantitative research means that it can be reductionist and this often prevents exploration and interpretation of individual experience. This would be seen as a limitation of the method for this particular study as one of the aims is to obtain as much information as possible about the participants' wider views. Therefore this approach was not considered to be the most suitable for this study.

3.2.2 Qualitative approach.
The aim of qualitative research is to seek answers to questions about the what, why and how of a phenomenon rather than ask questions about how many, or how much? (Green and Thorogood 2009). The field of qualitative research is more diverse than the
quantitative method and covers a very wide range of theoretical perspectives. These are discussed in more detail later in this chapter. In essence, qualitative research seeks to understand how individuals or groups experience phenomena by using an inductive method that may develop a theory arising from the data itself. Punch (2005) described qualitative research as a set of social dialogues and principles that are conducted in particular social contexts in order to frame and represent human constructions. Qualitative research is a method of generating theory from the data rather than proving hypotheses in the manner of quantitative research.

3.2.3 Mixed methods.
The mixed method of research began to emerge around 1985 (Punch 2005). Since then the division between qualitative and quantitative methods of research has gradually diminished. Punch (2005) argues that, although there are distinct differences in types of data and methods of analysis, there are also similarities and the aims of the two methods are to some degree interchangeable. It is often advantageous, particularly in clinical research, to look at the individual experience and relate this to the results of an objective assessment. According to Teddie and Tashakkori (2009), mixed methodologists offer an alternative to the qualitative and quantitative methods as they advocate using whatever methodological tools are appropriate to answer each specific research question. While a mixed methods approach would allow the use of both qualitative and quantitative methods, giving the advantage of using the data from the auditory profiles, I decided that the audiological data collected in this study, while sufficient enough to indicate trends, would be insufficient for the purposes of analysis and would be used only as a form of qualitative data. Thus it would not be a mixed methods design in its truest sense but be more in keeping with the Glaser’s dictum that everything can be considered as data (Glaser and Strauss 1967).

As the proposed study would generate data with participants about their experience of acquiring hearing impairment, a method was required that was inductive and captured the individual experience while facilitating the generation of themes or theory from the data that would be able to inform and develop practice. For this reason, I decided that a qualitative approach would be most appropriate. From the preliminary literature review it became evident that previous research in this area of Audiology had been
predominantly quantitative. Although this has resulted in a large evidence base for the technological aspects of rehabilitation, it has provided less information about the impact of psychosocial aspects of acquired hearing impairment or non-technical aspects of rehabilitation. As discussed earlier, it was this gap in the literature that influenced my choice of method.

3.2.4 Overview of Qualitative Methodology
As previously stated, a qualitative approach appeared to be the most effective method for this study. However there is no single qualitative method, rather this term applies to a range of methods. Qualitative researchers make philosophical assumptions and bring their own paradigms, world views and beliefs to their study (Creswell 2007). These world views and beliefs must be openly acknowledged as they will influence the choice of methodology selected.

Researchers as individuals hold a range of philosophical assumptions regarding ontology, epistemology, axiology, rhetoric and methodology (Creswell 2012). These assumptions have major implications for practice. The summary below is adapted from Creswell (2012).

Table 3.1 Philosophical assumptions with implications for practice

<table>
<thead>
<tr>
<th>Assumption</th>
<th>Characteristics</th>
<th>Implications for practice</th>
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<tr>
<td>Ontological (the nature of reality)</td>
<td>Reality is subjective and multiple as seen by participants in the study</td>
<td>Researcher uses quotes and themes in words of participants and provides evidence of different perspectives.</td>
</tr>
<tr>
<td>Epistemological (How the researcher knows what he/she knows)</td>
<td>Researcher attempts to lessen distance between him or her and that being researched.</td>
<td>Researcher collaborates, spends time in the field with participants and becomes an insider.</td>
</tr>
<tr>
<td>Axiological (the role of values in the research)</td>
<td>Researcher acknowledges that research is value laden and that biases are</td>
<td>Researcher openly discusses values that shape the narrative and includes his or her own interpretation in conjunction with the</td>
</tr>
</tbody>
</table>
Interpretation of the participants

<table>
<thead>
<tr>
<th>Rhetoric (the language of research)</th>
<th>Researcher writes in a literary, informal style using the personal voice and uses qualitative terms and limited definitions</th>
<th>Researcher uses an engaging style of narrative, may use first person pronoun, and employs the language of qualitative research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methodological (methods used in the process)</td>
<td>Researcher uses inductive logic, studies the topic within its context and uses an emerging design.</td>
<td>Researcher works with details before generalizations, describes in detail the context of the study and continually revises questions from experiences in the field.</td>
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</table>

A paradigm describes a general perspective of how the world is experienced, providing a framework for how reality is seen by the individual researcher. There are different paradigms and diverse assumptions between qualitative and quantitative researchers regarding the nature of reality (ontology) (Hall et al. 2013). The most commonly cited paradigms are positivism, post-positivism, and constructivism. The differences between these reflect the differences in philosophical ideals and have an effect on the process and interpretation of research. Therefore understanding the researcher’s paradigm is an important part of understanding the context of their studies (Creswell.2007). My personal paradigm is discussed later in this chapter.

3.2.5  Positivism

This underpins the philosophical approach traditionally taken by researchers in the physical and social sciences. Positivists use deductive reasoning in order to generate hypotheses with an emphasis on rational objective and logical thinking. They assert that the world is ordered and predictable and a true reality exists (Hall et al. 2013). They hold a dualist and objectivist epistemology, assuming that the focus of the enquiry exists independently of human interaction. They strive to avoid contaminating studies with their personal biases, using orderly systematic methods to collect data and focusing on confirmation of a predetermined hypothesis. An important criterion of this paradigm is to use findings to predict and generalise (Hall et al. 2013).
3.2.6 Post positivist

Post positivists have a critical realist reality (Hall et al. 2013), claiming that though a true reality exists; we can never fully understand it. They use a modified dualist objectivist epistemology. According to post positivists perfect objectivity can never be fully attained as each human being has their own perceptions and bias, but it is possible to discover knowledge of the world that it is separate from our minds. Prediction and control remain important for post positivists but research is conducted in more realistic settings and there is an increased use of qualitative methods. The emphasis is on disproving rather than verifying a hypothesis by using triangulation (where data is collected from a variety of sources). The dominance of positivism is now being taken over by post positivism with an increase in the use of qualitative methods (Hall et al. 2013).

Researchers who have belief systems aligned with post positivism will use a scientific approach to research not unlike the approach used by a quantitative researcher (Creswell 2012). Their research will have elements of being reductionist and will rely on logic and empirical data. They will have a cause and effect approach to research and will be deterministic, obtaining data based on a priori theories. They will use multiple levels of analysis for rigour, often using computer programmes to assist with data management, and will write in the form of a report with a structure resembling quantitative approaches. Teddie et al (2009) express an opinion that post positivism, while seen as a replacement, is still strongly linked to the traditional quantitative view of science.

3.2.7 Constructivism

The constructivist paradigm is a relativist ontology in which reality is believed to have multiple constructions depending on the individual. Constructivists believe that knowledge is highly conceptualized by political, historical, cultural and other issues (Hall et al. 2013). The epistemological position of constructivism is transactional and subjectivist and reality is assumed to be local and specific to the participants (Hall et al. 2013). The researcher and the focus of the enquiry are linked with findings that occur in the natural world and are created between the interactions of the enquirer and the focus of the study. This perspective believes that humans do not discover knowledge so much as they make or construct it and then interpret it.
Researchers who have a belief system aligned to social constructivism will seek to understand the world in which they live and work. The researcher looks for multiple views rather than producing a few categories, and they rely as much as possible on the participants’ views (Creswell 2012). They believe these views are formed by interaction with others and the historical and cultural norms in the participants’ world. They generate theory from the participants’ experiences by using areas for exploration that are broad and general and address the process of interaction. Researchers also recognise the influence of their own experience on interpretation of the data. This paradigm is evident in Phenomenological studies and Grounded Theory.

Having decided on their philosophical stance and paradigms, the researcher can now choose an approach that is relevant to the research area. As previously noted the differences between these paradigms reflect the differences in philosophical ideals and have an effect on the process and interpretation of research, therefore understanding the researcher’s paradigm is an important part of understanding the context of their studies (Hall et al. 2013). Consequently my own position in relation to these paradigms is discussed later in this chapter.

### 3.3 Some specific approaches to Qualitative research.

There are many approaches described in the literature. The following, more commonly used, approaches are summarised below; Narrative research, Phenomenology, Grounded Theory, Ethnography, Case study, Hermeneutics, the Empirical Phenomenological method and Heuristics.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Characteristics and use of approach.</th>
<th>Key References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narrative</td>
<td>Used to explore in depth experiences for a single or small group of individuals. Involves producing “field texts” i.e. notes taken during interactions with the participants, compiled over a period of time.</td>
<td>Clandinin and Connelly (2004)</td>
</tr>
<tr>
<td>Method</td>
<td>Description</td>
<td>References</td>
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<td>-----------------------</td>
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<tr>
<td>Grounded theory</td>
<td>The approach developed by Glaser and Strauss as a result of their study of dying. The central approach to this theory is to find a core category derived from a series of open, axial and selective coding. However Grounded Theory has developed and become more constructivist over time.</td>
<td>Glaser and Strauss (1967) Charmaz (2006)</td>
</tr>
<tr>
<td>Ethnography</td>
<td>Widely used in anthropological studies. The method involves extensive and repeated interactions with subjects in order to study them in their own environment.</td>
<td>Seale et al (2004.)</td>
</tr>
<tr>
<td>Case study</td>
<td>A method of studying a single case or small group of cases in depth.</td>
<td>Seale et al (2004.)</td>
</tr>
<tr>
<td>Hermeneutic</td>
<td>Looks at the meaning and interpretations beneath the phenomena. In this method the researcher aims to put aside his or her own interpretations and prejudices in order to understand the meaning beneath the data.</td>
<td>Moustakis (1994) (Gadamer 2006)</td>
</tr>
<tr>
<td>Empirical Phenomenological</td>
<td>This involves two levels. In the first level a series of open ended dialogue and questions are used to obtain descriptive data. In stage two the researcher conducts a reflective analysis and interpretation of the data.</td>
<td>Moustakis (1994)</td>
</tr>
<tr>
<td>Heuristic</td>
<td>An autobiographical method of research</td>
<td>Moustakis (1994)</td>
</tr>
</tbody>
</table>
in which the researcher seeks to explore a personal challenge which may have universal significance.

3.4 Evaluation of methods for this study.

For the purpose of this study I felt that two methods, Phenomenology and Grounded Theory were the most appropriate methods to achieve the aims of this study. In this section I have discussed the suitability of Phenomenology and Grounded Theory in more depth. I have then discussed the key issues of paradigms, ontology and epistemology that influence the choice of methodology, and the key concepts of; theoretical frameworks, prior knowledge of the substantive area, theoretical sensitivity, and the role of the literature review. Finally, I have then discussed my own ontological and epistemological position in relation to my choice of methodology.

The aims of this study were to describe the lived experience of acquiring hearing impairment and to analyse these experiences in order to develop a set of themes or a theory that would enhance practice in aural rehabilitation. This experience involves not only the physiological changes in the hearing, but the individual’s thoughts and feelings, and the emotional reactions to the hearing impairment. In other words the body and mind combine to give the lived experience, and these cannot be separated. The Cartesian dualism of mind and body grew out of the need to separate the “mechanical” body which was lifeless and needed to be animated by the mind from the spiritual aspects of the being (Murray and Chamberlain 1999). This mind/body dualism was first addressed by Plato but later developed by Descartes and paved the way for the biological model of health that allowed the body to be separated out from the mind and treated as a separate entity. Dualist approaches prevent a holistic view of phenomena, whether we take the empiricists’ view of the physical basis for existence or the constructivists’ view of the central role of the mind in structuring perceptions (Murray and Chamberlain 1999). For the purposes of this study a non-dualistic approach was taken, putting aside assumptions and listening to the participants’ narratives. Knowledge is contextual, so it was important to remember that the participant’s knowledge can differ from the professional’s and may be more valid in the context of
the lived experience. Murray and Chamberlain (1999) cited an example of Deafness where the doctor sees this as something to be “fixed” perhaps with cochlear implantation. However a Deaf adult may prefer to be accepted as different rather than seen as defective, but what of the adult with acquired hearing impairment? They may feel they are between worlds; no longer hearing but not able to identify with being Deaf. Many assumptions are made about their experience. It has been suggested that they go through a grief process as described by Kubler-Ross (1973) in which the first stage is the person’s denial that there is a hearing impairment. In my opinion, alternative explanations may be that perhaps the person is not in denial but is not yet aware that there is a hearing impairment. Acquired hearing impairment happens over a period of time and can be very subtle in the initial stages, so it may be the case that other people become aware of breakdowns in communication before the individual with the hearing impairment. Alternatively, since the biomedical model of health care places the responsibility for coping onto the person, their way of coping may be to conceal the problem, or avoid areas that are problematic in an attempt to demonstrate to society that they can cope.

Constructivists believe that there is no one correct view of the world and that events have different meaning and implications for different people. For this reason it would seem that a research method that aims to have no preconceptions or assumptions, and allows the individual to express their view of the world would be the most appropriate for this study, this would suggest a Phenomenological approach. However, as one of the aims of the study was to devise a model that could inform practice, a method that allowed the views of the participants to be formed into a theory would be more suitable than a method which reported individual narratives. As the data would be collected by an experienced Audiologist and Counsellor, it should also be borne in mind that the researcher’s experience might influence the interviews or interpretation; therefore it was necessary to use a method that acknowledged the experience and input from the researcher but also employed reflection and reflexivity to ensure the data is not influenced. This also indicates the appropriateness of Constructive Grounded Theory.
At this stage, I decided to look at the philosophy and methodologies used in Phenomenology and Grounded Theory more closely and in the next section I have outlined the significant areas in terms of development and methodology.

3.4.1 The origins of Phenomenology and Phenomenological research.
Phenomenology is both a philosophy and a methodology. It originated in Germany pre World War I, and was discussed in 18th century texts by Kant and Hegel (Dowling 2007). Early accounts of descriptive phenomenology are attributed to Bretano whose work influenced Husserl to adopt intentionality, i.e. the concept that every mental act is related to an object, and therefore internal experience is being conscious of something (van Manen 1990).

Lifeworld is what people experience pre-reflectively without interpretation (Dowling 2007) therefore Husserl believed that for experiences to be understood they should be as free as possible from cultural influences and that description should be obtained before interpretation is attempted. Husserl described this as a natural attitude (van Manen 1990) i.e. free from interpretation but not without judgment. Consequently an epoche (similar to bracketing in Grounded Theory) is required to allow exploration without influence from presuppositions and preconceptions (Moustakis 1994). According to Husserl the aim of phenomenology is the unbiased study of things as they are. To facilitate this, he devised Phenomenological reduction (Dowling 2007). Phenomenological reduction provides a means of looking at the phenomena in its purest form, as it appears to the individual. In Phenomenological research this involves a two staged system as suggested by Polkinghorne (1983) in Dowling (2007), where the researcher first obtains a description of the essence of the phenomenon (van Manen 1990) and then focuses on the experience itself in order to form an intentional analysis (Dowling 2007). Exploring the essence can involve imaginative variation where the researcher imaginatively manipulates aspects of the experience in order to see where the boundaries of the essence lie. This process must be transparent and acceptable to other researchers in order to provide the Phenomenological, "nod" as described by van Manen (1990).
Heidegger’s Hermeneutic Phenomenology shares some aspects of Husserl’s work in that both valued the human experience as it is lived. However, Heidegger disagreed with Husserl’s stance on description rather than understanding, believing that lived experience is an interpretive process. In order to facilitate this interpretation he advocated the use of Hermeneutics as a research method (Dowling 2007).

At the beginning of the 20th century, phenomenologists such as Jean Paul Sartre and Maurice Merleau-Ponty developed earlier theories of imagining (Moran 2000) and perception (Merleau-Ponty 1945). Later in the century there followed constructivists in Phenomenological hermeneutics such as Gadamer and those who aligned with the new philosophy such as Crotty (Moran 2000). More recently, the work of Findlay in Health (Ballinger 2006) and Van Manen in Education (van Manen 1990) has developed the discipline of Phenomenology.

Two of the current approaches to Phenomenology are Hermeneutic Phenomenology and Transcendental Phenomenology (Creswell 2012). Each seeks to provide a rich description of the lived experience of a phenomenon. This usually involves in depth interviews, observations and notes. The key steps in conducting Phenomenological research are; finding a phenomenon of interest to study, establishing whether the question is best addressed using Phenomenological methods, bracketing out personal experience while collecting data from individuals who have experienced the phenomenon, horizontalisation of the data to produce themes that are then used to provide a deep description that captures the essence of the experience (Moustakis 1994). This would meet the first aim of this study.

3.4.2 The origins of Grounded Theory.

Grounded Theory was developed by Glaser and Strauss (1967) during the modernist phase of research for the purpose of developing theories that were derived from data and human interaction (Hall et al. 2013). At that time the positivist paradigm still dominated research and qualitative research was widely considered to be less scientific and rather anecdotal (Hall et al. 2013), a view that has persisted in scientific disciplines for many years.
Glaser and Strauss challenged these opinions, proposing that studies could move beyond the descriptive phase to develop theoretical explanations for how humans behave (Hall et al. 2013). Glaser and Strauss were both sociologists but at the time they developed Grounded Theory they were both working in nurse education. Nursing was in the process of moving more towards research activity and it has been suggested that this gave Glaser and Strauss the opportunity to introduce their theory in a profession new to research, in order to obtain more latitude (Moore 2009).

Glaser and Strauss also addressed a problem that had not been addressed by positivists: How could theories be constructed directly from the data? Indeed, they advocated using an induction method to develop theories that emerged directly from the data (Hall et al. 2013). Grounded Theory has since been viewed as a qualitative approach to research but Glaser and Strauss were in fact critical of qualitative research because they felt it was too descriptive, lacked theory and did not produce enough scientifically reproducible facts. In fact they explained that in generating grounded Theory their purpose was to systemize qualitative research and bring qualitative and quantitative research together in order to use the best of both methods to obtain the theory (Glaser and Strauss 1967). Glaser and Strauss’ collaboration resulted in the merging of two contrasting approaches to sociology, Glaser favouring a more structured approach to interpreting data, using rigorous and analytical guidelines to codify quantitative data. Strauss, reflecting the philosophical tradition of the Chicago school, was more influenced by symbolic interactionism (Hall et al. 2013).

Symbolic interactionism suggests that people do not just respond to their environments but actually give meaning to them through interactions. According to Blumer (1969) cited in Hall et al (2013) symbolic interactionism held three basic premises;

- That the meanings these things have for people will determine which actions they perform with these things.
- That meaning is derived from social interactions.
- That there is an interpretive process that is used to direct and modify the meanings as the situations is dealt with.
Although Strauss was influenced by symbolic interactionism, Glaser felt that symbolic interactionism and grounded theory were not linked, as symbolic interactionism is about meanings and their construct, whereas grounded theory is about discovering patterns in data using constant comparisons (Walls et al. 2010). Certainly neither made this link implicit in their relationship and it is not evident in their earlier work (Moore 2009). This difference of opinion demonstrates the schism between Glaser and Strauss’ thinking, which eventually led to a split in the partnership and the subsequent development of two individual paths; Glaserian Grounded Theory (also known as Classic Grounded Theory) and Straussian Grounded Theory.

It has been suggested that the differences between Glaser and Strauss were confined to methodological aspects rather than ontological or epistemological aspects of the theory (Heath and Cowley 2004). Epistemology relates to how knowledge is gained in the relationship between the researcher and the subject of the research. In Glaserian grounded theory a more positivist stance is taken with the researcher remaining objective, or detached from the participants, whereas constructivist researchers may have a more subjective integrative relationship with the participants and may be more subjective. However, McCann and Clark (2003) disagree with Heath and Cawley (2004) on the basis that while Glaser took an interpretive approach based on a critical realist’s ontology and post positive paradigm, Strauss and Corbin, with their development of the structured approach to data analysis governed by rules, moved towards a more socially constructive ontology within a post-structuralist paradigm.

3.4.3 Glaserian Grounded Theory

Glaser focused on methods rather than any underpinning theoretical position. Considered a critical realist, his work continued to align with his original approach. His emphasis on emergence reflected the belief that the relationship between the researcher and the focus of the study should remain objective in order to ensure that the researcher does not influence the emergence of the theory that is then used for verification. He encouraged the researcher to look for true meaning in order to ensure that the theory that emerged was devoid of bias or interpretation by the researcher (Hall et al. 2013).
3.4.4 Straussian Grounded Theory.

Strauss’ background as a pragmatist and symbolic interactionist shaped the development of his approach in collaboration with Juliet Corbin. They claimed a feature of Grounded Theory is its ability to respond to change. They shifted away from the positivist to a relativist approach with constructivist leanings and asserted that multiple perspectives must be sought during the research inquiry. They rejected the positivist view and assumed reality is a product of interpretation and construction by the enquirer rather than something that exists and is waiting to be discovered. They insisted that analysis involves interpretation. In contrast to Glaser their epistemological stance is non dualist and subjective (Hall et al. 2013). In Straussian Grounded Theory the researcher and the participants develop the theory together. The researcher is actively involved and actively encouraged to draw on his experiences. This may lead to criticism regarding lack of generalisability and reproducibility but this is not considered to be problematic in Straussian Grounded Theory as the relativist view is that reality is constructed not found (Hall et al. 2013). Despite these developments some parts of their approach still held aspects of post positivism. This includes the structural systematic coding framework known as the paradigm model, which was criticised by Glaser for forcing the data into preconceived ideas and using the concept of ‘fit’ as a criteria for evaluation (Hall et al. 2013). Strauss also moved Grounded Theory towards verification (Charmaz 2006). While this normally represents a positivist/ post positivist attempt to establish truth, Strauss and Corbin used the word to mean “evaluating for trustworthiness.” Thus they moved towards an ontological relativism in a constructivist paradigm (Hall et al. 2013).

Since its introduction in the 1960s, Grounded Theory has been interpreted and developed in various ways and is now viewed as a way of conceptualizing data rather than a rigid set of rules and procedures. There is now significant variation in the way the methodology is interpreted and carried out (Hall et al. 2013, Gibson and Hartman 2014). Some Grounded Theorists align closely with the post modern approach, i.e. a reaction against the scientific objective modernist viewpoint, that asserted reality is a social construct and therefore subject to change. Social construction has its roots in Phenomenology. Social constructionism postulates that all knowledge is constructed from social interaction during which people form impressions from other people and
respond appropriately. This associated meaning then becomes entrenched and the interaction is formalised. Hence peoples’ understanding of reality is constructed and embedded in society over time (Hall et al. 2013). Charmaz was the first to unequivocally name her work as constructivist (Hall et al. 2013). She aligned herself with social interactionism i.e. that research offers an interpretation rather than uncovering reality. She emphasised multiple realities and local complex situations, rather than identifying the core category described by Glaser (Hall et al. 2013).

According to Walls et al (2010) there are no absolute rights and wrongs in qualitative research rather there are different ways of looking at things. However it is important that the researcher is able to justify their choices without compromising the project (Gibson and Hartman 2014). The Grounded Theory approach enables researchers to align to their own particular world view and use methods that are flexible and practical. Grounded theory studies are situated in various paradigms, positivist, post positivist and constructivist (Hall et al. 2013).

In the late 1960s when “the scientific method” (quantitative research) based on a positivist paradigm was dominant, any method of data collection other than unbiased collection of facts was rejected. As previously noted, qualitative research was seen as impressionistic, anecdotal, unsystematic and biased and its acceptance was limited only to a preliminary exercise for refining quantitative interviews. This resulted in qualitative researchers refining existent theory, but rarely led to the development of new theory (Charmaz 2006).

3.4.5 Building Grounded Theory
Grounded Theory is a method of generating and coding data at various stages to uncover a core category that describes the phenomenon being studied. It is not a linear process, as its many elements are intertwined (Murray and Chamberlain 1999), but the typical stages are described succinctly by Charmaz (2006). The first stage is to collect data from a small sample which is then coded. This is known as open sampling. This initial data is subjected to open coding, this means the data is broken apart and assigned codes that are later used to build categories. Following this original coding a further purposeful sample is recruited in order to confirm or elaborate
categories and indeed to create new categories. At this stage the research starts to build links and relationships between the categories. This is known as axial coding, although Charmaz (2006) refers to this as focused coding. This method forms the basis of the constructivist Grounded Theory, whereas Classic Grounded Theory does not “force” the information into categories but rather allows the theory to emerge via the method of constant comparison. Throughout the process inference and deduction and a constant comparative method are used to examine the categories, making links and relationships and looking at where they do not apply in the data. The final stage in the process is discriminate sampling, where further sampling is done to achieve saturation, i.e. a point at which no new categories arise from the data, and to identify one core category that links to all the categories. Throughout the process the theory must come from the data and be proved in the data using a triadic process of data collection memos and coding. Negative responses are used to test the theory.

Over the course of the last 48 years, Grounded Theory has increased in popularity and is widely used in the field of nursing and, increasingly, in psychology. It has been suggested that, over the years, it has been adapted and is no longer precisely applied (Gibson and Hartman 2014). There is no doubt that many studies now draw from Grounded Theory but do not adhere to Strauss and Glaser’s original concepts Charmaz (2006) said that studies now “Aimed to develop rich conceptual analysis of the lived experience and social worlds instead of intending to create substantive or formal theory” (pg. 9), and proposes that Grounded Theory is seen as a set of principles and practices rather than prescription and packages. These developments have raised one question; if the method is adapted is it still the same method? Charmaz (2006) proposes that it is, but Morse et al (2009) suggest that researchers use the principles of Grounded Theory as guidance rather than a prescriptive method, and Dey (1999) believed that there is no such thing as a specific Grounded Theory methodology in the sense of a structured methodology that is clearly defined and identified. They suggested researchers use Grounded Theory strategies more flexibly and in their own style. Consequently it is important that the researcher clearly explains the reasons for their choices for the benefit of those reading the research.
Although it has already been stated that the relationship between researcher and client is subject to the beliefs and experiences of both and that participation in an event influences the outcome, it is also important that the researcher does not allow prior knowledge of the subject to contaminate the data and they must be vigilant and reflective throughout in order to ensure robust data.

Despite these variations in the interpretation of the method in practice, Strauss and Corbin suggested four criteria for evaluating a good Grounded Theory. These are outlined by Murray and Chamberlain (1999) pg. 184. The theory should:

- Fit well within the phenomena being researched and present the individual reality faithfully
- Be comprehensible both to the people being studied and to others involved
- Provide generality
- Provide control in the sense of clarifying the condition under which the theory is applicable.

### 3.5 Key concepts in Grounded Theory

#### 3.5.1 Substantive or Formal Grounded Theory.

According to Glaser a Grounded Theory can be formal or substantive. The substantive theory is modifiable and relative to the people who experience the phenomenon, whereas the formal theory is developed further, meeting the criteria of fit, relevance and modification garnered from a range of sources (Strauss and Corbin 1990).

#### 3.5.2 Reviewing the literature.

As Grounded Theory is an inductive method of research intending to generate new theory grounded in the data, it does not set out to prove existing hypotheses. According to Kennedy and Lingard (2006) the postpositive ontology of Grounded Theory requires that the researcher remain at an objective distance to limit the influence on the data. In this regard attention must be given to the role of the literature. There are apparently contradictory perspectives about the role of literature in Grounded Theory (Walls et al. 2010). This also applies to other qualitative methods of research. Cutliffe (2005) stated that avoiding a literature review prior to data collection is more likely to lead to the emergent theory being more grounded in the data. However Giles et
al (2013) felt a review of the literature was necessary in order to find gaps in the knowledge. It would seem that both views have well supported arguments, but Culliffe suggested that Giles’ stance stemmed from an assumption that we need to know what is going on with the phenomenon in order to choose the methodology, whereas others such as Stern (1994) assumed that there was already knowledge about the phenomenon and a decision had already been made to use Grounded Theory.

Most research methodologies require the researcher to commence with a review of the literature in order to formulate the research question. However, Grounded Theory is a general inductive method ending with a theory rather than beginning with a hypothesis, and literature is typically used as a comparator for the emerging theory. Glaser certainly warned the researcher against searching the literature before collecting data to avoid contamination with preconceived ideas (Hall et al. 2013). Glaser (1998) recognised that reading the literature was problematic in Classic Grounded Theory because it could restrict the freedom required for theoretical discovery (Walls et al. 2010). Some preliminary reading needs to be done to establish that the area needs to be researched but Glaser, while acknowledging that this is the case, contests that the researcher must not conduct a review of the literature in the substantive area while establishing the area of research. He explains that this is not because the literature is irrelevant in the process rather that the literature is relevant to the area under study and has to be discovered just as the theory has. Strauss disagreed with Glaser, on this aspect of the theory (Evans 2013) and later he and Corbin (Strauss and Corbin 1998) advocated reviewing the literature early in the study because it stimulates theoretical sensitivity, provides a secondary source of data, stimulates questions, directs theoretical sampling and provides supplementary validity (McGhee et al. 2007). Glaser strongly disagreed with this view, and outlined his view that there were several levels of reading in Grounded Theory and that reading professional literature should not be undertaken until coding had commenced.

In Constructivist Grounded Theory it is expected that most professionals would be familiar with the extant literature in the field (Walls et al. 2010). Therefore we must consider whether Classic Grounded Theory researchers can suspend who they are and what they know. In view of this, Walls (2010) questioned whether knowledge of the
substantive area is an advantage or disadvantage. Uninformed observers of Grounded Theory may construe this process as a neglect of the literature (Walls et al. 2010), however the purpose of this is to keep the researcher free from influences that could impede the openness required for theoretical discovery, and not to ignore current relevant knowledge (Glaser 1998). Glaser explained that when the Grounded Theory is nearly complete then a literature search in the substantive area can be undertaken at the stage of sorting the data and can be woven into the theory as part of the data for constant comparison. Therefore the literature should be read at two points; firstly reading in other substantive areas to increase theoretical sensitivity and secondly when the emerging theory forces the researcher to look at both divergent and convergent literature. This is consistent with the use of literature in Hermeneutic Phenomenology where the literature is used to strengthen the description and interpretation.

3.5.3 Theoretical frameworks
A theoretical framework cannot be specified at the outset of a Grounded Theory study as this will emerge and become integrated during the study. According to Cutliffe (2005) the researcher should not be forced into setting out a specific framework at the beginning as to do this would be unrealistic, incongruent with classic Grounded Theory and methodologically unsound. Further, Green (2014) argues that Grounded Theory takes as its theoretical framework the philosophy or epistemology upon which the researcher has based their approach.

3.5.4 Knowledge of the substantive field.
Grounded Theory differs from more traditional research methods in that analysis and theory are developed at the same time. This can cause difficulty for the researcher in predicting the overall shape of the project (Backman 1999). Although Grounded Theory is used to generate new theories, it can also be used where there is some knowledge of the area being studied and the researcher is seeking new points of view (Strauss and Corbin 1990). The difficulty here is the current knowledge may direct the research and impair the detection of these new points of view (Olshansky 1996). In order to address this Backman (1999) stated that the researcher must bracket this knowledge, in other words suspend their prior knowledge and approach the data without preconception or bias. However they do concede that the researcher is also a social being who creates and recreates social process, therefore their previous experiences are also data, and
these experiences add to the richness of the data and may in fact help the researcher to understand the process.

Charmaz (2006) believed that suspending knowledge and experience is impossible and often undesirable, and Walls (2010) believed that prior knowledge may be an advantage as it could help the researcher pick up nuances and subtle meaning in the data. Fernandez (2005) suggested that, since constant comparison forces researchers to state their assumptions and knowledge in memos which subsequently become data, this process would validate alter or reject the researcher’s observations and minimise the potential for bias. Further, Fernandez (2005) believed that knowledge need not be a threat to the theory provided the researcher maintains an open minded reflexive approach to the collection and analysis of the data and uses the constant comparative method strictly.

3.5.5 Theoretical sensitivity
A lack of knowledge of the subject may lead to a lack of theoretical sensitivity, but researchers can build theoretical sensitivity by immersing themselves in the data and concurrently studying the extant literature. A lack of theoretical sensitivity is less likely to be problematic where the researcher has experience in the substantive area.

3.6 Rationale for my choice of methodology.
Eaves (2001) shared a personal communication from 1996 in which the writer (M Chesler) suggested that it did not matter whether you agreed with the stance of Glaser and Strauss, Strauss and Corbin or Glaser. The important issue was what you take from their respective stances, how you interpret this, and how you argue for and defend your choices.

Mills et al (2007) suggested that researchers should choose a research paradigm that is congruent with their beliefs about the nature of reality, in order to ensure that their research design is robust. They suggested a conscious examination of these views is necessary in order to unearth the epistemological and methodological possibilities available to the researcher.
3.6.1 Positioning myself in the study.
My personal world view is that reality is constructed by the individual relative to their beliefs and shaped by their experiences and interactions with others. My experience as a Humanistic Counsellor has helped to shape my view that individuals are instinctively experts in their own lives but are influenced positively or negatively by others. In order to help individuals move back towards their authentic self the Counsellor has to interact with the individual in a non-directive way. My experience has shown me that these interactions can help the individual gain insight, and I think it would be difficult for me to take on the role of a researcher that was objective to the point of holding myself distant from the participant. However, having worked in Audiology for 40 years it is inevitable that I will have prejudices and opinions that need to be bracketed or, if I am unable to bracket these completely, acknowledged and discussed in terms of their impact on the study. Birks and Mills (2015) suggested researchers outline these prejudices prior to commencing the study in order to be transparent and aware. I believe my prejudices and preconceptions are that participants will express reluctance about wearing hearing aids because of how they look. Despite the fact that hearing aids remediate problems with communication, in clinical practice many individuals still express concern about hearing aids being seen. This is an area that needs to be explored in more detail. I believe the reasons for this paradox are unclear and a better understanding could contribute to rehabilitation. The type of hearing aid may be very important for the participants. When digital hearing aids first became available on the NHS there was an increase in the referral of new patients. Many of these patients were asking to be referred because they thought digital hearing aids were better than analogue in terms of sound quality, but were disappointed to find that the hearing aid was still a BTE aid as they had assumed that digital automatically meant smaller. Against this is the trend in private practice for existing clients to revert to BTE aids to improve performance so I believe new clients will be preoccupied with the look of the aid while experienced users will be more concerned about sound quality. However, as yet, I have no explanation for why this should be the case. Finally, I believe that participants will discuss popular misconceptions about hearing loss and hearing aids and I need to be conscious of the fact that these could seem familiar and insignificant to me and therefore I need to be vigilant, otherwise opportunities to discuss their impact on the participant in greater depth could be missed.
I am confident that I would be able to interact without directing, as my training and practice as a Humanistic Counsellor enables me to allow the interviewee to take the lead. By using reflexivity, self-awareness and supervision I could contribute to the data rather than contaminate it. It is important to me that each individual narrative be shared and valued in its own right, but it is also important that these narratives be used towards a collective understanding of the phenomena of acquiring hearing impairment, in order to inform patient centred services. For these reasons I felt that a method that encompassed aspects of Phenomenology and Grounded Theory would be most effective. According to Gibson et al (2014) this is an accepted method that is being used more frequently, with researchers in Phenomenology using techniques from Grounded theory to code and identify themes, as in the study by Gibson and Kendrick (1998).

Although this relativist post constructivist world view suggests that Constructivist Grounded Theory would be the most appropriate choice, I do align with Glaser’s position that rather than increasing theoretical sensitivity, reading the extant literature would influence my views developed from experience in the substantive area. Therefore I have provided a two stage literature review, the first stage covering the literature up to 2003 when the study began and the second covering the relevant literature as part of the analysis.

3.7 Conclusion
A qualitative approach appeared to be the most appropriate method for this study. As a researcher, I identify with social constructivism, and one of the aims of the study is to explore individual experiences in order to construct a theory that illustrates the experience of acquiring hearing impairment. This could best be done by using unstructured interviews focusing on the individual’s experience. However in order to provide some structure to the method, I decided to draw on constructive Grounded Theory methods to code and categorise themes. The completed thesis is therefore presented within the Phenomenological tradition by describing each individual’s experience drawn from interviews, observations and notes, while demonstrating how coding and developing themes were constructed in the Grounded Theory tradition.
Although the thesis does not claim to produce a Grounded Theory per se, it does draw heavily on the method to construct themes that can be further tested in future studies. This is discussed further in the reflective chapter (Chapter 7). This method allowed me to bring my own experience to the study provided I was mindful of the risk of contaminating the data. As a qualified Audiologist, I have knowledge of the theory of audiology and rehabilitation but, initially I had no direct experience of acquiring hearing impairment. Nevertheless there was an awareness of the impact of clinical experience in order to ensure the themes emerged from the data, and that my own experience enhanced the data but did not contaminate it. In order to do this the method had to be carefully designed and reflexively applied. The method used in this study will be discussed in detail in the next chapter.
4 Method

4.1 Ethical approval

I obtained ethical consent from both Queen Margaret University and NHS ethics committees before starting the study. Copies of the documentation are shown in the appendices (A and B). Subsequently, ethical approval was requested from the University of Dallas in Texas (UTD) before recruiting participants from a conference at the university. It was decided by the research committee chair at UTD that, as the participants were not students or staff of the university but were attending the conference as private citizens, there was no need to submit an application to the committee. I was asked to send a copy of the consent form I would use and this was approved (Appendix C). I was then asked to make a short presentation regarding the research to the delegates, asking them to contact me if they wished to take part.

4.2 Recruitment of Participants

Participants were recruited from three sources.

- ENT Department, NHS Fife (Interviewed in 2004)
- Summer Intensive Aural Rehabilitation Conference, University of Texas, Dallas (UTD) (interviewed in 2006)
- Centre for the older person’s agenda (COPA) database. (interviewed in 2007)

4.2.1 Participant demographics

Demographic details for all participants are shown in table 4.1. overleaf.
Table 4.1. Summary of participant demographics.

<table>
<thead>
<tr>
<th>ID</th>
<th>Recruited from</th>
<th>Male (M) /Female (F)</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHF 1</td>
<td>NHS Fife</td>
<td>M</td>
<td>63</td>
</tr>
<tr>
<td>NHF 2</td>
<td>NHS Fife</td>
<td>M</td>
<td>71</td>
</tr>
<tr>
<td>NHF 3</td>
<td>NHS Fife</td>
<td>M</td>
<td>84</td>
</tr>
<tr>
<td>NHF 4</td>
<td>NHS Fife</td>
<td>F</td>
<td>84</td>
</tr>
<tr>
<td>NHF 5</td>
<td>NHS Fife</td>
<td>F</td>
<td>71</td>
</tr>
<tr>
<td>NHF 6</td>
<td>NHS Fife</td>
<td>F</td>
<td>80</td>
</tr>
<tr>
<td>DALLAS 1</td>
<td>Rehabilitation Conference, Dallas</td>
<td>F</td>
<td>67</td>
</tr>
<tr>
<td>DALLAS 2</td>
<td>Rehabilitation Conference, Dallas</td>
<td>F</td>
<td>72</td>
</tr>
<tr>
<td>DALLAS 3</td>
<td>Rehabilitation Conference, Dallas</td>
<td>F</td>
<td>52</td>
</tr>
<tr>
<td>DALLAS 4</td>
<td>Rehabilitation Conference, Dallas</td>
<td>M</td>
<td>58</td>
</tr>
<tr>
<td>DALLAS 5</td>
<td>Rehabilitation Conference, Dallas</td>
<td>F</td>
<td>48</td>
</tr>
<tr>
<td>COPA 1</td>
<td>Centre For the older persons agenda database</td>
<td>F</td>
<td>68</td>
</tr>
<tr>
<td>COPA 2</td>
<td>Centre For the older persons agenda database</td>
<td>M</td>
<td>84</td>
</tr>
<tr>
<td>COPA 3</td>
<td>Centre For the older persons agenda database</td>
<td>M</td>
<td>58</td>
</tr>
<tr>
<td>COPA 4</td>
<td>Centre For the older persons agenda database</td>
<td>F</td>
<td>77</td>
</tr>
<tr>
<td>COPA 5</td>
<td>Centre For the older persons agenda database</td>
<td>M</td>
<td>70</td>
</tr>
<tr>
<td>COPA 6</td>
<td>Centre For the older persons agenda database</td>
<td>F</td>
<td>68</td>
</tr>
</tbody>
</table>
COPA has a membership of older people known as the Hub. An email was sent to all members via the hub newsletter providing information and inviting them to participate.

The first participants were recruited via referrals for assessment of hearing to the ENT department, at an NHS hospital in Fife. With the ENT consultant’s agreement I sent an information letter and consent form (appendices D and E) to all clients who met the criteria for inclusion. The letter was sent to clients attending his clinics within an eight week period. The criteria for inclusion were; an acquired hearing loss either self-reported or identified by the GP, with no additional ENT problems; no reported history of cognitive difficulties; no additional illnesses or disabilities that would prevent them from attending for interview. Forms were sent to 20 individuals, 7 returned the completed consent forms, and all participated in the study.

The second group of participants was recruited from attendees at the SIARC conference in Dallas, Texas. As previously mentioned, following a presentation about the project to the attendees on the first day they were then asked to indicate if they wished to take part in the interviews. Five participants were recruited from this conference. Permission was also given to attend the group rehabilitation sessions and make field notes that could be used in the analysis. All of the participants had acquired hearing loss and met the same inclusion criteria as the first sample.

The last group of participants was recruited via the Centre for the Older People's Agenda (COPA) database. In addition to interviewing these participants additional audiological

<table>
<thead>
<tr>
<th>COPA</th>
<th>Centre For the older persons agenda database</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Centre For the older persons agenda database</td>
<td>M</td>
<td>77</td>
</tr>
<tr>
<td>8</td>
<td>Centre For the older persons agenda database</td>
<td>F</td>
<td>75</td>
</tr>
<tr>
<td>9</td>
<td>Centre For the older persons agenda database</td>
<td>F</td>
<td>63</td>
</tr>
<tr>
<td>10</td>
<td>Centre For the older persons agenda database</td>
<td>M</td>
<td>53</td>
</tr>
</tbody>
</table>
assessments were carried out to allow comparison between objective and subject methods of assessing acquired hearing impairment. A grant was obtained from COPA with myself as Principal investigator (PI). Co researchers on the grant were Ms Pauline Campbell from Queen Margaret University, and Dr. Maria Wolters from Edinburgh University. As there was a considerable time commitment for participants a payment of £25 was given to each participant on completion of the data generation to cover travelling costs and other expenses.

The COPA study involved three stages. In the first visit the participants took part in an in depth recorded interview, reflective memos and a journal were also created. These were then reviewed and coded by myself then independently reviewed by Dr Wolters. At a second, separate visit the participant completed a range of audiological assessments, described in more detail later in the chapter. In order to ensure that the analysis of the interviews was not influenced by the audiological test results, these were carried out by Ms Christine Johnston, research assistant to Ms Pauline Campbell. Following the assessment, only the participants were given a verbal and written report of their results. Participants then attended a further interview session with me in order to review and confirm the content of their first interview and discuss their thoughts and feelings about the outcome of the assessments. Following this they were then invited to participate in a focus group with their significant others. The statistical analysis of the results from the audiological assessments was carried out by Dr. Wolters and a report written for COPA by myself and Dr. Wolters. Twelve participants were recruited via this database, giving a total of 24 participants in the study.

4.3 Data collection

4.3.1 Audiological profiles
The audiological profile of the 10 participants recruited via COPA was recorded on a separate visit after the first interview and the testing was carried out by a different researcher. As part of a modernisation project for Audiology a client journey was established that outlined the tests that should be undertaken during assessment in audiology clinics. These consist of pure tone audiometry and uncomfortable loudness levels. The purpose of these tests is to identify the dynamic range i.e. the range
between the threshold of hearing (the quietest sound the person can detect) and the uncomfortable loudness level (the level at which the person finds listening to the sound uncomfortable). This range is used to programme hearing aids in order to ensure that quiet sounds are audible but loud sounds are tolerable. However these tests do not provide information about how the individual perceives and understands speech. In this study a more comprehensive audiological profile was obtained. A full audiological history was taken, covering medical and social aspects of hearing impairment. This was followed by otoscopy. This enabled the Audiologist to examine the external auditory meatus and tympanic membrane to check for any abnormalities that might affect hearing.

4.3.2 Pure tone Audiometry
This was carried out according to the British Society of Audiology BSA (2011) recommended procedure. In this test TD39 supra aural earphones were placed over the ears and, after instructing the participant in how to respond, a series of test tones are presented. The intensity of the tone was reduced in incremental steps until the subject no longer indicated they could hear the tone. The quietest tone the person could hear was recorded at the following frequencies 250Hz, 500 Hz, 1 kHz, 2 kHz, 4 kHz and 8 kHz. The test was then repeated using a bone conductor which is placed on the mastoid process behind the ear, and measures the thresholds heard by bone conduction through the mastoid bone. Thresholds were obtained using the same procedure for frequencies between 500Hz and 4 kHz. Masking was used throughout the test when appropriate.

4.3.3 Uncomfortable loudness level.
The uncomfortable loudness test was carried out at two frequencies in each ear. Using TD39 earphones pure tones were introduced at a level that was audible to the participant and the intensity was increased incrementally until the person indicated that the sound had reached a level where listening was becoming uncomfortable.

4.3.4 Tympanometry
Tympanometry assessed the function of the middle ear and tympanic membrane. This was carried out according to BSA recommended procedures. Middle ear pressure and compliance were recorded for each ear.
4.3.5 Otoacoustic emissions
The cochlea is a dynamic organ and a functioning cochlea will produce an echo in response to an auditory stimulus. This is known as an otoacoustic emission. Each participant was tested for the presence of a transient evoked otoacoustic emission.

4.3.6 Speech Audiometry.
This was carried out in a sound proofed booth. Using TD39 headphones, a list of isophonemic words was played through a calibrated CD system. Participants were asked to repeat either the word or part of the word they heard. Each word was allocated a maximum score of 3 points (1 per phoneme) and there were ten words in each list. The first list was delivered at an intensity that was audible to the participant, and the intensity was increased by 10dB HL for each list until a score of at least 27/30 was obtained. The intensity was then reduced to a level 10dBHL below the level for the first list and decreased in intensity by 10dB for each subsequent list until a score of 3/10 or less was obtained.

4.3.7 Random Gap detection test
This is a test of temporal processing. Individuals with poor temporal processing have difficulty in perceiving rapid change in formant frequency in ongoing speech. In this test a series of tones at 500Hz, 1, 2, and 4 kHz and a white noise click were presented randomly with time intervals of 0-40msecs and the participant asked to indicate whether they could hear one or two tones.

4.4 Interviews
I have described the interview process according to the setting and recruitment of participants. This appears to show 3 groups of participants, but this is an artificial distinction. In fact the interviews were analysed and reviewed individually with review and coding of each interview being concluded before the next participant was interviewed. I have divided the participants into three groups only to facilitate clarity in dealing with a large amount of qualitative data.

4.4.1 Interviews. (Group 1)
Open ended interviews were conducted with the first group of participants. These interviews took place in an office in the Audiology department at the Victoria Hospital in
Fife. The interviews were recorded using a portable digital recorder. Each interview lasted approximately one hour. Only one interview was carried out per week to allow time for transcription and reflection. Additional reflective memos were also produced. Each interview was transcribed and anonymised, then checked for accuracy in terms of contact and meaning with the interviewee. Open coding was then carried out. In open coding the transcribed interview were reviewed line by line, and codes were allocated to each piece of information. This stage of coding was also applied to field notes, i.e. observations that were made by me immediately following the interview, and reflective notes. These notes were related to the content of the participants' dialogue and to any insights I may have gained from studying the data.

On reflection I noted that there was a wide range in the length of time since the hearing loss had been noticed, between 2 and 14 years, and many of the participants could not remember some of the details of how they became aware that their hearing had changed. All of the participants had also either decided to try hearing aids or had been persuaded to do so by their family and as the interviews were carried out in the Audiology department immediately before their assessment it was perhaps inevitable that the interviews were focused primarily on hearing aids. I therefore decided that a second group of participants should be selected in order to confirm open codes obtained and explore whether there were any new codes. In order to explore the effect, if any, of service provision and culture a purposeful sample was selected from participants at a rehabilitation conference in Dallas.

4.4.2 Interviews (Group 2).
The participants from the Dallas conference were all interviewed during breaks in the conference with subsequent communication conducted by e-mail. These interviews were also transcribed and anonymised, checked for accuracy in both content and meaning, and then coded.

4.4.3 Interviews (Group 3).
At this stage categories had begun to emerge and further purposeful sampling took place, recruiting from the COPA database. All of these participants indicated that they were beginning to notice a hearing or communication problem but were not yet at the
stage where they had had this investigated. These participants attended for initial
interviews at Queen Margaret University. The interviews were carried out in one of the
clinical skills rooms. This interview was open ended and lasted between one and one
and half hours. At the initial interview two of the participants were found to have been
fitted with hearing aids in the period between volunteering for the study and being
interviewed. Although this meant they had already been assessed, I decided that they
would not be excluded from the qualitative part of the study. They did not however
have a further audiological profile completed. Following the completion of the
audiological profiles, the qualitative and quantitative data was reviewed and a further
interview was arranged to review this data and explore themes in greater depth.

4.5 Focus groups

Two focus groups were also arranged in order to explore identified themes within a
group setting. Although Phenomenological studies are normally conducted with
individuals, there is precedence for this (Dowling 2007) and the use of focus groups fits
with units of measurement used in Grounded Theory. These focus groups were
facilitated by myself and were made up of participants from the COPA study and their
family members. The purpose of the focus groups was to explore the patient journey in
more detail and a patient journey tool was used to record the data from these sessions.
This tool was originally designed following seminars in “Defining hearing” at the Ida
institute in Denmark (Ida Institute 2014). The format for the tool was designed by the
faculty of the institute, comprising a group of anthropologists and Audiologists
(Professor Kris English, Dr Harvey Abrahams and myself). The tool was developed into
an online interactive tool that could be used to map out individual patient journeys and
after discussion with the director of the Ida institute it was agreed that it could be
piloted at the focus groups. The tool consists of an interactive board with electronic
notes that can be colour coded. The principle is that the participants describe the
patient journey as they imagine or have experienced it. Each stage is given a different
colour code and similar comments can be grouped together to create themes. In the
focus groups individuals contributed their thoughts and these were debated and then
grouped on the patient journey tool by myself. In practice the patient journey tool allows
the individual to brainstorm thoughts and feelings that arise in relation to their
experience of acquiring hearing impairment. These thoughts and feelings are recorded
on the “electronic” note. Notes can then be assigned to different categories that represent stages on the journey and can thus be used by the Audiologist to explore issues that are significant to the individual and significant others in order to provide counselling and support. When the tool was first used during seminars at the Ida institute a group of experienced Audiologists outlined the patient journey from the Audiologist’s perspective drawing on their own clinical experience. In the focus groups for this study the tool was used to construct a composite patient journey based on the experience of two groups of adults who were beginning to experience acquired hearing loss.

4.6 Analysis of Data

Data from both the interviews and the focus groups were transcribed and open coding was carried out manually, codes were independently checked and agreed by a co-researcher on the COPA project and an additional Audiologist and qualitative researcher at Queen Margaret University using the NVivo qualitative software package. In addition to the data obtained from participants’ research memos and field notes, a reflective journal was kept throughout the study; this was also analysed.

4.6.1 Open coding

The purpose of open coding is to “open up” the possibilities in the data (Punch 2005). In this stage of analysis the data is examined closely in order to identify categories and possible theories. The empirical data is raised to a more abstract level by labelling or coding in order to make comparisons across the data and formulate questions. Punch (2005) explains that there is one type of question that is distinct to Grounded Theory. This question has three forms:

- What is this piece of data an example of?
- What does this piece of data stand for or represent?
- What category or property of a category does this piece of data indicate?

Using these questions, the interview data was examined and labelled, identifying first order categories.
4.6.2 Building categories
This stage of coding takes first order codes and looks for interconnections between them. In this way the first order data is raised to a higher, more conceptual level and connections can be made in order to develop theories. Following open coding the data was reviewed and connections between the categories were explored.

4.6.3 Selective coding and core theme
In this final stage a core theme was selected. This core theme is the analytical integration of the theoretical codes and is known as the core category in Grounded Theory. The core category emerges from and is supported by the data.

4.6.4 Examples of open coding and categories.
In the first stage of coding each transcription was coded line by line. Examples are shown in table 4.1 below.

<table>
<thead>
<tr>
<th>Transcript extract</th>
<th>Open coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>“They said you have slight hearing loss, but I never really noticed it myself”</td>
<td>Pre-awareness</td>
</tr>
<tr>
<td>“I think it was more because I started to notice there was a problem, before I wasn’t thinking much. Once someone drew my attention to it I seemed to be more aware of it being there.”</td>
<td>Becoming aware</td>
</tr>
<tr>
<td>You would sit there and you were missing out on bits of what was going on. I became really aware of it then when that was going on.”</td>
<td>Consequences of hearing impairment. Becoming aware.</td>
</tr>
<tr>
<td>I wonder if I should learn to lip read and all this…mind you I never got down to doing it but it’s all on your mind</td>
<td>Seeking solutions</td>
</tr>
<tr>
<td>“There’s probably hundreds of thousands of them but I never paid much attention</td>
<td>Thoughts about hearing aids.</td>
</tr>
</tbody>
</table>
“I think it’s got benefit … there’s definitely some benefit because when you switch it off you hear the difference but mostly in the background noise.”

“I am afraid it will go into my ear and I won’t get it out”

Knowledge about hearing aids

Fears regarding hearing aids.

These extracts demonstrate codes that have relationships e.g. pre awareness, and becoming aware. It is therefore possible to start to build and test these relationships as shown in table 4.2.

<table>
<thead>
<tr>
<th>Open Code</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre awareness</td>
<td>Awareness of hearing impairment</td>
</tr>
<tr>
<td>Becoming aware</td>
<td></td>
</tr>
<tr>
<td>Opinions about hearing aids</td>
<td>(Issues about) Hearing aids</td>
</tr>
<tr>
<td>Fears about hearing aids</td>
<td></td>
</tr>
<tr>
<td>Knowledge about hearing aids</td>
<td></td>
</tr>
</tbody>
</table>

As subsequent transcripts were coded, further information was added to each of the codes and the categories were developed and adapted as necessary.

4.7 Analysis of Audiological profiles

The final stage of analysis was to look at the results of the audiological assessments in relation to the participants’ subjective assessment of their hearing. This analysis was discussed with the participant in the second qualitative interview. In the thesis this data formed part of the qualitative data only. The data from the audiological profiles were reported at the Proceedings of the European Federation of Audiology Societies conference in Heidelberg in 2007.

In the following chapters the data from the interviews and focus groups, including the participants’ opinion of the impact of auditory profiles in relation to individual cases will be discussed. As the data from the interviews builds the theory, it is necessary to
include ongoing analysis and discussion from the data at each stage. More detailed discussion of the resultant themes in relation to the extant literature then follows.
5 Findings.

5.1 Introduction

In this chapter I will present the data obtained from the interviews and focus groups and discuss how the open coding led to the identification of categories and ultimately the core category. I have discussed each participant’s interview in sequence. In the case of the participants who had a full audiometric assessment, I have also indicated the results obtained followed by the second interview. I have included direct quotes from the participants to illustrate meaning. The quotes are labelled with a Code NHF/Dallas/COPA followed by an identity number and then the lines of the transcript from which the quote was taken. Copies of twenty of the transcripts are available in Appendix C. The remaining transcripts were imported into NVivo directly and are available as sound files. Examples of coding are shown in Appendix D.

5.2 Open coding

5.2.1 Participant NHF1

The first participant (NHF1) was a 63 year old male who had a history of noise exposure having worked in various factories and with the coal board. After being alerted to his hearing loss by a colleague at work he waited two years before seeking help. He had recently tried a hearing aid.

Open coding of this interview produced thirteen codes; pre-awareness, becoming aware, acknowledging hearing loss, ambivalence, seeking solutions, stigma, impact on activities, deaf behaviour, external locus of evaluation, emotions, others reactions and hearing aids.

Pre-awareness related to the time before the participant personally became aware of the hearing impairment. A measurable hearing impairment may have been recorded or noticed by others but the individual was not conscious of its presence. Several references were made to the fact that he had been unaware of a problem. For example the hearing impairment came to light after a colleague suggested he have a hearing
test as the colleague felt he was having difficulty communicating, and the result came as a surprise to him;

“They said you have slight hearing loss, but I never really noticed it myself”

NHF1/Interview 1/L23

The next code was becoming aware and related to the process of the individual becoming aware of impairment in the light of emerging evidence. Once the hearing impairment had been pointed out to the individual he became more aware of paying attention to his hearing ability and gradually became aware that he was experiencing some difficulty;

“I think it was more because I started to notice there was a problem, before I wasn’t thinking much. Once someone drew my attention to it I seemed to be more aware of it being there.”

NHF1/Interview 1/L41-43

Despite acknowledging the possibility of a hearing impairment there was a period of ambivalence. When asked to think about how he became aware of the hearing impairment he stated;

“Actually it was when I was working with the coal board; I was always saying ‘What? What?’…..they said you have a slight hearing loss… but I never noticed it myself”

NHF1/Interview 1/L19 – 23

He was able to acknowledge that he was asking for information to be repeated but did not make a connection between this behaviour and the possibility of a hearing impairment. During this period of becoming aware, the client considered seeking solutions without using the services of an audiology department. Although he admitted to being worried about his hearing and considering solutions he did not actively seek out classes;

“I was worried In case I went deaf altogether. I said to myself I wonder if I should learn to lip read and
At this stage the participant had not considered the use of hearing aids. The main reason applied to the next code, stigma. He referred several times to his concerns about how people would feel about him if they saw him wearing a hearing aid and was even more concerned about their reaction if he were to wear two. He admitted that the most important thing to him was that the aids were not seen by other people and explained that he had delayed wearing a hearing aid because of his concerns. Ambivalence was influenced by the impact on activities. The participant moved from ambivalence to a greater awareness of a problem when there was an appreciable influence on his daily life;

“Well when you are going out socially having conversations and you are just picking up bits of conversation and were trying to work out what was going on and it was the same when you were going on courses. You would sit there and you were missing out on bits of what was going on. I became really aware of it then when that was going on”.

An interesting code was deaf behaviour. The participant explained that once the hearing problem had been pointed out to him he began to act in a way that fit with a hearing impaired person even when he actually heard what was being said;

“I started- even thought I could hear what they were saying- I started to say what was that? Just an automatic habit…. Or maybe it’s just a habit I got into. I’ve programmed myself to say you’re missing half the thing. They are halfway through saying something and I am almost automatically saying what? I think I must have programmed myself to that loss”.

This code seemed to be related to the next code, external locus of evaluation. This code related to whether the persons’ self-image was influenced by others. This
participant indicated that his behaviour started to change in relation to his diagnosis, and his acknowledgement of hearing impairment came not primarily from his own evaluation of his hearing, but of opinions offered by others.

Several emotions were expressed in relation to the hearing impairment, hearing aids and the reactions of others. The participant admitted that he was worried about his hearing in case he went deaf altogether; he also expressed annoyance with the impairment. There was also anxiety about other peoples’ reaction to hearing aids and how people would feel about him if seen as a hearing impaired person. Others reactions appeared to have a bearing on this participant. His family reactions appeared not to be supportive. Although friends accommodated the hearing impairment by repeating phrases;

“Aye they noticed it, the usual comments about being deaf in your old age, but they were quite tolerant”.

NHF1/Interview 1/L60-61

At home it was a different experience;

“Aye they repeat things but at home I get the sarcastic remarks from my wife and the grand kids say ‘oh granddad!’” NHF1/Interview 1/L127-128

The final code, hearing aids related to the participant’s experiences with technology. As the interview progressed it became apparent that there were many aspects relating to hearing aids including feelings about hearing aids, beliefs about hearing aids, stigma in relation to hearing aids, and efficacy of hearing aids. As there was a relational aspect to all of these codes they were provisionally grouped together into one category. In this category the participant shared his views about hearing aids, explaining that he has rarely seen anyone with two hearings aids although he thought;

“There’s probably hundreds of thousands of them but I never paid much attention”.

NHF1/Interview1/L78
It appeared that hearing aids were not something he thought about prior to being told that he needed them. Once he got the hearing aids he had concerns about what people would think if they were visible, despite this he felt there was some benefit from them and was resigned to wearing them. Interesting in the interview he suggested that the benefit was not appreciable;

“I think it’s got benefit … there’s definitely some benefit because when you switch it off you hear the difference but mostly in the background noise.”

NHF1/Interview 1/L141-142

Despite this limited benefit he seemed resigned to wearing the hearing aid;

“I suppose I will just have to persevere and wear it. I will probably get used to it and then not think so much about it”.  

NHF1/Interview 1/L97-98.

Memo notes from this interview indicated that this man’s work history seemed very important and it seemed really essential that he explain that he had an important position at work. I wondered if this was because he might be feeling marginalised now because of his hearing impairment. He seemed saddened by the fact that his family were frustrated with him now that he could not hear and I wondered if the loss of hearing had changed his image in the eyes of his family and friends to someone who was less capable and more dependent, while he preferred to see himself as a capable efficient person of some authority. It seemed as though he was not ready to take on this new image. I noted that he seemed embarrassed during the interview when he talked about what I have termed “deaf behaviour”. He seemed to have taken on the role of a deaf person as soon as an expert had told him that he had a hearing impairment, but his behaviour and self-image seemed in conflict. He was worried about the future but seemed to have no outlet for discussing these concerns. He also discussed his concerns about how other people viewed him as a hearing aid wearer and seemed unconvinced about the benefits of hearing aids and yet he was still resigned to wear them almost as though he viewed this as his lot in life. I noted that during the interview I had the impression of speaking to someone who was isolated and unsupported who was taking on the role someone had created for him without fitting into it because he was embarrassed about being a burden to anyone. Perhaps that was why he was so concerned about telling me that he had worked in noise- although this was minimal
throughout his career—so that he could demonstrate that this hearing impairment was not his fault.

I noted three areas that I wanted to check for in the next interviews. Was it the case that most people did not think about hearing aids until they felt they were essential to their communication? Were hearing aids viewed as a “better than nothing” or only available solution? Was this stoical approach to living with hearing impairment particular to this client or common to other participants?

5.2.2 Participant NHF 2
The second participant (NHF2) was a 71 year old male who had no history of noise exposure and had only recently been diagnosed with hearing impairment. He disclosed that he felt this was linked to a recent diagnosis of terminal cancer. In contrast to the first participant he had discussed hearing aids with friends and, despite having received negative information, he was very keen to try a hearing aid, had definite ideas about the type of aid he wanted—a BTE—and had no concerns about it being visible. This was due in part to his background in engineering;

“Well I am quite happy about it because I understand it will be digital so that’s good, and I think I am probably happier to have an external one than one that goes inside although I know they are more expensive but I just think the external one is likely to be more efficient

NHF2/Interview 1/L133-136

I wondered if his lack of concern about the hearing aid was due in part to his illness. Perhaps he viewed this as another aspect of the illness to be treated and less important in the grand scheme of things. In the memo I noted that I was reminded of patients I worked with in an Oncology unit in Edinburgh. These patients had a hearing assessment prior to commencing chemotherapy, and were subsequently reviewed throughout their treatment to monitor and manage any hearing loss caused by the chemotherapy drugs. At the first assessment these patients had recently been informed about their illness and the need for chemotherapy. Their priority was to commence treatment and increase their chances for survival and although they were clearly informed that one of the side effects of the drugs was permanent hearing
impairment, this was lower in their list of priorities at that time and did not prevent them from commencing treatment. As treatment progressed and they noticed changes in their hearing they were still relatively unconcerned about this seeing it almost as a “necessary evil” in order to regain their health, but when they successfully completed treatment and were in remission, the deafness gained a higher priority often causing anger and distress. I wondered if this might be the case with this participant, and if his attitude to the deafness would change in the longer term, unfortunately it was not possible to follow this up.

In addition to adding information to the existing codes, this interview resulted in further codes being identified in relation to the assessments and the NHS. The first code was about the assessment itself. This participant raised concerns about the assessment he had at the hospital. He was curious about one particular aspect;

“I had the hearing test before the wax was taken out and I realise that some of it is done through bone conduction but I would have thought it better to have done the wax removal before the test.”

NHF2/Interview 1/L90-92

The second code demonstrated confidence in the NHS. Despite having spoken to a private dispenser and the urgent need for a consultation this participant preferred to consult the NHS first,

“No I think I was treated fairly promptly and the private guy who came to see me was surprised that I had been treated so quickly. He had heard stories of people having to wait a lot longer. I may have been given priority – I don’t know because of the cancer. I don’t know but anyway I am perfectly happy with it”.

NHF2/Interview 1/L166-169

Although there were many differences between this participant and the first participant many of the codes established in the first interview were confirmed. This participant’s locus of evaluation was also external. Despite the fact that he was experienced in the field and had some concerns about the assessment he was;

“… quite prepared to accept that they [laugh] know what they are doing”.

NHF2/Interview 1/L103-104
Despite his considerable experience and the impact of the hearing impairment on his life he was prepared to base his decision on whether to have a hearing aid solely on the Audiologist’s recommendation;

“No the Audiologists said I needed a hearing aid based on the results she had so I guess they can tell”.

NHF2/Interview 1/L101-102

As with the first participant there was evidence that hearing impairment was perceived as something the individual had to deal with as described in the biomedical model. Both participants appeared to feel that they needed to wear hearing aids in order to communicate with others and seemed reluctant to cause others inconvenience. Despite the fact that this participant was well informed and appeared very assertive one comment seemed to suggest that he was compliant with the needs of the service rather than his own;

“The only minor thing was that the first appointment clashed with an event that I didn’t really want to miss, for personal reasons, I didn’t want to miss it, and that meant there was another month before I had another appointment which surprised me a little because I phoned up immediately. Having said that I think the time I had to wait was perfectly reasonable. The problem with the NHS is that all these old people like us—there are quite a lot of us…”

NHF2/Interview 1/L170-175

Despite the fact that he suspected his GP had requested an earlier appointment because of the advanced stage of his illness, he accepted the delay in his appointment without question and almost seemed to take responsibility for this – the fault being the fact that there were so many old people like him and that was the problem with the NHS not a system fault. Again this seemed to fit with the first participant's desire not to be a problem to anyone.

Although the stories of these two participants differed there still seemed to be a common theme of stoicism and acceptance that this was an inevitable event in their lives and the only solution available to allow them to maintain social interaction.
5.2.3 Participant NHF 3

The third participant (NHF 3) told a similar story to the first. An 84 year old male with limited exposure to noise throughout his career, he had been aware of a hearing impairment for three years, He did not acknowledge the impairment until it started to affect his lifestyle significantly. He originally sought solutions including trying to lip read before he decided he needed hearing aids. This participant’s wife also had acquired hearing impairment and wore a hearing aid, but interestingly he said she had never spoken to him about wearing a hearing aid. It appeared that again the client had an external locus of evaluation as, although he decided to ask for a referral, he appeared to be influenced by his wife and had almost resigned himself to the fact that she would manage this for him;

“No, she hasn’t told me about it yet- but once I get it I’m sure she will keep me in line. She manages hers okay”.
NHF 3/ Interview 1/ L79-80.

A further code emerged from this interview regarding private consultations. This client expressed a desire to have a smaller hearing aid similar to those he had seen advertised. Despite this he would not consider consulting a private Dispenser. He seemed suspicious of their practices;

“I like these wee ones you see advertised in the papers but I wouldn’t go privately it’s a con. They tell you the price in these adverts and then- it’s like going for glasses and the price is never the same once they get you in. There’s no need for the prices they charge.
NHF 3/Interview 1/ L84-87

Again there seemed to be a grudging acceptance of hearing aids as the only solution. Although the type of hearing aid was important to this participant and unavailable to him via the NHS he was still, albeit reluctantly, prepared to be referred to Audiology services now that he could his no longer enjoy socialising or watching his favourite TV programmes;

“Well (sighs) I don’t know. If I have to wear it I’ve got to wear it, it’s to my advantage cos I want to be able to hear when I go out”.
NHF 3/Interview 1/ L91
5.2.4 Participant NHF 4

The next participant, (NHF 4), an 84 year old female who had worked in a mill, had also noticed a hearing impairment for quite some time. She was unsure of how long she had had difficulty but was able to calculate that it must have been more than fourteen years. She remembered her husband complaining that she had the TV too loud and since he had been dead for fourteen years she assumed she must have had difficulty for at least that length of time. Like previous participants she tried to find solutions to this and explained that, as she felt she only had difficulty hearing in her right ear, she made sure people sat on her left side so that she could have a conversation. She freely admitted that she would have continued to manage in this way and only came for a hearing aid because her daughter, who had recently moved her to this area, had suggested it. In fact she said that her daughter had, “had her at every clinic there was”.

Two further codes emerged from this interview, that of pleasing people and the other regarding being uninformed. This participant expressed many concerns regarding the hearing aid which to a professional might seem irrational but they seemed to stem from the fact that this lady had no previous knowledge or experience of hearing aids to draw on;

“Well I was on my own and I didn’t know if I would manage to use it. What if it went right into my ear and I couldn’t get it out. Or, if it was really big and everybody saw it…… (Pause)……And what if it was too loud and gave me a headache and I couldn’t turn it down. I hope I can manage”.

NHF 4/Interview 1/L58-60

Part of her concern was her image and how people would perceive her;

“I hope its no’ a big thing that people can see. I look bad enough without that. I just got new dentures and my daughter says all I need now is a wig. What if I don’t have enough hair to hide it?”

NHF 4/Interview 1/L79-81

Despite her concerns about hearing aids she was also concerned about pleasing her daughter. She admitted that she knew she needed a hearing aid but would have “managed fine”; she only came because her daughter persuaded her. She also wanted to please the professionals and expressed concern in case she said anything stupid.
Although she had many concerns about the hearing aids, like the other participants now that she had taken the first step in being referred she seemed resigned to using the hearing aid rather than positive about trying it;

“No I am not, [keen to wear it] I am fine the way I am, but I suppose it I could hear better I would wear it”
NHF 4/Interview 1/L68

5.2.5 Participant NHF 5
The fifth participant (NHF 5) a 71 year old retired teacher was still ambivalent about whether she had a hearing impairment. She was aware that she was turning her TV up louder and that people were commenting on it but she felt she could hear one to one and was undecided as to whether she had a problem. She admitted that she felt she managed fine but explained why she had come to the clinic;

“Well I suppose it must be the case with most of the people who come in; I wanted my daughter off my back.”
NHF 5/Interview1/L5-6

This participant also wanted to please her daughter and despite describing quite negative comments from her family she was at pains to rationalise this;

“My daughter, she said to me, ‘You would be too proud to wear a hearing aid’ I mean she’s not nasty or anything she’s only concerned”
NHF5/ Interview1/ L13-14.

Again there was the suggestion of an external locus of evaluation regarding the hearing impairment, although this participant had finally decided two years ago that she may have a hearing problem and discussed this it with her GP, she explained why this had not been investigated further at the time of the consultation;

“Well I have been waiting for two years for the test because I think the doctor thought when I was chatting to him, you know, you do not need anything”
NHF5/Interview1/L24-25
Despite her concerns she was influenced by her doctor's opinion or at least his perception of the situation and did not take the matter further. As before, this participant discussed her ambiguity, and in fact was still not convinced that she needed a hearing aid. Having said that, she also believed that a hearing aid would be the only possible solution; if the professionals told her she needed one. She explained that she had experienced communicating with hearing aid users who all had negative outcomes but she did not think this would influence her as she wanted to make up her own mind. What did concern her was the aid being visible and confirmed that this was extremely important to her, so important that she was unsure whether this would influence whether or not she wore the aid.

5.2.6 Participant NHF 6.

The next participant (NHF 6), an 80 year old female retired machinist, was aware that she was not hearing her family properly. Again there had been some ambiguity about the hearing impairment. Her daughter had first raised the possibility;

> "Well, probably when my daughter was at home on holiday and she said, “You will need to get a hearing aid because the neighbours are going to complain about that television” and from then on it’s just been, no I’m not, yes I am, you know?"

NHF 6/Interview 1/L13-15

This lady had a dual disability being registered blind and she depended on her husband. Unlike the other participants she was keen to try a hearing aid and explained that her husband already had to read to her and now had to sit close so that she could hear what he was reading. She explained that she felt he “had an awfy lot to put up wae” and her main reason for getting a hearing aid was to relieve his burden. She was positive about the hearing aid because her husband wore one and managed well so she was sure he could take charge of this for her. She also made a comment about having “done well to get this far”. Reflecting on this I wondered if what I had originally thought was a stoical acceptance might in fact be a belief that hearing impairment was a natural part of the ageing process and viewed by the participants, not as has commonly been labelled as a disability, but a natural part of the life cycle.
This participant also demonstrated a need to please others, not only her family but the professionals. She was keen to have a hearing aid and felt that the only way to get one was to, as she described it “Answer the right questions in the right way” This struck me as being more than pleasing the professionals and looking at this in conjunction with the comments made by a previous participant about her GP judging whether or not she needed help, I felt there was an element of “gate keeping” in which the participant felt she had to act in a particular way in order to gain access to services. Gate-keeping therefore became a further open code.

Having analysed the first six interviews, memos, field notes and the reflective journals a series of open codes was compiled and preliminary categories were beginning to emerge. The table below shows the preliminary categories, the breakdown of codes in each category and the emerging relationships.

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5.3 **Review of first six interviews.**

Although preliminary categories emerged from this data there were some issues which needed to be considered. This group of participants was very similar in terms of being from the same area of the country, being registered with the same NHS board, and attending an Audiology clinic- referred to in their appointment letter as a “Hearing Aid clinic”. This and the fact that the Interviews were carried out in the same department may have influenced their responses. Although it was explained that the interviewer would not be involved in their care they were aware that I was employed in the department they attended, and given that a code emerged around the role of the professional as gatekeeper I was concerned that they may have been guarded in their responses in case it had any implications for their treatment.

I was also concerned about the fact that having an appointment for a “Hearing Aid clinic” may have focused the interviews on the issue of hearing aids. It would be anticipated that the participants, many of whom had waited for a considerable period of time for an appointment, would be concerned primarily about obtaining a hearing aid and would not be thinking more widely about their experience. I noted in the memos that the participants could not remember much of the details about how their hearing problem had impacted on their life between the time it was first noticed and their arrival.
at the clinic and given the waiting time many of them could not remember exactly what event had led to the decision to move forward to referral. They were aware of noticing a hearing impairment for some time but could not specify a particular event that moved them to action. I noted that I wanted to explore this further.

I was also concerned that these participants would all go through the same rehabilitation "process"; that is the fitting of a hearing aid with no additional rehabilitation sessions. I wanted to explore the participants’ perception of rehabilitation and whether this met their needs and felt that this could not be done effectively within such a homologous group. An additional purposeful sample needed to be recruited in order to test out the emerging categories, identify any further categories that might emerge from further interviews and provide data about experiences of aural rehabilitation. A further purposeful sample was therefore recruited from the rehabilitation conference being held at the Callier Centre, University of Texas, Dallas (UTD). Although these participants were attending an intensive course of rehabilitation, they were all experienced hearing aid users who had been fitted in different US states and therefore it could be assumed that they would have differing experiences prior to coming to the conference. The interviews from these participants are discussed in the next section.

5.4 Open coding. Dallas Participants.

5.4.1 Participant 7. Dallas 1.
These interviews confirmed previous data collected. The first participant (Dallas 1) a 67 year old office worker, also described a state of pre-awareness in which she thought that the telephones in the office were faulty. When a colleague asked her if she had considered having a hearing test she was confused and asked why. When he told her that she was the only one complaining she was shocked but did not question whether or not this was the case, she immediately made an appointment to see an Audiologist;

“When someone tells you that you are the only one that’s complaining, -Oh!” It was like, ‘oh you guys can hear on the phone up front and I was the only one that couldn’t?’ - obviously that tells you something is wrong with you”. Dallas 1/Interview 1/21-92
This participant also confirmed that she originally blamed herself for the hearing problem and described how the diagnosis was delivered:

“I went and had my hearing tested, and they said,” Yes your hearing is going down” and I said “What caused it?” and they said a multitude of sins which I had all done. Too much medication, scarlet fever….um….loud noises.”

Dallas 1/Interview 1/L14-17

It was interesting that she described illnesses such as scarlet fever as part of “a multitude of sins which she had done.” It seemed she immediately took on the burden of responsibility for the hearing impairment. However unlike the first participants, this lady seemed to have moved on from this place, due to a number of aspects that were coded; taking control, sharing responsibility, using the system, attitude, self-management and helping others. I was struck by this woman’s strong sense of self and as she described her journey it became apparent that this ability to move on seemed to be linked to two things that helped her gain acceptance, seeing positive aspects in the situation and her spiritual beliefs. She recounted what was for me a poignant story about the positive aspect of her hearing loss:

“Thinking back growing up I was very attractive….., I’ll say beautiful, I could hear -not real good -but I could hear, I didn’t know I was hearing impaired and I would hear people make comments about me someone would say “oh she’s pretty” “yes but she knows it” -no I didn’t, and they’d say “she’s stuck on herself” I would hear people talking about me and I would hear these negative statements about me and it bothered me and for a long time. That’s a lesson that I had to learn but it was stigma from my appearance so when I became hearing impaired- I don’t hear those statements any more (here she smiled) But I mean you know my self-esteem and my confidence and everything is better because I don’t hear someone saying “oh she is stuck on herself” or “She thinks she’s pretty” or all of these little things that I can’t control”

Dallas 1/Interview 1/L222-2442
Given that her hearing impairment helped to ease her anxiety. She saw it as a blessing and explained how she viewed it;

“I didn't ask for this, this is something that came on me by the grace of god and I accept it.”

Dallas 1/Interview 1/L154-155

Being able to move on for this participant involved many different aspects. The first stage was being able to accept her hearing impairment. The next seemed to be her attitude. She freely admitted that she “had an attitude” and was not going to lose it, this meant she dealt quite assertively with others in communication. She related how she persuaded her husband to improve his communication skills;

“I thought it was my attitude- I do have an attitude and I'm going to keep it -because I couldn't understand my husband and he (mumbles) so I said well if you want to talk to me, you WILL get my attention you WILL look at me you WILL and that was my attitude”.

Dallas 1/Interview 1/L97-100

This attitude also gave her the confidence to deal with other relationships by handing over some of the responsibility for communication, which in turn helped her increase her self-esteem and value her own self–worth;

“I am able now to, in my own emotional state, accept what I want and I don't if ah, you know something happens between us and I say, “well you need to look at me” and I tell you that I need you to communicate better and you don't respond- that's fine- I don't let it bother me because I feel like I have given you the ball and you dropped it. Well I didn't drop it so that's your problem.”

Dallas 1/Interview 1/L247-251

This confidence extended to coping with difficult work situation and using the system to get what she was entitled to even at the risk of causing conflict in the office,

“I would go to an interview sit there and talk, answer their questions correctly like I heard everything they said and understood everything. Then I would get
the job and then if I am expected to answer the telephone I would have to tell them I need a booster, I need this because I am a hearing Impaired, by law I am not required to tell them and so when I got hired and they discovered that I couldn’t hear …..They had not planned for that and they were not very happy to have to accommodate me, but it is by law something that I am entitled to and something that I need to maintain my position.”

Dallas 1/Interview 1/L138-152

Moving on also meant taking more control and self-management. When the Audiologist suggested a cochlear implant after a further deterioration in hearing was recorded this participant questioned the Audiologist about the implications of this operation, demonstrating a clear knowledge of the possible risks. Having had her beliefs confirmed she instructed the Audiologist to remove her name from the list as she was not interested in pursuing this. She then took on the responsibility of learning to lip read in order to maximise communication and use her residual hearing and subsequently approached her Audiologist and asked her what else was available to help her. This led to a more collaborative and equal relationship between herself and the Audiologist in which they shared information and debated the future management plans. Interestingly the part of the interview in which the participant relayed the story of the referral for implant demonstrated a good example of the Cartesian duality in practice. The participant had been working with the same Audiologist for many years, when the participant’s hearing deteriorated to the point that she fitted the criteria for cochlear implantation the Audiologist said, “Now we can help you”. From the Audiologist’s perspective the hearing loss could now be “fixed” using a biomedical solution. The participant, confused by this remark replied, “What do you mean? - you been helping me all this time”. Her perception being that the Audiologist’s role was to provide support to help her come to terms with the hearing impairment.

The final stage of moving on was helping others. This participant felt that the purpose of her journey was to use her experience to help others. She felt that her only concerns were for the future of her sons, so that they did not damage their hearing and experience the same difficulties she had, and for other people who may be going through this same experience. She believed that there were not enough people who
were willing to inform others about hearing impairment and how to cope with it and felt that speaking publically at various groups and conferences served a purpose that was not entirely altruistic;

“So that’s my role in life to talk positively that is more or less my position in life now. Sharing and helping gives me gratification”

_Dallas1/Interview1/L335-336_

5.4.2 Participant 8. Dallas 2
This interviewee (Dallas 2) confirmed many of the categories that had already arisen. This woman was in her early seventies and still running her own company. She had suffered from fluctuating hearing impairment for many years and although she had tried hearing aids several times, she had not yet purchased a set.

She described the process of becoming aware of hearing impairment quite clearly; having suffered from perforated tympanic membranes after a flight she lost her hearing temporarily. Although her hearing returned after a period of time it was not quite so acute as before but she felt it, “Wasn’t bad enough to pay attention to” After each subsequent infection she would decide it was time to get a hearing aid but “never quite got round to it”. Throughout the interview she insisted that her only reason for not obtaining a hearing aid was procrastination. She had no concerns about wearing the aids but just kept putting it off. Despite this explanation I wondered if there might still be some ambivalence as some of her comments suggested that, although there was emerging evidence of a hearing impairment, “Oh the hearing that I’ve lost, just unbelievable, the tests show that” she had not yet fully accepted that she had a level of hearing impairment requiring intervention. She spoke about her family’s reaction to the hearing impairment and the impact this had on her;

“I’ve got a sense of humour about myself and so the mishearing of different things with my family................. well actually it just isn’t funny anymore, and they say when are you going to get hearing aids?”

_Dallas 2/Interview 1/L24-28_
She admitted that she had started to withdraw from family events and attempted to rationalise this;

“I have started to withdraw from social events...ah some social situations I go to... but then I rationalise it. I say well I am happier at home reading or really happier at home doing something else.”

_Dallas2/Interview 1/L236-238_

Despite the impact on her relationships she frequently referred to her procrastination;

“There is no earthly reason why I haven’t I think I just keep thinking; well they are going to come out with something newer.”

_Dallas2/Interview 1/L28-29_

In my notes I debated whether this was in fact procrastination, or lack of acceptance of the reality of the situation. There were frequent references to looking for a cure or looking for something better, and this suggested to me that the participant had not fully accepted the reality of her hearing impairment. At this stage the participant seemed to be in the pre-contemplative stage of the change cycle (Miller and Rollnick 2012) and not yet in a position to move forward to a final decision. Although this participant was still struggling with the decision to go ahead with amplification, she had developed coping strategies, some of which were based on ego defences such as rationalisation and denial some which were practical, and some which were linked closely to her spirituality and ability to see positive aspects of the hearing impairment.

Referring to the Kubler-Ross model of grief (Kubler-Ross 1973) she described herself as “being in denial and acceptance at the same time” which may explain her ambiguity. She went to great lengths to conceal her hearing impairment in the workplace, disguising her inability to hear thus;

“I have learned when they ask me questions I will simply say ‘mmm help me understand your question better- what that was again? Or when my back’s to them when I’m writing on the flipchart, Well I say ‘I am writing on the flip chart and my back’s to you I won’t hear really what you are saying because I’m concentrating on what I am writing so wait until I turn around and face you.’ so all these little tricks
you come up with but really they aren’t little tricks
they’re reasonable.”

Dallas 2/Interview 1/L42-49.

As with the previous participant, she had drawn on her faith to help her cope and make sense of the situation;

“Losing my hearing is not to me something momentous, horrible that I needed to be angry about......... I’m driving down the road and I say, “Okay Lord you took my hearing away. I don’t know the reason for this but there must be a reason, but I can still talk and I can still see....., okay Lord I can’t hear I don’t know what the reason is, but please let my hearing come back, and so I haven’t experienced the anger.”

Dallas2/Interview1/L188-204.

Seeing the positives certainly made a difference for this participant. She explained that she had a great faith and a great sense of humour which she attributed to her Irish roots. This sense of humour helped her to see the funny side of miscommunication with her peers. She also saw the experience of losing her hearing as a source of personal development;

“I think you really sense who people are ...you get a sense of which people are because of how they respond to your not hearing which is very, very interesting. It helped me to know myself better- how I cope with things and how I look at things and how there are some things I accept that isn’t my doing and it’s a higher power doing it and I have to learn how to live with it.”

Dallas 2/Interview 1/L294-307

As before there was a sense of using the experience to help others. This participant described the help she had received from the other conference delegates and staff which helped her to explore her needs, and expressed a wish to help others find a way of coming to terms with hearing impairment.

On reflection I realised that this participant appeared to have an internal locus of evaluation. Although she had frequently tried hearing aids and had been encouraged to do so by the staff at the institute, she appeared not to have been influenced in making a
decision to purchase hearing aids, but had come to this decision based on her own beliefs and experience.

This led me to question whether the external locus of evaluation fitted into the model that seemed to be emerging. I had first thought that there was evidence for a directive approach to rehabilitation based on the clients need for expert advice on the subject of amplification. I had originally thought that the lack of knowledge about rehabilitation would lead to an external locus of evaluation, but now there seemed to be evidence to suggest that some clients have an internal locus of evaluation despite this lack of information and knowledge. This did not seem to fit with earlier participants’ experience, and was the first negative case I had had. On reflection it now seemed that clients may have different needs based their locus of evaluation, but both internal and external loci were relevant to the process and the category should be redefined as locus of evaluation, and explored further to ensure that both internal and external loci fitted into the model.

5.4.3 Participant 9. Dallas 3.
The next participant (Dallas 3) was a mature student in her early fifties. She described a similar experience to the previous participants in that she had had a hearing impairment for a long time that had first been noticed by others. She described two distinct stages, the first of which she had been unaware of. She had lost a significant amount of hearing as a toddler. Or rather her mother discovered her hearing impairment when she was a toddler. Until ten years ago her hearing had stayed fairly stable, so for her, her hearing until his time had been normal relatively speaking and she was not aware that she had any problems. She explained that she;

“…Got along fine. I went to – I travelled to France went to Spain- didn’t have any problems”.  
Dallas 3/Interview 1/L207-208

Things changed ten years ago when she experienced what she described as a “dramatic” drop in her hearing which she noticed because, whereas before she felt she had had a loss of volume she now became aware of a loss of clarity, and she found that that had an impact on her life. She described feelings of fear around participating in
everyday activities for example, travelling on public transport, and not being able to hear what was being said. She described a particular incident after the 9/11 terrorist attack when she was in Washington DC and suddenly realised if there were an emergency she may not hear instructions and would have to ask for help. She said she originally had concerns around hearing the telephone etc. but now that her hearing had deteriorated she had very real fears about communication with people. Despite this she did not see herself as someone who was handicapped. Her self-image was of someone who was independent and coped very well and she seemed bemused about the fact that she accepted financial help from an organisation that helped handicapped people when she didn’t see herself as a disabled person.

She had developed a variety of coping strategies, the first of these was to take control and to make sure she always planned ahead. This ensured she could conceal her hearing loss as far as possible. For example she explained;

“It helps to know that I have a fresh packet of batteries, so if it goes out -and my hearing aid gives me plenty of warning. If I have a fresh pack of batteries as soon as it gives me warning I just pop another one in and that does control my anxiety.

Dallas3/Interview1/L115-120

She also used concealment as a coping strategy. Despite her concerns about missing vital information she still preferred not to volunteer information about her hearing impairment unless she absolutely had to;

“So there’s still some reluctance, it’s like….. I will try to do as much as I can on my own and when I absolutely need to I will let someone know I’m deaf. Like people I first meet I usually don’t say anything....”

Dallas3/ Interview1/ L170-172.

Further into the interview she started to talk about picking up that people at school were teased if they were different and it was better not to say anything and I wondered if an ego defence was in play here and that she had introjected, perhaps from teachers or her mother, that people do tease people who are different and she would find life easier if she kept the information to herself. She did volunteer that she had never been teased
at school and that her teachers had been very supportive but she was aware that she had picked up this belief about being handicapped. She talked about her feelings of being labelled as a handicapped person and this linked into the *self-image* code she was grateful for the hearing aids and the help she had been given by the organisation but she said;

“It’s still slightly puzzling to me? It’s like to a certain extent you get certain dispensations for being handicapped and I’m still puzzled about that, it’s like I understand it? I don’t know if it’s a stigma or something, I haven’t quite figured that out but at the same time If I took my hearing aids off I would be in a world of trouble, so I guess I’m like- as I said before I’m still thinking the way I did up until that dip ten years ago.”

*Dallas 3/Interview 1/L223-231*

As we explored this more she realised she hadn’t “caught up with” being someone who had hearing loss. We talked about how relationships had developed to cope with the loss of hearing and what was helpful to her and she was very clear that what was most helpful was when friends were able to work with her rather than take control of the situation. For example she described a situation where she had gone to a very noisy restaurant with a friend who stepped in as she described it “quite graciously” to work with the waiter rather than taking over and ordering the meal. She also described another friend who automatically put subtitles on the television when a group of them gathered to watch a movie so there was no issue about having to ask for that and she explained,

“If someone steps in and helps me or cues me in a way that is gracious then I don’t feel like something’s wrong”

*Dallas 3/Interview 1/L254-255*

She did however describe other situations where she had been assertive and explained that she had not heard something only to be met with impatience and sometimes abusive treatment. Talking about gaining help e.g. through subtitles being provided rather than being something she had to ask for, led us to a subject which had not been raised in previous interviews which I have coded as Society’s role. This participant
talked about handicap being related to circumstances, and as such a social construct, which could be influenced by society’s reaction to hearing impairment. For example she described going to a movie theatre and thinking how much better it would be to have listening devices advertised so that she could point to the poster and request one rather than having to explain what she needed to someone with no experience of the systems. In this way deafness might become more “main-stream” and lose some of the stigma she felt was still attached to the condition. This led to a discussion about deaf awareness and how society could be more aware of the impact of hearing impairment and how to communicate. This participant felt that hearing impairment was on a continuum rather than being hearing/non hearing and everyone would benefit from a better understanding of how acquired hearing impairment develops. She suggested that the best way to remove stigma was to educate children;

“Kids are generally very open and they love to learn. They love to help if they know it will make a difference. A lot of people with grandkids, if they are hearing this stuff in school then they will know ‘oh when I talk to Grandpa I need to come up and stand right close to his ear’ so I think classes like that would help”.

Dallas 3/Interview 1/L324-331

She felt that there needed to be more global awareness of the problem which she saw as the responsibility of the first world countries. She talked about having rehabilitation conferences on a larger scale and explained;

“You know what crosses my mind? I often wonder about doing something like this globally, because I am very fortunate to be in a first world country. I often think to myself ‘God what if I had been born in Egypt or Burma? I’d be sitting in a corner somewhere you know -or in the street. I know in a lot of cultures handicapped people are seen as useless. I’m sure there are some people in Burma with the same type of hearing loss but our lives are completely different!”

Dallas 3/Interview 1/L336-395

I noted in my journal later that I had been surprised by this part of the interview. Earlier this participant had said that were it not for the voluntary organisation paying for her hearing aids she would have to resort to buying cheap hearing aids from a newspaper
or magazine and yet she felt that she was fortunate that she was able to have the level of service offered to her. In the UK she would have been fitted with two hearing aids free of charge and as a student in full time education would have been able to access additional technology and services to help her complete her studies. Our perspectives of the level of service varied and after the interview I was aware that I had strong feeling of frustration. Later I was able to reflect on these feelings and realised that I felt frustrated that this person who, despite a considerable hearing impairment and financial obstacles, had managed to support herself and study to doctorate level, with very little help in relative terms. I realised that I was over identifying with this participant who was the same age as me and studying for a doctorate having self-funded her bachelor and Master degrees. I realised I had to be particularly vigilant in looking at this data to ensure my own internal processes did not influence the analysis.

5.4.4 Participant 10. Dallas 4.
The next participant, (Dallas 4) a man in his mid-fifties, had also experienced hearing impairment from childhood after being exposed to gunfire while hunting with his father. Despite the fact that he realised he could not hear well in class, he chose to conceal his hearing impairment and refused to move nearer to the speaker. He knew that he could probably compensate for his hearing impairment to some degree by moving nearer to the front, but stated that “*He knew the problem was there but never had the initiative to do anything about it.*” The hearing impairment affected him throughout high school and college but he felt he adapted well and said it was his “*Conscious decision not to do anything until he reached the age of 55.*” When other members of the family began to use hearing aids he considered the idea but dismissed it as he felt he was coping well. It was not until the hearing impairment began to affect his performance at work that he considered seeking help. In meetings he found that he could not follow conversation if there were “asides” going on at the same time. His coping strategy was to conceal the hearing impairment by asking individuals to take their conversations outside so that people could concentrate on the main topic. Eventually he realised that his strategy was no longer working and his family were beginning to comment on his difficulties in a rather directive way, “*They were reinforcing the fact that I had a problem and I had better do something about it.*” L53
He finally decided that he would get hearing aids and felt that they had changed his quality of life. Having experienced this improvement he regretted waiting so long to do something about his hearing impairment and wanted to use his experience to help others. Although the hearing aids had improved his quality of life they were still not perfect and he still had not come to terms with being hearing impaired. His coping strategies varied from completely avoiding situations to bluffing, which he admitted no longer worked for him, to being assertive. His choice of coping strategy varied depending on the circumstances and he seem to find it easier to be assertive with family and friends than with work colleagues. He explained;

“I used to listen to music but now it drives me crazy because I hear all those background noises so if someone turned on music I would want to move to a place where I can't hear it anymore and I have a lot of friends who would turn on music when I go over to their house and I just told them 'basically you put me out of the conversation you know? I might as well go home!'”

Dallas 4/Interview 1/L145-151

Having to cope with the background noise had caused him to withdraw from social events and he felt people viewed him differently because of this;

“I think people were beginning to see me as anti-social because I didn’t participate in things and I got to the point where if I couldn’t understand the conversation going on I would really tune out. Tune out to the point where I wouldn’t even listen to them anymore, I’d be doing or thinking something else.”

Dallas4/Interview1/L163-167

A new category emerged from this interview, which I have called rehabilitation. This participant spoke about the benefits of rehabilitation but I felt at this stage it would be inappropriate to have a code that included the word benefit as this might make an assumption about the effect of interventions. This participant spoke about the help he had received from the staff at the conference not only in addressing technological problems he had with his aids, but in providing information and the space to discuss and debate feelings about hearing impairment and introducing him to new coping strategies he was keen to use. The information he had received at the conference had
led him to realise that Audiologists could do much more for him and his family. There appeared to be a relationship between this code and the code *professionals* particularly around the relationship with the professionals. He felt that he had not been given information from his Audiologist that might have been of use to him and that he had not been consulted in the rehabilitation process. The Audiologist had made recommendations on his behalf which led to him being unable to acquire other technological solution that he tried at the conference. He was extremely upset about this and intended to speak to his Audiologist about it. I found it interesting that he said he wanted to ask her “*why have you done this to me?*” He felt he had not been consulted about decisions she had made that affected him and felt this was something he needed to address;

> “You know you go in as a patient and you don’t know anything about this field and now I feel like I’m going in armed with a little bit of information that I would like to go in and say, what about this? What about this? What about this?”..... I’m going to go back to her now and say, ‘Why did you do that? Why did you do that?’... Because if she had suggested this to me I would have said I will not wear them I wouldn’t do that, but yeah, the communication didn’t take place and it should have.”

*Dallas4/Interview 1/L227-259*

This participant also confirmed that he felt society had a part to play in facilitating information. Referring to social situations he again explained why he gave up trying to communicate;

> “You can see the frustration in their faces when they repeat things four or five times and I’m not getting it, but they are not using coping skills to help me so ..?”

*Dallas 4/Interview1/L161-163*

He also discussed how he began to realise that hearing impairment affected not just the person with the loss but others around him, by recounting an incident when he has become frustrated with his father in law while watching television;
“When he doesn’t wear them (the hearing aids) he plays with the volume control and with mine on, he drives me crazy and so I take the remote away from him and I say “go put your hearing aids on and he uurgh! You know? He kinda....I can see now how people with a hearing loss affect ME, it’s not just me with the hearing loss anymore it’s... someone... It’s tough on both sides of the hearing loss.”

Dallas 4/Interview 1/L180-212

5.4.5 Participant 11. Dallas 5.
The final interview in Dallas did not yield any new codes but several of the existing codes were confirmed in the interview. This participant, (Dallas 5) a woman in her forties, had an atypical hearing loss. At the age of 29 she had a sudden viral infection that left her quite debilitated. Following a stay in hospital she transferred to a nursing home, and about six months after the illness she started to realise that she could not hear. The hearing impairment was further complicated by the fact that hearing aids did not help. A neurologist explained that the virus had attacked the brain and it seemed there was a processing disorder. While the hearing aids gave volume this participant found that unbearable and since they did not improve speech discrimination she found them of limited use. Throughout the conference I noticed that this lady singled me out frequently. At first I thought this was because I was a guest at the conference but I noticed that she did this with others and she explained that she coped by selecting one person and getting up close to them so that she could watch their face. Provided she had one person’s sole attention and there was no background noise she is able to carry on a conversation. The hearing impairment had had a profound effect on her life. Prior to her illness she had an extremely busy working life. She had a managerial position with a lot of responsibility. She also had a young family. When she became ill she lost her job and had to rely on her relatives to care for her and her daughter. She found this really hard to accept and the resultant hearing impairment made her more isolated. She described sitting in the nursing home looking through the window at her old school where she had remembered;

“I used to sit and cry because I was named the most fun in my senior class and no one was coming to see me, everyone in our town was horrified. But people don’t like to go to hospital and they thought
this woman was so hyper and worked and seemed to know everything...how did this happen to her? They were scared”

Dallas 5/Interview 1 /sound file.

Twenty years on from this illness she still had difficulty in company and admitted that she sheltered herself, limiting her outings to a few settings where she knows the people and can have one to one conversations.

She admitted being angry with God when she lost her hearing and there was almost a suggestion that she had brought this on herself. She explained that she had been brought up as someone who should be polite and help others but this led to her being unable to say no to any request for help at work. As her job became more stressed she started to resent the many requests that were being made of her time, and reached a point where she asked God if he could please stop people asking her to do things. Shortly after this she became ill and lost her hearing. She explained;

“I remember asking him to quit having people asking me for something to do now like I say to him now, I want them to ask me stuff -- because I was overwhelmed. 19 years ago I wanted to shut everybody off and now it's like you shut my ears off for nineteen years, now GIVE EM BACK! I admit I was angry with God”

Dallas 5/Interview 1 Sound file

Despite a nineteen year history of coping with this hearing disorder, this participant did not relate to other deaf people. She often commented that it was different for her and said the hardest thing for her during the conference was learning how to speak to a deaf person because she would go up and shout into their ear rather than looking at their face. She did not see herself as deaf and did not seem to have come to terms with this, she spoke of not being able to stand living in the real world and not hearing anyone and wanting to be normal again although she realised this would probably not happen. Although Audiology services had not been able to help her access speech she did feel she had learned about deafness and was able to help others. She was keen to help her father adapt to his new aids. I wondered if that was part of the journey for her because of her upbringing and her need to help others or if it was a way of giving
meaning to what had happened and giving her life a purpose. She spoke frequently of the emptiness of her life and how she tried to fill the days within her means by doing puzzles or going to exercise classes, but there seemed to be a great sense of loss and regret. Prior to her illness she could not understand how people could be patient enough to sit down and read. Now she used books as a means of escaping;

“I read a lot and I get my life in the book. My life isn’t the boring life it’s the life in the book but then I am disgusted when the books over, I don’t want it to end.”

Dallas 5/Interview 1 /Sound file.

She was very aware of others reaction and had often found herself the “butt of the joke” when she misunderstood the conversation, but here she had made some progress, rather than being upset and withdrawn, she had started to become more assertive with family members;

“When I went to my boyfriend’s we used to stand in his garage and we used to talk about things. Well everybody would sit there and talk and they’d be telling a joke or something and they’d look at the floor and tell the rest of it and everyone would laugh and I’d say ‘can you just tell me what the punch line is?’ So well, many people can’t tell you one part of something and if I say I got all of it until then and then he’d go you’ve got selective hearing and I would say, ‘I do not, as long as you are all sitting talking to us face to face I do fine but when you all of a sudden decided to change your facial things to the floor the volume isn’t coming my way!’”

Dallas5/Interview1/Sound file

5.5 Additional codes and categories

The codes that were established in the first interviews had been confirmed and several new codes were added during the course of these interviews but it now seemed that there were no new codes emerging. I was able to review and connect the existing codes to develop categories, updating the previous table.
Table 5.2: Additional codes and categories

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<thead>
<tr>
<th>Category</th>
<th>Related codes</th>
<th>Relates to:</th>
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<tbody>
<tr>
<td>Hearing Aids</td>
<td>Stigma</td>
<td></td>
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<tr>
<td></td>
<td>Feelings about hearing aids</td>
<td>Concerns about hearing aids, Beliefs about hearing aids</td>
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<tr>
<td></td>
<td>Knowledge about hearing aids</td>
<td>Stigma, Being uninformed, Efficacy of hearing aids</td>
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<tr>
<td>Relationships</td>
<td>Pleasing people</td>
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<td></td>
<td>Others reactions</td>
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<td></td>
<td>Burden</td>
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<td>Contact with services</td>
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<td>Professionals</td>
<td>Gatekeeper, Assessment</td>
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<td>Becoming aware</td>
<td>Pre awareness</td>
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<td></td>
<td>Ambivalence</td>
<td>Impact on activities, Communication difficulties, Accepting</td>
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<td></td>
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<td></td>
<td>Ageing process</td>
<td>Stoicism</td>
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<td>Responsibility for solution to problem</td>
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<td></td>
<td>Locus of evaluation</td>
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<td>Taking control</td>
<td>Using the system, Self-management, Helping others, Attitude</td>
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<tr>
<td>Society’s role</td>
<td></td>
<td>Sharing responsibility</td>
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</table>

I felt I was beginning to construct a model that reflected the process of acknowledging hearing impairment, seeking help and adapting to hearing impairment. The period of
time between acknowledging the impairment and taking action varied for each participant interviewed but for many of them this stage had been reached some years ago and the detail of what had caused this transition was still unclear. To explore this area in more depth a further purposeful sample was selected. On this occasion from a group of individuals who were aware that they had difficulty communicating in particular settings, but who had not yet sought help for their difficulties. These were the participants recruited through the COPA database.

5.6 Open coding COPA

5.6.1 Participant 12. COPA 1

The next participant (COPA 1) was a 68 year old former telephone exchange operator, who had noticed hearing problems for 5 years. She felt her left ear was worse. She had originally been more concerned about troublesome tinnitus but became aware of the hearing impairment later. When asked about her hearing impairment she explained that she was not deaf but had a dullness of hearing which meant she did not have the clarity she needed. For most of the interview she talked about her relationship with the professionals. She had been seen at her local ENT department with regards to her tinnitus two years before the interview. Although she had no real concerns about her hearing at that time it was a tested as part of the assessment. She did not feel the relationship with the staff was particularly helpful and in fact was contributed to her decision not to go ahead with a hearing aid fitting. She described a series of appointments. At the first appointment she had a consultation with the doctor and then a pure tone audiogram was carried out. Following this she was advised by the doctor to come back in a year. When she went back she saw a different doctor who repeated the tests and then she was asked to come back two or three months later to see another doctor. He again advised her to come back in a year and then the tests were repeated. At this point the doctor told her there was nothing they could do for tinnitus but he would give her a hearing aid as that might help. She was then given another appointment to be measured for the hearing aids, but when she arrived at the hospital she found out that she needed to have yet another appointment to have this done as she had only been allocated a five minute appointment. Given that it was quite a journey to the
hospital she decided not to continue with the appointments. She felt the doctor’s attitude to the hearing aid did not inspire any confidence;

“The doctor more or less said ‘well it’s not going to help you but we’ll give you this anyway’. Like I will give you a chocolate and that will keep you happy. Why go through this if it’s not going to help, so I felt like this is something I just have to live with.”

COPA 1/Interview 1/L162-166

It seemed this was not the only reason she had refused a hearing aid, as she made a comment about “being so against the hearing aid to begin with” but she clearly felt the attitude of the professionals was not conducive to rehabilitation. Part of the reason for not wearing a hearing aid seemed to be the fact that she had not yet decided whether she needed one, she felt she had difficulty hearing but explained;

“I’m not deaf, I am dull of hearing, and if people’s voices are loud I know they are loud but sometimes they mumble. I don’t want to think about it. I’m not deaf I am dull of hearing when I get deaf I will wear a hearing aid.” COPA 1/ Interview 1/ L252-254.

Comments from friends had also influenced her feelings about hearing aids. Her friends had rather negative views about hearing aids and she seemed to take these on. Although she had never tried a hearing aid, she felt they were not useful and did not want to wear one. However she did want help with difficulties and was open to any kind of help, even if it was just having someone to talk to and offer advice about how to manage this lack of clarity, but she was not convinced that this would be offered;

“I would imagine anything that would help I would go for it. I just feel they are too busy. You go up there and the place is bursting with people because they only get ten minutes and then they have another patient.”

COPA 1/Interview 1/L182-193

Throughout the interview I had a sense that there was a lot of rationalisation going on as this participant swung back and forth between a desire for help and using the doctor’s rejection of her need for a hearing aid to justify withdrawing from the situation.
I had a sense that this client was indeed carrying out a cost benefit analysis, which became a new code, and had decided that at this stage the hearing aid “was too much trouble” She was using some coping strategies albeit only with close family, and had resigned herself to living with her lack of clarity until she became deaf at which point she would consider a hearing aid.

The pure tone audiogram for this participant showed thresholds of < 20dB HL in both ears at the low frequencies, and a sloping loss ranging from 25dB HL to 55dB HL in the high frequencies. Bone conduction results defined the loss as sensorineural in type and tympanometry confirmed that there was no conductive element. Speech audiometry was carried out and the participant was able to correctly identify 50% of the words at 35 dB HL which correlated well with her PTA results. The report she was given indicated that she had a mild to moderate loss.

In the second interview we discussed the results of the audiological assessment and she expressed surprised at the results she had been given. She said she felt embarrassed about the fact that she had felt she had a problem when the experts had confirmed that she did not. I believe this indicated an external locus of evaluation. Prior to the assessment she was convinced that she had a hearing impairment and cited several examples of where this had affected her quality of life. Immediately following the assessment she expressed her embarrassment about being wrong and had immediately disregarded her own opinion in this matter despite the fact that during the second interview she continued to offer examples of situations that she found problematic. She seemed disappointed in the results of the assessment and admitted that she was seeking solutions; she said she was “looking for a miracle”. She expected the professionals would be able to tell her what was wrong and how to fix it and was unsure how to proceed with the information she had been given. She continued to express her belief that she was not deaf but had difficulty in communicating in certain circumstances and when asked whether she felt she had a hearing problem or a communication problem she said she felt the latter was a more appropriate description, and felt her problem was situational. If she was in a cinema for example she found the sounds “blaring” and impossible to understand, but if someone spoke softly or mumbled she could not understand that either.
When asked about hearing aids she seemed ambivalent. She would be prepared to wear hearing aids if they helped, but did not think she was deaf, and since the professionals had confirmed this belief by saying she just had to learn to live with it, felt there was no need to pursue this. If, however there were any other means of help available she would be happy to accept that although she was not sure what would help her. This again suggested a dependence on others to find solutions for her.

She spoke of the need to educate others in effective communication and deaf awareness, and had particular concerns about young people and their exposure to leisure noise. She felt this was something that needed to be addressed before any permanent damage was done. She also expressed a desire for information for people like herself who felt they had a problem but had been told by professionals that they did not require a hearing aid. She felt there was no advice available to help deal with communication difficulties and that this would be helpful for many people. She also felt that, although many people would use the internet as their first source for information, this needed to be available through a variety of sources as not everyone had access to a computer. Her suggestion was to incorporate this into open days targeted at the ageing community or through community centres. She also expressed a need for preventative action to educate people about good hearing and how to avoid the effects of noise.

In both interviews many of the codes that had already been identified were affirmed, in addition a new code, cost benefit analysis emerged, relating to the individual’s assessment of the severity of the hearing loss and its priority on their life. In this particular case, although the hearing impairment was affecting her social life and causing her to withdraw, coexisting illnesses were taking priority over help for her communication problem and even if a wider range of helping strategies as identified by the participant were available to her, she felt that she would not be able to prioritise differently at this time.

5.6.2 Participant 13 COPA 2
The second COPA participant (COPA 2) was an 84 year old retired civil servant who had noticed deterioration in his hearing over three years. Initially he only had difficulty
hearing his sister but this progressed to include other people. He explained that he had no difficulty with volume but the clarity of the speech was poor. Despite volunteering the information that his hearing was deteriorating he still rationalised his difficulties, explaining that people do not enunciate clearly any more as there is no pressure in school to develop clear speech. He also noted that he had difficulty hearing the radio and telephone because presenters and call centre staff speak too quickly and have accents with which he is not familiar. He did remark that this did not apply to his sister and yet he could not hear her, but quickly decided that his was because she had an extremely quiet voice.

The pure tone audiogram confirmed that he had a bilateral symmetrical mild to moderate loss. Tympanometry was within normal limits but speech audiometry did not correlate well with his pure tone results. Although his pure tone average was at 35dB HL he needed the level of the speech recording to be between 55 and 60 dB HL in order to correctly identify 50% of the phonemes. This might explain why he felt he had sufficient volume but not enough clarity in conversations. We discussed how he coped with the hearing impairment and he admitted that he did a lot of bluffing to get through conversations, although if he felt information was important he would be assertive enough to ask for it to be repeated.

Again the concept of cost benefit analysis was raised. This participant believed that he would happily wear a hearing aid when the need arose, but at the present time he felt the hearing impairment was not impacting on his life. He explained that he had never been a particularly social person and now his wife’s disability meant that they had withdrawn from socialising completely. He therefore felt that he could deal with the impact of the hearing impairment, which he also saw as an inevitable stage in life having reached the age of 83, by reducing his social circle and using the coping strategies he had developed. Should the problem begin to have more of an impact on his life he would consider wearing a hearing aid and making use any other services the NHS offered. He had great faith in the NHS and felt he would be happy to leave the decisions in the hands of experts.
A very interesting thing happened during this interview. As the participant looked more closely at what he had originally described as a minor inconvenience he seemed to gain some insight into the extent of his hearing problem and seemed to become more aware of the impact on his life. As this happened he began to avoid talking about the hearing impairment by, as he put it, “digressing” onto other non-relevant subjects. It was very difficult to keep him on track and when asked about his hearing he related a long story about his education and missed opportunities. He also related a story about his limited success at school brought on by lack of opportunities for higher education and a similar story about his time in the Navy. He then went on to tell me about his success at work and how his potential was noted despite his lack of formal qualifications. I was aware that I was frustrated during this interview and after several attempts to bring him back to the topic under discussion I realised that he had nothing more he was willing to say.

I reflected on this at great length following the interview and recorded the following notes in my reflective journal;

“This was a particularly difficult interview for me. On the surface it seemed as though COPA 2 had very little to say beyond the factual evidence he had noticed regarding his hearing. It was really difficult to keep him on track and I wondered at first if he, like one of the earlier participants, felt the need to justify his lack of education and highlight his abilities in order to show himself as a competent person. At first I thought this was the case but in reviewing the interview I realised there were several long unrelated conversations, all instigated by a question about the impact of his hearing loss. At the time I had let these unravel thinking each one would end by relating to some aspect of his hearing problem but none of them did. On reflection I think it was best to stop the interview when I did as I was conscious that COPA 2 looked more and more uncomfortable as I tried to return to the subject. I am now beginning to wonder if I was seeing a phenomenon similar to the “flight into health”. It will be interesting to see how COPA 2 reacts to the results of his hearing assessment in the second interview.

Memo for COPA 2 interview 1

The flight into health is a term used in counselling to describe a patient’s response to a stage in therapy. Often when the person starts to gets close to painful memories, they
are unable to look at these and suddenly explain that they feel much better and would like to withdraw from therapy. The response is often so sudden that the person will cancel or fail to keep their next appointment. In this case I felt there was a possibility, given the participant’s ambivalence and rationalisation, that he was resisting exploring the issue. I noted that this may have an impact on rehabilitation. Often Audiologists will seek to direct patients using motivational interviewing or by trying to persuade the patient to have a short trial of a hearing aid in the hope that this will help them to appreciate the benefit and continue use. However if the patient is resistant to exploring the problem it may be that directive approaches such as those described may be counterproductive at this stage of the journey. Interestingly this participant subsequently contacted me to say that he was unable to attend to complete the second interview

5.6.3 Participant 14. COPA 3.
The next participant (COPA 3) was a man in his late fifties. Interestingly although friends and family had remarked on his hearing impairment, at the beginning of the interview he was still unsure as to whether he thought he had difficulty hearing. As the interview progressed however, his awareness increased and he gained some insight into the effects of his hearing impairment. Although no new codes were identified, he did provide further evidence for some of the existing categories. He had become aware that he was constantly asking people to repeat themselves particularly in background noise. Although he recognised that this must be annoying for other people he was unsure if this was due to a hearing impairment or to people mumbling in background noise;

“If I don’t see their mouths I don’t understand what they are saying. The guys must feel like parrots because they are saying things two or three times -and I don’t think I’m deaf

COPA3/Interview1/L15-16

Reactions from family and colleagues had not been supportive; in fact he explained that he had not shared his difficulties with his ex-wife because she would not understand. He felt he was often the brunt of the joke with work colleagues also;
“He says...obviously a wee smart remark... but I didn't hear it and everyone is sniggering and I have missed it totally missed it”.
COPA 3/Interview1/L209-212

The impact on family was wide reaching and starting to affect his relationship with his children and grandchildren also;

“My daughter’s fed up with it; my daughter’s totally fed up with it. I’ve got two wee grand kiddies. They’re lovely people and if they are running about and my daughter or son in law are talking I can't make out what they are saying I want to be able to hear what they are saying. To be fair I would rather just go along to see them and give them a wee cuddle and leave because to have a conversation.......I said ‘darling I didn’t hear you’ and she said ‘och it disnae matter’. I would have loved to have known what the child said to me but it’s gone and it's gone forever”
COPA 3/Interview1/L167-195

This breakdown in communication had led to withdrawal from social situations, which he had rationalised. During the interview for example, he explained his withdrawal from conversations was due to the fact that he really felt he “didn't have too much input into the conversations anyway.” He had also developed coping strategies to help him communicate with others, which included asking people to face him and speak clearly. Despite these coping strategies he still did not relate to having acquired hearing impairment.

As the interview progressed he gained some insight into the impact of hearing impairment on his life and the fact that he was withdrawing from social situations because of this. I was concerned that I may have influenced his thinking during the interview but when I raised this he felt that talking about the hearing impairment had led him to discover this rather than anything specific I had said.

He had some knowledge about hearing aids. Having read brochures given to him by an ENT consultant he has seen previously. He had received conflicting information from this consultant. He had originally consulted him some time ago because of a sinus complaint and the consultant had arranged for an audiogram to be recorded as part of
the assessment. He advised the participant that he did not need a hearing aid but gave him a brochure for a local Hearing Aid Dispenser. This had been confusing for the participant but since he personally felt he did not have a hearing problem he did not pursue this. Again there was some ambivalence about hearing aids. The participant said that he would quite happily wear a hearing aid if he needed one, but he did not yet need one. He admitted that vanity might influence whether or not he wore a hearing aid but would think about this when the time came. He had very clear views about how hearing aids should be obtained and felt it would be important to get good information from professionals about all the options but then have the freedom to make the choice about amplification.

The audiological results showed normal hearing in the low and mid frequencies in both ears, with a moderate high frequency loss in the left ear and a moderate to severe loss in the right ear. Tympanometry showed reduced movement in the right ear, which would be in keeping with the history of childhood ear infection and operations the participant described. Otoscopy showed bilateral tympanosclerosis. Speech audiometry gave a score of 50% at 35dB HL in both ears.

An appointment was made to carry out the follow up interview but the participant telephoned to cancel the appointment as he was being fitted with hearing aids that day. He attended for the second interview two weeks later and discussed his assessment.

We discussed whether the interview had influenced his decision to have hearing aids or whether there was another reason for doing this. He did not think it was the discussion so much as the assessment that had influenced his decision;

“I think the test did it, when it was suggested that I need them. I needed to do something. It’s never going to be cured medically but maybe technically or mechanically it can help me. The Audiologist said to wear them in my workshop would not be a good idea, and believe it or not the last couple of weeks I have been in my workshop a lot more so am not getting the chance to wear them except at night time”.

COPA 3/Interview 2 /sound file
He explained that the hearing aids did not necessarily make things better just “different” but he had been told that it would take a while to adapt so he was willing to persevere as he had a goal;

“Hopefully within the next two or three months my social life will get better because I would rather not go anywhere because I am laughing with people but I don’t know what they are laughing at”.

COPA 3/Interview2/sound file

Despite having obtained hearing aids he was still using the same communication strategies as before. When I asked him how he was coping in the workshop without them he said that he did not listen in the workshop, he did all the talking that way he didn’t have to listen to anyone. We discussed whether he would have sought help through his GP if he had not been taking part in this study and he thought he probably would have in ten years’ time, he thought the study had been, “fabulous” because;

“I find I have been very fortunate to have had the chance to do this because I would have gone about..... in the office for instance my wife could say something to me and someone would say ‘she’s talking to you’ and it’s got to be a nuisance for them saying everything two or three times I don’t think until you realise how it affects the other person”

COPA 3/Interview2/Sound file

He also felt that there was a lack of services for people who had noticed a hearing impairment but were not yet ready to wear a hearing aid. He described this as a void and felt it would be more beneficial to have services for people that were not linked to hearing aid sales. He gave an example of a well man clinic where a range of medical tests were carried out to ensure good health and asked why hearing and sight were not checked as part of this medical when they were as important as many other bodily functions. He suggested that having the ability to go for a hearing test at a centre that was independent of hearing aid sales might encourage people to go for screening. He also felt this could more effectively be advertised using the media or the internet rather than information at a GP surgery.
With regards to service he raised some points about adequate training and provision. He realised that additional screening would have an impact on NHS services and wondered whether GPs had adequate training to screen and refer and whether there would be enough trained Audiologists to support the referral. He felt that the relationship between patient and professional was crucial and that those giving advice should be skilled and have up to date information, this would create trust between the patient and the Audiologist. Finally he talked about reasons for not wearing hearing aids and he admitted that vanity might play a part in whether or not the hearing aids were worn. He thought that for some people making hearing aids a “fashion” item might work but there were many people like himself who would prefer to have something invisible and felt that when hearing aids became small enough to be invisible people might be more inclined to wear them.

Following his interview I still had some concerns about this participant’s sudden decision to buy hearing aids and reviewed the interviews to check for any direction on my part. As previously stated it seemed that the participant had gained insight from the discussion without it being directive, and while it is inevitable that participating in a situation will influence the outcome I do not feel that either this interview or the participant was directed. I have reflected several times on the reason for this sudden decision and, having listened to the interviews several times, I realised that his was in fact in keeping with the participant’s personality. Throughout the interviews he spoke of other situations where he took action quite spontaneously and I feel the decision to buy hearing aids may be more to do with his personality and his response to the findings from the assessment rather than the interview itself.

5.6.4 Participant 15. COPA 4.
The next participant, (COPA 4), a 77 year old retired accountant, had experienced a sudden unilateral hearing impairment. Seven years ago she experienced a sense of disorientation followed by a facial palsy. An acoustic neuroma was diagnosed, and removed within a short time period. Following removal of the acoustic neuroma she lost all hearing in her left ear. Prior to the surgery she had been unaware of any hearing impairment although her manager at work had remarked that she was not hearing properly. After the surgery a pure tone audiogram revealed a hearing impairment in the
right ear also. She was not aware of the extent of this hearing impairment herself but she felt, that since the Audiologist at the time had said, “It’s up to you if you want to try a hearing aid but you don’t need one”, suggested that the loss was minimal. At the time of the interview she was aware that she was missing out on music and in conversations where there was background noise but had not gone back to the department to request further assessment. She was a very assertive woman who had a stoical approach to life and this, she believed helped her to cope with the hearing impairment without the need for professional help. Again no new categories emerged from the initial interview, but she confirmed some of the earlier categories. She firmly believed that a positive attitude and an assertive stance helped to resolve communication problems. She described herself as a realist and explained;

“If it’s going to happen it’s going to happen there’s nothing I can do about it. In my book you have to face things or you go down”.

COPA 4/Interview 1/L238-239

This stoic attitude did not however mean that she would put up with situations or behaviour that she felt were unacceptable and was active in educating the public and improving services for people with hearing impairment. She described one incident where she felt angry about the attitude of staff in her bank,

“Halfway through the conversation the girl said something and I said, ‘Pardon?’ and she went ‘tut’. I said, ‘Please do not do that in my presence.’ I wrote to head office…. I recently got a nice letter back saying how insensitive and it’s something they are very conscious of because I asked them how much training they got and according to them it’s a big thing in their company but for some reason it didn’t work that day”

COPA 4/Interview1/L42-53

She also described a personal “bugbear” of hers. The speaker who asks, “Can you hear me?” Of course it is evident that if you can hear the question you will confirm that you can hear, but if you did not hear the question you will not respond so no one is going to say “No, I cannot hear you”. She found it difficult to understand why hearing people could not see this caused difficulty and suggested in meetings they ask
everyone who can hear them to raise their hands. She explained that this would give an immediate visual clue to the speaker of those who did not hear the question. She believed these simple but effective techniques needed to be more widely publicised within the hearing community. Although she believed society had a role to play she felt that deafness is a disability that is not acknowledged and felt that individuals need to take control, ask for what they need and educate the public to provide this. She also felt that individuals with acquired hearing impairment should seek out sources of help and advice away from the Audiology department. This may have been related to the fact that she felt the professions had given her no information about anything other than hearing aids and in fact she had questioned the Audiologist at her local hospital about links to Deaf action, a support charity run by Deaf people, and had suggested these be put in place immediately in order to provide a seamless service for the public.

The assessment showed a total loss of hearing in the left ear. In the right ear the low and mid frequencies were within normal limits but in the high frequencies there was a moderate to severe hearing loss. Tympanometry, which was normal, had only been performed on the left side because of difficulties obtaining a seal on the right side, and speech tests indicated that she was able to correctly identify 50% of the phonemes at 40dB HL.

Although she felt she was missing out on some auditory information she did not feel ready to consider amplification and had developed many coping strategies which helped her to manage the loss in everyday life. She was assertive in every situation she encountered and recommended telling people of the presence of a hearing impairment; although she accepted that many people felt they could not do that. She also explained to speakers that they needed to come round to her right side; otherwise she would not be able to hear them. In a bid to control the conversation, which she admitted she did quite often, she would ask closed questions in order to direct the answer. An example she gave would be to ask a friend if they wanted something to drink. Rather than give a choice of drinks she would be more specific and offer one type so that her friend had to answer yes or no. She felt more confident that she would be able to hear and understand a one word answer. Similarly in a shop, if she misunderstood the assistant rather than ask “did you say twenty eight or thirty eight
pence?” She would ask “Did you say twenty eight pence?”, again forcing a yes or no response. She felt strongly that in addition to educating the public, individuals with hearing impairment should seek out services such as hard of hearing clubs, lip-reading and sign classes. She explained that not only were the skills training these classes provided helpful, the social interaction and opportunity to conduct conversations with a variety of people helped to maintain listening skills, and helped people to conduct a social life with people who would understand their difficulties. She herself wore a badge from Deaf Action alerting people to the fact that she had a hearing impairment but she was also aware of health and safety issues. She described a scenario where she booked into a hotel and told the staff that she had a hearing problem and needed to know the drill for fire. Normally this would result in reception staff giving written instructions and taking note that she might need assistance, but in this case the request resulted in her being given a sign to hang on the door that said “Deaf”. She was a bit apprehensive about this and asked the receptionist if she thought it was acceptable to advise everyone in the hotel that there was a deaf person on their own in the room. She was concerned that the receptionist felt the wording was appropriate and pointed out the dangers of advertising this fact to anyone who passed through the corridor.

I realised afterwards that this participant displayed many of the traits I had observed in the Dallas participants i.e. single-mindedness, acceptance and assertiveness. There seemed to be a set of characteristics emerging that influence how patients felt about their hearing impairment and their feelings about services.

5.6.5 Participant 16.COPA 5.
The next participant (COPA 5) was 70 years old and retired. He had had some exposure to noise in his earlier working life, but had realised this would cause him problems and changed careers. He thought he had had difficulty for about five years and explained how he became aware of this;

“How do you know you’ve got hearing loss? Your wife tells you so”.

*COPA 5/ Interview 1/ L38-39.*

He had a very clear understanding of what he thought had affected his ability to hear;
“I’ve a feeling there’s a lot more to it. Mainly in terms of processing speed, because pretty well everybody complains in crowded halls especially in halls with bad acoustics, that this is where they suffer.

COPA 5/ Interview 1/ L59-60.

He related hearing impairment to an ongoing process of ageing which he believed continued throughout life. He explained that he had once been an outward bound instructor but knew that he could no longer do this as he had felt he became less physically able to cope as time passed. He saw this as a natural progression and was something that needed to be accepted;

“Once upon a time I used to be an outward bound instructor. I was too old to be an outward bound instructor in 1979. You know I just couldn’t run up and down a load of mountains ahead of a lot of 18 year olds. So these things come and hit you. But they were there all the way along.”

COPA5/Interview1/L228-237

He viewed hearing impairment as the same process. He was aware that it was around but did not feel it had yet “hit him”, that he needed to make changes in his lifestyle to accommodate it and because of his understanding of sound processing did not feel hearing aids would be helpful to him. Interestingly although he said that the hearing impairment had not affected his lifestyle he did refer to an increase in problems and on some level acknowledged that circumstances had changed. He believed a large part of coping with hearing impairment related to attitude and being fatalistic. He was prepared to do what he could within his own resources and to accept that was doing all he could and had to accept limitations;

“Well there was that famous... that you see on t-shirts and where ever, Desiderata. Where it talks about accepting the things you can’t change and changing the things you can and having the wisdom to know which is which. And so that's about. That's where it's at. Yeah. If, If. You know. If you can’t do something straightforward does something about something then goes do it. If you can’t then you can’t.”

COPA 5/Interview1/L241-252

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Despite this attitude he did admit that if his hearing got worse he may be less likely to socialise and may withdraw rather than wear hearing aids. He explained that;

“Further down the line, I would be more aware of these things. I would be less inclined to go to them, activities where this is likely to be the state. That’s about there. That’s what I would really. I would become a bit more reclusive perhaps”

COPA 5/ Interview1/ L166-171

He was indeed sceptical about the efficacy of hearing aids, basing his beliefs on his knowledge of the subject; however there was also an element of stigma attached to wearing a hearing aid which he described as a “badge of decrepitude”. He found it difficult to explain why this bothered him, and felt it was not related to age or looking older, he felt it was a connotation of disability and found it hard to identify with this. He mused over whether he would become fatalistic about this too and suggested that perhaps if hearing aids were smaller “hypothetically invisible” people would be more inclined to wear them. As he reflected on this however he realised that cosmesis was not the main issue for him, as the existence of an “invisible” aid would not encourage him to wear one. As he explained;

“As I say I tend to be an awkward bugger. The fact that I knew it was there. Would be as important as if somebody else knew it was there”.

COPA 5/Interview1/L339-340

The audiological profile for this client showed that he had normal hearing in the low to mid frequencies bilaterally while in the high frequencies he had a bilateral moderate loss. Tympanometry showed a slightly reduced compliance in both ears, but he had a history of middle ear infections which may account for this. He also had bilateral tinnitus. The result of his speech audiometry was consistent with the pure tone audiogram in fact he could correctly identify 50% of phonemes at 15dBHL. This may explain his concerns about processing speed. He was aware that he could hear speech at normal levels but was unable to distinguish what the speaker was saying. He had correctly deduced that his problem was not related to volume but to processing of speech information. He therefore believed that hearing aids would be of little benefit,
although he conceded that directional microphones might have limited benefit in specific situations.

In the course of this interview I began to see some similarities emerging between this participant and previous participants, in terms of personality and attitude. Although few new codes were emerging within this group, I was aware that a journey seemed to be unfolding that was common to all the participants, the elements within that journey however varied according to their personal attitudes and beliefs, as did the participants’ requirements at each stage of the journey. So, even although two participants were strong assertive individuals their needs differed, and this seemed to be unrelated to the length or severity of the hearing problem. For example this participant and the previous participant were both very assertive informed individuals, but one was still at a stage in the journey where he was ambivalent about whether or not the hearing impairment was affecting his lifestyle while the other had moved from asserting her own needs to becoming active in the process of publicising deaf awareness to the wider community. It seemed that the first individual had not identified with being deaf while the second had taken ownership of this as part of her-self construct.

5.6.6 Participant 17. COPA 6.
The next participant (COPA 6) was a 68 year old retired social worker. She had first noticed hearing difficulties seven years ago when she realised she had to turn the television up louder than normal. She was on medication for hypothyroidism and found that her hearing reverted to normal immediately when her medication was reviewed. Although she felt her hearing was normal at the moment she was not entirely sure and thought participating in the study would give her the opportunity to find out. Her experience in social work had led her to form opinions about society’s role in managing hearing impairment and we discussed this at length.

She described herself as the type of person who liked to keep on top of things, and explained that had her hearing not recovered she would have pushed for anything that would help. At this stage in the interview it transpired that she was the wife of a previous participant. I found it interesting that when he spoke about his wife telling him he had a hearing problem he remarked that, unlike him his wife, would go after every
cure available regardless of cost. She explained that her philosophy was to seek help and use anything that was available to make things better. At this point I asked her if she would have considered a hearing aid and again in, common with many other participants, she agreed that she would try this but with reservations;

“I mean I don’t like the idea, any more than I like to wear glasses, but I would overrule that because I want to be...Yeah..... It would be a nuisance to wear a hearing aid. There would be battery implications. And all sorts of little extra implications, which as you get older all sorts of things, the implications of things mount up.”

COPA6/Interview1/L94-108

She did associate hearing loss with old age, which she admitted was a life stage with which she did not identify;

“Whether your knee is giving you jip today or something like that. And it’s just a constant reminder, don’t bother we’re aging. You know? So you end up without being able to do things absolutely spontaneously and automatically certainly I think it’s a cumulative thing as you get older It’s one of the things that you don’t realise is going to happen to you. Oh it happens to everybody else. But oh no, I’m not going to get old”.

COPA 6/Interview 1/L110-120

She spoke about approaching the professionals for help and advice and felt that it was important that the professionals understood that individuals would approach deafness in different ways, and were empathic during the consultation. She related this to her experience with medical staff during the episode of deafness she had experienced seven years ago and worried those doctors might not take this seriously;

“That would be my ultimate frustration. Would be if they said oh well it’s not really that bad. You don’t really need this. My frustration would come at that point. I think it is very important, I think that people… It doesn’t matter what you’re talking about..... People’s reactions
are very different. It might impinge on others. But from where the individual is I think there is a complete difference in how people will respond to it. And erm I think it's quite important that professionals pick up on where the person is at. You know. And don’t just say oh it doesn't matter. Or it's not very important”
COPA6/Interview1/L136-155.

We explored this further and the subject of whether doctors should rely on tests results or individual’s feelings about their hearing impairment was discussed. As a social worker she felt that doctors needed to approach information giving sensitively and explained;

“It probably, If you have test results it’s probably quite important to bring them to somebody’s attention that this is the situation. As much as it can be an objective test, but having said this is the situation and maybe not to go like a bull in a china shop to say that it is the situation. Or maybe to go at it slightly from the other side, and going and saying how do you feel about it?”
COPA6/Interview1/L173-179

The role of the medical staff in explaining the tests results might lie in confirming hearing impairment, or making patients aware that their hearing was not as acute as it once was, but she felt this needed to be done in a way that supported the individual and helped him come to terms with the issue;

“If you’ve got somebody and other people in the family are saying, ‘Oh for heaven’s sake dad, you’re not hearing’. He’ll say, ‘Oh yes I am fine.’ It needs somebody from outside to say, ‘Well actually your results haven’t been that brilliant, and it might be helpful if you consider such and such’ or whatever”.
COPA6/Interview1/L191-194.

She stressed the importance of addressing concerns in the early stages rather than being dismissive of a mild hearing impairment, and felt that the GP did in fact have a role as “gatekeeper”. A role that was important enough to influence patients’ decision to seek treatment;
"If you come to first port of call -might well be a GP or somebody if you are going. And if they are a bit dismissive or even that might be in a sense almost a block about whether you might bother to pursue it any longer. Or wait a time. If it’s not too you know too extreme a problem. You know erm. It might be quite extreme. They might be in a fair amount of denial about the whole hearing aids thing.”

COPA6/Interview1/L211-216

I asked her why she thought people who had noticed a hearing impairment did not decide to try hearing aids and again the issue of a cost benefit analysis was raised. Having no experience of hearing aids she compared this to contact lenses;

“How much are you actually gaining by doing it? Unless you’re going to get the gain, you’ve got to get the gain from a hearing aid or whatever before you’ll really feel it’s worth having. Until it’s seriously inconveniencing them, it’s got to go over a certain level, level of erm incapacity as it were.”

COPA6/Interview1/L230-234.

We also discussed ways in which hearing aids could be made more acceptable and she thought this would only happen when they had a different image, although she remarked, “I don’t think anybody’s going to wear a hearing aid for fun, are they? She felt the image of hearing aids was poor, and that people felt they were bulky, unattractive and implied disability. She did not see this image changing though as there did not seem to be the will to explore this;

“Nobody as far as I know has made a fashionable hearing aid. …..Most people that I know you could say it’s a vanity thing. But that’s down to what they look like and all the rest of it….. I’m not fashion conscious and never have been. But er I think yes it would make a difference to me. If it. If I haven’t got to wear a lumpy something rounds my ear.”

COPA6/Interview1/L253-280

Again she made the comparison with glasses and hearing aids, and pointed out that the image of glasses had changed from when she began wearing them to a more fashionable item in her granddaughter’s case;
"I mean my granddaughter has already started wearing glasses and she, I know when I started wearing glasses I really thought oh this is awful. In fact she's 7 and everybody's made her think about oh you've got a lovely pair of pink glasses. And she seems to be happy as Larry. You know. But I don't know whether. It would be a much more difficult ballgame to try and get her to wear, if she needed it. But a hearing aid would be much more of a performance wouldn't it?!

COPA 6/Interview 1/L305-313

This participant felt that a lot of the difficulties with adapting to hearing aids arose from the delay in obtaining hearing aids. Given that hearing aids were more complicated than glasses she felt individuals needed to source these at a time when they have the manual dexterity and perseverance to acclimatisie. Again she related this to her experience with glasses;

"My feeling is it probably is. My feeling is. But I think one of the other problems is that it's that they're not as straight forward, again from my experience. It isn't straight forward. You don't get a prescription plonk it on your nose smashing. It's all a bit more high-tech than putting a pair of glasses on!"

COPA 6/Interview 1/L285-297

She felt strongly that there was a need for support in the early stages of hearing aid acclimatisation to ensure that older people were able to access help and advice to deal with this new technology. She felt this needed to be carried out as a matter of course to allow the Audiologist to gauge the progress rather than rely on patients reports of their progress, she explained;

"It gets more difficult you know. Whether you're talking about learning on computers or whatever you're talking about. It's something which I think that this may be a bit of a problem is. That when they are prescribed. Somebody whatever they are like to look at or however good they are. Somebody doesn't really spend a lot of time. Or get a review or they're getting on with it or coming back for it. A wee time coming back and having a look at it and how've you been getting on. People
The role of the GP in the process of rehabilitation was discussed, in particular provision of information in the surgery. This participant raised the issue of the amount of information available in the surgery and whether anyone actually took notice of it but she did feel that identification of hearing impairment and appropriate information and advice needed to start before the hospital assessment and thought this should be partly in the domain of the GP;

“I think we have information overload. I mean I know it’s very good to go to a surgery and you’re sitting waiting for your appointment and you can see leaflets for everything. You can see MS society, doesn’t matter what and I mean I think well I just switch off.”

COPA 6/Interview 1/L367-372

She believed the GP surgery was a good place to start the assessments, perhaps even in an informal way, in order to prevent unnecessary hospital appointments and felt the GP was in a position to do this as they had the role of “gatekeeper”; by providing an initial assessment the GP could then give advice on management of mild hearing impairment without the need for further referral. The issue of whether the GP, would be sensitive to the impact of mild hearing impairment on the individual was raised;

“I don’t think it’s going to be a huge amount of help to send everybody, every Tom, Dick and Harry to a specialist. It just won’t cope. But it might, at that point be worth saying something like if you are having a bit of difficulty you might just. You know. If you think it’s a problem, acknowledge it’s a problem to other people. And say yes speak a bit louder”.

COPA 6/ Interview 1/ L439-444.

The role society has to play was also raised as an issue for this participant. She also believed that society did not acknowledge the impact of deafness and was unprepared to deal with his, partly because of a lack of deaf awareness and partly because she felt society hides the problem. She explained how in the past children with hearing
problems were often removed from mainstream education and this meant that, in general people, could exist without having contact with deaf people. Consequently they did not develop the skills to recognise this in others until the experience became personal to their family or friends;

“Where you’ve got children, it was historically the thing to put them into Deaf schools and they’ve been withdrawn from the mainstream of society. But erm. And you’ve got the communication problem with the people who have……. who may have been taught reasonably well but have got an impediment before getting into full life. But who have got that bit of contact, sort of thing. But in a sense it’s mainstream or nothing”.
COPA 6/Interview 1/L524-529

Interestingly, although this participant denied any hearing impairment at the present time, and could not think of any situation where she had difficulty hearing, the audiological assessment showed a mild, slightly asymmetrical high frequency loss, the left ear being slightly worse than the right, with a reduced compliance in the right ear. There was a 20dB HL difference between the speech reception thresholds with the right ear being at 20dB HL and the left at 40dB HL

5.6.7 Participant 18. COPA 7.
The next participant in this cohort (COPA 7) was a 77 year old retired office worker. He felt his hearing was generally good but not perfect and had noticed it had been gradually deteriorating over a two year period. He did not think he had had to make adjustments to his life but remarked that his wife thought that he now spoke more loudly and turned the television up too loud. Deafness seemed to have made a significant impact in their relationship as his wife wore a hearing aid and there seemed to be a lot of blaming going on. For example he explained that he used his wife as an excuse for some of the adjustments he made to cope with his own hearing loss;

“Although when I speak on the telephone she tells me I’m speaking far too loud. She keeps telling me to lower my voice.
When I play that (the television) I need it louder than my wife when she comes into the room but her sort of
He blamed his hearing impairment on age and again was quite fatalistic about it saying “When you get to my age you should be thankful there’s not much wrong with you”. He went so far as to say it should be getting worse at this age, almost as if this was an inevitable part of life.

In the course of this interview no new codes arose but several of the earlier codes were again confirmed. The participant’s circumstances, given his wife’s recent diagnosis of deafness, meant that he was experiencing the issue not only from the individual’s perspective but also from the perspective of the significant other coming to terms with changes in his relationship with his wife. He explained that communication often broke down, with him blaming his wife for not hearing him when he asked a question, and his wife blaming him for not hearing her reply. Despite this change in their life style he had not personally sought help from Audiology services and preferred to make changes in his behaviour to accommodate the hearing loss. He was in fact still unsure if his hearing had deteriorated as he had not been assessed and did not trust his own judgement in this matter. Despite the fact that he was aware he was missing out on conversations, he still wondered if perhaps he was wrong in his assumption that his hearing had deteriorated;

“I attend quite a few meetings and I, I find that if I’m sitting alongside someone and I can’t see their lips and they’re not pointing at me it has an effect. So I usually try to sit opposite the people who are likely to be doing a lot of talking. Erm whether that’s.. whether that really does any good I don’t know. But logically I feel that in order to hear everything that’s going on at a meeting I position myself to see the person who is likely to be doing most of the talking. And it may be that er that there isn’t any evidence to prove that my hearing has gone but I just have a feeling that it’s. Or maybe it’s a wrong feeling.”

We explored whether this uncertainty had prevented him accessing help from Audiology services and he explained that he thought he had not pursued this because he had “probably been too busy doing other things”. He explained that he had other health
problems that he felt he had to prioritise, for example arranging an eye test, and thought that most people keep putting things off until they have to happen. He seemed resistant to have his hearing assessed and when he went on to explain his experience of his wife’s assessment and acclimatisation to hearing aids, which had not been positive, and I wondered if this might have had an influence on him. In fact I noticed he was resistant initially to discussing this, and pointed out that although he had accompanied his wife on her visits to the department he had not participated in the consultation and had not discussed these with his wife. He therefore “did not know enough about it” to decide whether he should attend for assessment;

“I was only aware that you know it seemed to take a while that she was away and when she came back she didn’t tell me a lot of detail about it. So no I don’t really know what would be involved. But it doesn’t er frighten me as much as er perhaps some er visits to the hospital would but I haven’t thought about it yet she had some sort of advice, I suspect not very technical or very authoritative advice that it would never get any better and she just accepted that.”

COPA 7/Interview 1/L116-132

This experience of Audiology services seemed, from the participant’s perspective to have impacted negatively on his wife, preventing her from seeking further help immediately. This led to a discussion about the participant’s opinion of Health Services in general,

“I think that evidence, in inverted commas, has put my wife off having anything done at all. It’s only when er. In the last year that she’s thought about having her hearing assessed and I think eventually her GP did persuade her to go to see the Audiologist, and as a result she’s got a hearing aid that she’s still getting used, still trying to get used to it”.

COPA 7/Interview 1/L137-143

I thought it was interesting that the participant drew parallels about his hearing to his eyesight and his damaged knee. Although he said he would wear a hearing aid if necessary, he also said that he wore eyeglasses as soon as he became aware of a problem, and carried a stick to help with his knee. He explained that he did not need
the stick but carried it just in case, yet he felt he had a hearing impairment but had not acquired a hearing aid. Although he was not in denial about the hearing impairment he was still ambivalent and I wondered if he was resistant to wearing something that would confirm a hearing impairment. I remarked in my reflective notes that I wondered whether he had not requested an assessment because he was not yet ready to accept that there was a hearing impairment. His comments about his reasons for participating in the project seem to infer that he was beginning to move towards doing something about the hearing impairment and in fact was looking for something to “push” him towards this;

“Well one of the things was when I responded to the invitation for this project, this research project. I thought well this is an ideal opportunity to find out something about it. And if I do need some attention it’s a prod. It’s a way of forcing me down that path that I. If it had been left to me I would have waited till I sorted out any problem with my knee and thought about it later on”.

COPA7/Interview1/L180-185

This led to further discussion about the provision of services for rehabilitation and this participant also talked about the value of screening services. He felt that most people, himself included, tended to put off doing something until the problem became impossible to manage. He alluded to the fact that people were often in denial and where other people highlighted there was a problem they would either suggest they were mistaken or use delaying tactics to prevent being pressured into doing something. However he felt that if a screening service had been available he might have made use of that. As with the previous participant, he also expressed concerns about the feasibility of such a service given the numbers, and whether the services would see this as a priority and publicise this effectively. He was unsure as to whether the public in general would find it useful;

“But I should mention that the cost of such a thing would be high. It would be factored in somewhere because I’m sure it would cost a lot of money But perhaps hearing loss or perceived hearing loss wouldn’t be high on the list but erm again it’s erm health service communicating to the general public. I think they play lip service to that and would like to do it
better but I don't think they know how to do it better. My personal feeling would be if I'd. If it had been brought to my attention that there was a screening clinic available at my local surgery I would have gone to it earlier. I'm not so sure that that would be the feeling of the general public. I doubt that.”

COPA 7/Interview 1/L193-232

This participant had very strong feelings about the role of the Audiologist and the relationship they should have with patients. He felt that an empathic relationship was important and that the quality of the relationship would affect whether he used the services. In keeping with the participants from Dallas he felt that the way in which the Audiologist approached the patient was important in providing a good service and that it was important that the patient saw the same Audiologist on each visit in order to build a rapport with that person. He felt patients should have choice of Audiologists where they felt the relationship was not working although he felt that some patients might abuse this,

“Erm only the attitude of the people who were trying to so call help me. If they were (pause) I think an Audiologist I suppose should be the same as a doctor. It should be a calling. They're doing it because, not because it's just a job, because they feel they are providing a service that can help people. Now maybe everybody is like that. But I would weigh that up first. And if, if for instance I went to get a hearing aid and I was put off by the attitude of the person I'd not go back.”

COPA 7/ Interview1/ L346-352

With regards to hearing aids, he had not thought much about this. He saw this as something he would have to consider at some point in the future but had not sought out information and most of his knowledge was based on his wife’s experience. He felt it was important that the hearing aid was small and unobtrusive, and adaptable to different situations. He felt more work needed to be done on hearing aids to make them more acceptable but thought that there might not be the money to do that as it was not seen as a priority.

His pure tone audiogram showed normal hearing in the left ear at the low to medium frequencies with a mild to moderate high tone loss. In the right ear he had mild loss in
the low to moderate frequencies with a mild to moderate loss in the high frequencies. Tympanometry could not be done because of the presence of wax in both ears, but speech reception thresholds correlated well with the pure tone thresholds. In the second interview we discussed this assessment and what it meant to him. He said he thought it was what he had expected and had not done anything with the results. He was ambivalent about taking any action. He said he thought he should take advice but did not think the results warranted that, and in any case he did not understand them but felt that his hearing was not a problem “for his age”. He did say that if he had an opportunity to have this done at a GP or a pharmacist he would have taken it but he was unsure of whether other people would. This led to a discussion about why people delay seeking help when they suspect they have a problem, and this participant felt it was because they were;

“Too busy or don’t think it’s important- or maybe they don’t know it’s broke!”

COPA 7/Interview 2/sound file

He also felt that communication was much more than hearing and thought this confused the issue for most people, so much so that they did not realised their hearing had deteriorated. He explained;

“Its concentration, If I am listening...fine if I am doing something (raised his hands and shrugged) Maybe it is age related… separate parts of the brain you need time to think about...you think you heard it but you miss one bit because you are concentrating on the last bit”.

COPA 7/Interview 2/sound file

Given this, he felt it would be beneficial to provide services other than hearing aid provision, such as communication training, not just for the individual with hearing impairment;

“It would be useful particularly for my wife, she doesn’t accept it’s her hearing she thinks it’s my speech etc. Training in communication, perhaps we could be better trained in speech.

COPA 7/Interview 2/sound file
He also recognised that this would be costly and queried whether widening access would be good value for money. He had noted that the NHS had tried to do this with other services by creating Community Health Forums but his experience had been that the information only gets to the people who were interested and, “flooding the markets with leaflets” as he put it, would cost money. He thought it might be more effective to provide access to simple screening tests. He described a conference for older people where screening tests for high blood pressure were offered and found it was very popular, although this conference was designed mostly for older people so he was not sure if this would reach younger people.

Again the issue of the individual's perception of deafness and hearing aids was discussed. He told me that his wife did not wear her hearing aids if she was going to a “classy place” Despite the fact that she has long hair that would cover the hearing aids she preferred to suffer rather than wear them. He personally couldn't understand this but realised that many people felt this way. He believed hearing aids had a bad image and this prevented people from wearing them.

He also noted that he felt society did not play its part in improving listening conditions and cited an old music hall joke about listening in a railway station. Despite the fact that this had been the subject of many jokes over the years no one had taken steps to improve the quality of sound in railway stations and he wondered why the public just accepted that this happened rather than trying to improve the situation. He believed society should make fewer assumptions and again described the same scenario as the previous participant where the speaker asks, “Can you hear me?” He felt more information should be provided about how help can be accessed. He felt that this would help everyone not just those with measureable hearing impairment as he was sure that most people struggled to communicate in some circumstances. He was however sceptical as to whether there would be enough influence to make this happen, as most people do not think communication is important until they have a problem. He also thought there needed to be legislation to enforce these changes, citing an example of the level of music in some shops, he asked when that became noise pollution. He felt the only way to change things would be a combination of educating people in
general and providing good information for people with hearing impairment. However he was not confident of immediate success;

“\textit{It will be a long road before people listen, you will be battering your heid off a brick wall for a long time}”
\[\text{COPA 7/Interview 2/sound file}\]

Despite these reservations he felt that hearing was more important than people realised and in some conditions could cost someone their life, a concern that he felt should be raised with NHS management. Therefore he felt it important that there be more screening opportunities at accessible locations so that people do not have to seek these out and disrupt their routine. He went so far as to suggest that people should be offered free gifts in order to motivate them. He felt these should not necessarily be part of the health screen offered by GP as he was unsure if they would be the best people to provide this service, he said;

\textit{\textquote{I go to the well man clinic but my hearing is not tested he never asks about my hearing or sight. There is only so much they can do in ten minutes- and my doctor is standing with the door open in 9 \(1/2\) minutes!}”}
\[\text{COPA 7/Interview 2 sound file}\]

5.6.8 Participant 19. COPA 8.
The next participant (COPA 8) explained that she did not have any hearing impairment but had come along to take part in the study because she wanted to help. However she very quickly described three scenarios where she experienced difficulties and like other participants described a mixture of maladaptive coping mechanisms and rationalisation to cope with the situations.

The first scenario involved the volume of the television when family visited. She admitted that they told her the television was too loud and when they turned it to a level they found comfortable it was difficult for her, but she insisted that she could hear it; it was just not at the level she wanted.
The second scenario involved hearing in crowds. She did not like to have conversations in crowds and said that she now avoided situations where she would be with more than one or two people because life was much easier if you avoided crowds and anyway it was “no hardship”.

The third scenario was talking on the phone but again this problem was caused not by hearing impairment but by people’s accents which were difficult to understand. Having discussed this she then seemed less certain that she had normal hearing;

“I haven’t actually noticed any difference in my hearing. Erm but perhaps there is. I don’t know. No erm. Having said that I would qualify that by saying that when the family come to visit. Er they do tend to have the television slightly lower than I would have it”.

COPA 8/Interview 1/L9-16

Until this point she had not considered seeking help for her communication difficulties but did feel when the time came in the future she would seek a solution, until then she did not intend to think about it. She did say that when she decided to seek help she would rather, “read up on it than consult a professional as there were many sources of information available”. When asked if better information in a GP surgery might be helpful she commented;

“But then you see you’ve got to be somebody who goes to the GP in order to get that. If the rest of your health is fine, how many times do you go? Once in five years sort of thing?”

COPA 8/Interview 1/L290-295

At the present time she felt that the only option was a hearing aid and while she said she could not see any reason not to wear one, she expressed some reservations, explaining that when she was with someone who wore a hearing aid she became embarrassed for them when they had difficulty operating it and hoped that something much better would come along by the time she needed one. This reminded me of one of the earlier participants from Dallas who had tried hearing aids several times but kept putting off the final purchase. She too kept hoping that something better would come along and did not want to make a decision about hearing aids until something better
was available. This participant felt that at the present time she could think of no reason not to wear a hearing aid but suspected when the time where having to wear a hearing aid became a reality she might feel more awkward about it. We discussed what, if anything would encourage her to seek professional help if she reached a point where there was a problem, and she immediately said she though it depended whether other people were involved;

“Well you see this is the whole thing. I am a widow and my family is all away and married. So I am living by myself. I think if you were living with somebody else you should do something about it quicker, because it can be an annoyance to other people which you don’t realise.”

COPA8/Interview 1/L185-188

Again this participant felt that society should be involved in managing hearing impairment and changing attitudes. She felt information should be more widely distributed and that we should look at other people’s experiences and be more open about deafness so that wearing hearing aids became a way of life, similar to wearing glasses. She thought this might be helped by the introduction of designer hearing aids as designer glasses had helped to change the image of sight problems. She believed the image of hearing impairment and hearing aids had to change, and gave an example of how people were content to wear blue tooth devices and iPods in their ear but were reluctant to wear hearing aids and thought that must be because of how society views deafness.

The audiological assessment showed that this participant did in fact have some degree of hearing impairment. Although she had normal hearing at the low to mid frequencies she had a moderate degree of hearing loss in the high frequencies. Tympanometry was within normal limits in the left ear and showed a slightly hyper mobile tympanic membrane in the right ear. Her speech reception thresholds correlated well with her pure tone audiogram. Unfortunately this participant could not attend for a second interview for personal reasons.
Participant 20. COPA 9.
This participant (COPA 9) was a 63 year old retired receptionist and telephonist. She had first noticed difficulty hearing in crowded situations about seven or eight years ago and had been assessed at that time by a private Hearing Aid Dispenser who told her she did not need a hearing aid. She had no record of that test result. She was still unsure as to whether she had a hearing impairment. She was aware that the TV was loud according to her son, but felt this was a fault of the television rather than her hearing. Where she did notice a difference was in the meetings she attended, however the experience she described seemed to be a consequence of a group of conditions not all of which related to hearing. She described being in an almost constant state of stress with many things annoying her. At first I thought she meant because they made it difficult to hear, but this was not the case. It was difficult to separate these out and decide how much of her problem was attributed to hearing loss;

“Er at meetings, if there’s a lot of people and we’re sitting at the back, you’re sitting at the back. Or, if it’s a noisy meeting. Er and I get missing. And I get quite crabby, because I’m missing bits because there’s volume or speaking and also I find that sometimes if we’ve got a meeting and it’s breaking into work groups and there’s about ten here and ten maybe there.”

COPA 9/ Interview1/ L36-41

It seemed initially as though she was describing a situation where background noise was making it difficult to hear which in turn made her irritable but then she continued;

“I said my coffee’s cold. Mind you, you made that coffee about half an hour ago. Of course it will be cold. It was my fault I said I shouldn’t have left it there. Erm... with the fan going on. The fan’s cooled it. And then it ended up wasted. And I don’t like fans. Well what a long roundabout way of saying you want the fan off.”

COPA 9/Interview1/L95-100

Her coping strategies were also linked to an array of issues, and she seemed unable to separate these. She admitted she was often seen as aggressive rather than assertive in addressing these problems. She said her normal method of coping was to “Give them
dagger looks,” although she did try, not always successfully, to adopt an assertive stance;

“Erm if I’m trying to be polite. And if I’m, I’m not being polite I’ll say will you be quiet please? Shh! But then you’re making as much noise telling them to shush. You’re still missing what’s being said.”

COPA 9/ Interview1/L70-75.

Despite these frustrations she did not want to stop going to meetings as she felt she had a limited social life and these were important to her. During the interview I was aware that this participant had difficulty concentrating on any particular topic and would often digress into a new topic in a way that made it difficult for her to focus on the question. She spent some time telling me about her fear of men who raised their voices and thought people saw her as stupid. She did however return to the subject reasonably quickly and told me her views on hearing aids. She said she had been influenced by stories of people struggling to use them and felt she would not be confident enough to wear an NHS aid which she viewed as large and bulky. She would prefer to wear a private one but could not afford this. However she was prepared to try to source funding either through a loan or payment plan rather than wear an NHS aid. There was again evidence of a cost benefit analysis as she talked about being happy to go for a hearing aid when the time was right providing she could have the type of hearing aid she wanted, but also said that if the hearing loss interfered with her social life she would “swallow her pride” and take whatever helped. She felt her own experience made her very aware of conditions for other people with hearing impairment. When she chaired meetings she insisted that all the necessary equipment be made available and used efficiently by speakers. She always insisted that loop systems were checked and that speakers provided notes in advance. Despite this she admitted that people with hearing aids annoyed her because they “took their time setting up their hearing aid to get it working with the equipment” She seemed to have a preference for adapting the setting rather than relying on personal amplification and recounted a story where she had argued with a speaker who was not accommodating;

“I had an argument with somebody at erm XX University teaching hospital. Somebody was giving a lecture and I said, ‘have you got this presentation in a hand-out copy?’ She said yes. I said,’ Well can I have
This participant had strong feelings about the services that should be available. She believed that pride prevented a lot of people from admitting to a problem and that if screening services and advice were available in the local community it might encourage people to go along for a test;

“Get people to realise that they go to a health person for early intervention. You do screening tests for everything else. Why do you not sort of do, even a pilot for a screening test for audiology?”

Community settings seemed to be quite important to this participant and as with an earlier participant she felt opportunistic tests might be more accessible particularly to busy people at specific Audiology centres. This would allow people to take control, another concept that was important to this participant;

“You pop into when you do your shopping…. You’re doing your shopping anyway. Maybe you’ve got time to kill. Or you’re waiting for… you’ve chummed somebody down and you’re waiting for them to finish they’re shopping you could nip in and you could say can I get a quick test for my hearing?”

She linked this lack of control to stigma and explained that unlike difficulties with vision where people can rely on notes, hearing impairment means handing over some of the control quite publically to someone else;

“And there’s not so much a stigma with wearing glasses as there could be a stigma with having a hearing aid. Because glasses you can take them off
put them on and you just request for could you get that in bigger print for me. Or could you enlarge, if it's a presentation. Is there anyway on the screen to enlarge that? Focus it a bit better. But with hearing you've actually got to admit to the whole room I've got a hearing aid. I've got a, a, a problem. Or I've got something that... that my body isn't perfect, and you've got to come out to a room full of people sort of saying, “Yes I've got a hearing problem”. And to some people that might be just a step too far.

COPA 9/Interview1/L771-780

Society’s role was also discussed. As this participant felt it was necessary for everyone to think about optimal communication, for example, by using microphones regardless of whether anyone asked for them to be used, and ensuring all equipment was automatically switched on and checked before any gathering. She explained that she often reviewed evaluation forms from her meetings and noted that people often complained about the acoustics. She felt that was unacceptable and remarked;

“Somebody’s struggled…and that to me in this day and age shouldn’t happen.”

COPA 9/ Interview1/ L841-842

Following the interview I made some notes as this had been a difficult interview for me. I found it difficult to keep this participant on track and questioned her motivation for taking part in the study. She appeared to be an extremely stressed anxious individual who easily lost her temper – perhaps because of the level of stress she experienced. She did tell me during the interview that her son had recently been diagnosed with autism and their communication was very difficult. He blamed her hearing impairment for this and she blamed his pedantic style of communication. I noted that I felt this participant had very little evidence of hearing impairment in conversation, but did spend most of her time serving on committees with professional members, and had expressed fear of being thought stupid. I wondered if she felt insecure and, as someone for who control was very important, lacking in control over her life. In any case I was concerned that this participant might need counselling and aware that I would have to be vigilant in the interview to ensure I maintained appropriate boundaries throughout the process.
The audiological assessment showed normal hearing up to 4 kHz in both ears with a mild high frequency loss in the left ear and a mild to moderate high frequency loss in the right. Tympanometry was normal in the left ear with a negative pressure on the right. The speech reception threshold on the left ear was 20dB HL and in the right ear 25dB HL. She also complained of positional vertigo and thought she might have had mastoidectomies as a child, but was unsure. Otoscopy showed some scarring in both ears with a small retraction pocket on the right; this was consistent with a history of childhood infections.

In the second interview the participant thought that the hearing assessment was what she expected. She said that she believed that her hearing was poorer when she was tense and felt it was better now that she was not stressed. She admitted that noise irritated her more when she was stressed. She said that she was quite relieved with the outcome of the assessment which confirmed that her hearing was fairly good and that she didn’t need a hearing aid. She admitted that she had considered cancelling the second interview following her assessment in order to go to the bingo!

Her one remaining concern was about hearing in noise. She admitted that when there was background noise speech was “useless”. She still felt she got angry quite a lot because she took on the role of the assertive person in the group who would ensure communication was effective. She said she would not mind taking on the role if it did not make her so angry. She also talked about her anger towards her son when he, as she experienced it, “accused her of being argumentative”. It was clear this participant felt that others did not attempt to communicate well with her and explained that her concentration was poor, and if people did not get her attention before speaking she would miss out part of what they were saying. This would lead to her losing her temper and feeling she needed space from them for a day or two before trying to mend the relationship.

It was clear that this participant was extremely stressed today and talked only about her son. I was aware that this was no longer an interview but that the participant was trying to confide in me. I felt it was inappropriate to continue with the conversation and I felt I had to be congruent with the participant and share my concerns. She admitted that she
felt she had gained everything she needed from the first interview and the assessment and admitted that she felt she needed counselling to address her stress and anger. She said she found me easy to talk to and had used the opportunity of having someone listen, to offload some of her concerns. She did however appreciate that this was not the purpose of this interview and was happy to bring the session to a close. She confirmed that she did not have anything more to add to the study. It was difficult to bring this to an end. I still had a feeling that the hearing impairment, although minimal, had significance for this participant. However she was not able to express this and, on reflection, ending the interview was the most appropriate thing to do.

5.6.10 Participant 21, COPA 10
The next participant (COPA 10) was a man in his early fifties who worked as an information officer designing websites. He had first started to notice difficulty communicating five years ago. At first he noticed that he needed the TV louder than the rest of the family, and then realised he had difficulty hearing in background noise, although he said he had no difficulty hearing work colleagues, He felt things have been gradually getting worse and he now has to make more effort to listen.

Although no new codes emerged from this interview, several of the codes identified earlier were again confirmed. He described his hearing problem as a “function of age,” a view his GP had confirmed. When asked why he had not yet sought help for this he stated that, “I think I find things a little irritating but am not yet aware of having to adapt activities” Despite this he explained that he had been using coping strategies such as getting close to people when he wanted to have a conversation, particularly in background noise. This would suggest that he may not yet have accepted that he has a hearing impairment even though he is adapting behaviour to ensure meaningful communication. On the subject of hearing aids he stated that wearing these would not be problematic

“I don’t think I would be bothered if they enabled me to hear. The choice of, you know, not being able to hear correctly and the... er... unsightliness or whatever of a hearing aid. The former ...er... outweighs the latter, or it would do for me”. COPA 10/Interview 1/L113-119
This comment was interesting because it demonstrated the participant's feelings about hearing aids, i.e. their unsightliness, and also reinforced the views of earlier participants that they would wear aids if they needed them. Reflective notes following this interview made the following observation:

Several participants have now alluded to the fact that they would wear hearing aids if/when they needed them. The interesting thing is that they have all remarked on the fact that they have noticed a change in their hearing and have developed coping strategies, but do not feel hearing aids are needed yet. Is this because they do not see themselves as someone who is deaf- this being something that will happen at a later stage- but rather someone who is having difficulty communicating in social situations for other reasons? I wonder if it might be beneficial to the study to ask the participants directly whether or not they felt they had difficulty hearing or communicating. This could then be compared to their audiometric results to see if there was a correlation.

Memo following COPA 10 Interview 1

This participant also admitted that he knew very little about hearing aids and in his mind saw them as “The 1948 version” He felt that information on hearing aids was not widely available and this might be part of the reason why many people did not come forward for help;

“From the patient’s perspective it is the fear of the unknown and the image you have and, er, also the admission... the fact that if you are going to get a hearing aid you are going to conk out. I think it is probably quite challenging for people who don’t want to do it- and I’m one of them.

COPA 10/ Interview 1/L138-144.

This led to a discussion about how individuals might access information and this participant felt that Audiologists needed to “market” their services more appropriately in order to encourage individuals to make use of services. He felt that information in GP or hospital waiting rooms was of limited use. He explained,
“I am a man in my fifties and I have no illnesses, so how often would I be in a doctor’s waiting room? And if I did go to see the doctor about my hearing it wouldn’t be until I reached a stage where I felt I had to have a hearing aid. I am more likely to see information if I am in my local leisure centre or library- and the information would need to be about hearing rather than hearing aids for me to take notice.”

COPA 10/Interview 1/sound file.

He felt that Audiology was not well known and that Audiologists needed to explain about other techniques for helping people cope until they needed a hearing aid. He also suggested the profession needed to review how it circulated information, for example using websites to offer information about taking care of hearing and useful communication strategies.

After his audiological assessment was completed, the participant was interviewed again and his results were discussed. He admitted the results surprised him, he felt that his hearing was better than the results had suggested. On reflection he did feel that he was beginning to accept the results, despite the fact that he had been told he had a hearing impairment, he did not think wearing a hearing aid was necessary. This contradicted what he had said in his earlier interview and again suggested that the decision to wear hearing aid/s may be due more to the impact on the person’s life and their beliefs rather than the results for audiological tests. This participant confirmed his belief that there should be more information about services other than hearing aids so that individuals could make informed choices at an early stage.

At the end of this interview a very productive discussion confirmed many of the early codes, however again no new codes emerged. It seemed that saturation had been reached. Although this was clearly the case from re-reading the interviews, it was a difficult decision to make. I reflected on this and made the following notes,

“During the last few interviews I am aware that I have felt uneasy. I have been frustrated about the fact that no new data is emerging but anxious about stopping the interviews. On reflection this is because of my anxiety about missing a significant piece of data which has caused me to think I should
schedule more interviews. However having taken
time out to think about this and review the data and
the literature regarding Grounded Theory it is clear
that, if examined objectively the data has reached
saturation and it can be assumed that no further
interviews are necessary for the purpose of this
study.

Memo 1 on saturation.

Although confident of this decision on the basis of the data obtained, I was also aware
that there were many areas that could be explored further, however these were not
directly related to the aims of this study and it was felt that these should be noted for
further studies, rather than explored at this stage because this additional information
might remove the focus from the main theory.

5.7 Focus groups themes

Two focus groups were also organised at Queen Margaret University during a COPA
conference. Participants in the study were invited to take part, as were their relatives
and any conference participants who had an interest in the subject.

As previously discussed, the Ida Patients journey tool was used to capture the data (Ida
Institute 2014). Each of the focus groups lasted for one hour and was facilitated by
myself. The main categories identified were pre awareness and becoming aware.

These fitted with the earlier categories identified in the interviews.

5.7.1 Pre-awareness

In this category family members expressed frustration that they could tell their relative
was having difficulty hearing, e.g. when listening to TV or on the phone, but were
unable to make the relative see that there was a problem. Participants expressed
frustration with their families who they felt over reacted to the situation and pushed
them into seeking help, albeit grudgingly. The following conversation took place
between a participant and her daughter;

“Mum, we are just trying to do what is best for you, you
are missing out on so much and it’s really hard to have
a conversation with you,”
“What is best for me is if you stop going on about
it, I am fine,”

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“You are not fine mum, you don’t hear me on the phone and your television is so loud the neighbours can hear it. You have got a problem and it is driving me mad,”
“I’ve not got a problem- you have!”

Focus group 1

It was clear from the body language and responses in the room that many of the participants related to this conversation. Although very little was said, the eye contact and wry smiles between participants and their relatives suggested this type of conversation had taken place frequently. This type of conversation is frequently observed during the clinical appointment and there seemed to be a similar dynamic here. Just as in the clinic setting the relative seemed to be taking the opportunity while a third party was present to express their anger or frustration while the participant (or patient) played down the impact of the hearing loss. In fact when reviewing the interviews of participants who had taken part in the focus group, it became clear that while they had been happy in the individual interviews to discuss the impact of their hearing impairment, they tended to deny problems when their relative tried to bring it to their attention. This has implications for rehabilitation programmes as dynamics between family members can influence outcomes.

Managing the hearing impairment or adapting to the situation was also reported by significant others who felt their relatives instinctively coped with their hearing impairment by reducing their social circle and only communicating in situations they could control. One of these coping strategies was rationalisation. It was felt that individuals rationalised their actions and participants were not sure whether they were consciously doing this, or whether they were naturally drawn to situations where communication was easier. Again a mother and daughter demonstrated this;

“My mum used to go the bingo every week with her friends, now she never goes she just invites them round for coffee. She never goes out and I think that is because she doesn’t hear”
“That’s not the reason, I stopped going because I never win, it’s a waste of money, and anyway it’s the same crowd every week, talking about the same things I get fed up listening to them. I would rather stay in and watch telly.”
The participant did not reply to this comment but it would seem her daughter had a point. Not going to the bingo because she is fed up with the people she sees there, then inviting them round to her house might suggest that she is not “fed up” with the company but would prefer to have an environment she can control when she socialises.

Another aspect that family found difficult was that participants noticed their friends were becoming deaf and although they accepted this, they did not identify with them. Participants did admit that they could see changes in their friends' behaviour and ability to communicate in noisier situations, and they felt their friends should get help in the form of a hearing aid. Despite this they did not identify with their friends. What was unclear was how this affected their opinion. Did they feel they were less affected because they could see others struggling but felt they were not. Or did they feel less able to admit to hearing impairment because they experienced this change negatively and did not want to be identified in this way? The reasons for this were unclear from the data collected and this is an area that needs to be explored with individuals.

5.7.2 Becoming aware
At this stage in the journey there was a growing awareness that the individual may have hearing difficulties. In this stage the individual started to acknowledge to themselves if not to their families that there was a problem. How they communicated this to their family was affected by the relationship they had and how their family had interacted with them up until this point. Many participants expressed concerns about admitting the family had been right and before admitting this they would spend a lot of time searching for information or testing out their hearing by comparing how well they could hear in specific situations in relation to others. This could have a significant impact on the individual’s decision to move forward. If they felt they performed favourably this reinforced their belief that their hearing was fine and no action was needed. At this stage, although participants were becoming aware there was a problem, they were not be ready to acknowledge this and therefore ego defences such as denial became evident. Again avoidance tactics came into play to ensure the hearing impairment was
hidden. The participants were all at the "pre aware" or "becoming aware" stage. None of them had reached the point where they felt they needed to acknowledge the problem and seek help but several of them were determined that they would seek help when they felt they needed it and would not be "pushed into it" by family, friends or their GP.

5.8 Audiological profiles.
As part of the COPA project the last 10 participants had an audiological assessment. The quantitative data does not form part of this study and therefore will not be reported, but the results allowed a comparison between the participants’ subjective assessment of their hearing and the audiometric findings. It also facilitated comparison of the test results for those participants who were seeking help and those who had not.

As previously discussed, hearing ability depends on much more than the Pure Tone audiometry results and therefore it would not be appropriate to draw conclusions from this small amount of data. However a trend was noticed. Participants with a hearing impairment of less than 30 dB HL tended to think they did not have a hearing impairment although they did have difficulty communicating for other reasons such as communication partners’ poor enunciation. Those with hearing losses of 30dB HL or more tended to think of themselves as someone with a hearing impairment.

Having transcribed and analysed all the data from the interviews, reflective notes and focus groups, the following categories were identified:

- Becoming aware
- Hearing Aids
- Relationships
- Contact with services
- Self
- Moving on
- Society's role.

The codes and categories obtained from individual and group interviews are shown in the table overleaf.
<table>
<thead>
<tr>
<th>Becoming Aware</th>
<th>The self</th>
<th>Relationships</th>
<th>Contact with Services</th>
<th>Hearing Aids</th>
<th>Moving on</th>
<th>Society’s role</th>
</tr>
</thead>
</table>

Table 5.3: Reasons for non-compliance with hearing aid use
These categories are inter-related and it is difficult to look at these as distinct categories with no connection to the others. For example “Relationships” links to “Contact with services”. However in order to fulfil the first aim of the study the participants’ description of the experience are described individually, in addition to this the coding was also identified across the data in order to meet the second aim of the study. In both Phenomenological studies and Grounded Theories the extant literature is discussed as part of the analysis however, Smith (2009) suggests that it may be more beneficial for inexperienced researchers to discuss the extant literature separately in order to provide clarity for the reader. For this reason I have discussed the theory in relation to the extant literature later in Chapter 6. The next stage of the analysis was to “re-immerses” myself in the data and use the categories to conceptualise the core category. This was a slow process of re-reading the interviews and making connections. Finally I decided to listen again to the recordings as the prosody seemed very helpful to me in terms of understanding meaning. In this way I was able to evaluate the data repeatedly until a core category that both linked and explained the other categories emerged. I was then able to construct a model that demonstrated a process of acquiring hearing impairment. The emergence of the core category and the model will be discussed in the following chapter.
6 The emergent theory

6.1 Introduction
In this chapter I begin by presenting the emergent theory of acquiring hearing impairment. The chapter begins with an explanation of the core category, Preserving the social identity, followed by a theoretical outline of this category and how this is managed by individuals. I then set out the sub core category of Evaluating the costs and benefits, together with its related properties, providing further details of the theory by discussing the circumstances in which the core and sub core category are enacted, and clarifying the concepts of maintaining the current social identity, and, taking on the adapted social identity.

The next section addresses the binary concepts of the module followed by an outline of the concepts of, ‘Perceived threat to social identity’ and, Level of confidence in intervention that influence the core category. The chapter ends with a summary of the integrated relationships within the categories.

Finally in chapter 7, I provide a reflective account of building the emergent theory. This explains the personal process involved in undertaking this thesis. I have presented this reflective chapter at the end of the results chapter in order to present the Phenomenological Grounded Theory in its entirety, without interruption or bias, and to enhance the flow of the thesis.

The concepts described in these chapters emerged following a systematic adherence to the methodology of Phenomenological Grounded Theory, including constant comparison of data and reference to extant literature. As it is recommended that the researcher provide sufficient illustration of the data while remaining true to the conceptual theory, I have provided one representative quotation from the data to illustrate each of the concepts, additional examples of data from the same categories can be found in the transcripts attached in appendix D. In Chapter 7, I have provided extracts from my memos recorded throughout the process to demonstrate how the theory emerged.

6.2 The core category.
Preserving the social identity is the core category of this theory. Tajfel and Turner (1979) described the social identity as a person’s sense of who they are, based on
group membership. Belonging to groups gives individuals their sense of social identity and individuals who acquire hearing impairment later in life may find they have to strive to maintain their position in established groups when their social identity is threatened by the onset of acquired hearing impairment. The social identity is maintained by several means; these may range from avoidance of complex situations where communication is difficult to developing new skills in order to compensate for physiological changes that affect communication.

Changes to the social identity may cause the individual to become isolated or marginalized within groups, and in order to justify continued involvement in these groups the individual must be able to participate fully. Therefore the individual with acquired hearing impairment may strive to ensure that he is not exposed as being different from the group.

In the early stages of impairment the individual may be unaware that there is a problem. In many cases individuals are alerted to difficulties by communication partners either at work or at home. At this stage the lack of awareness may mean it is difficult to accept that there is a problem but having been alerted to this possibility is sufficient to enhance awareness and make the individual more alert to instances where this may be the case. Once aware of the possibility of communication difficulties, the status quo may be maintained by subtle means such as manipulating the conversation i.e. breaking the social norms of conversation by talking more than normal. This ensures that the person does not have to risk questions from communication partners that may require specific answers and alert others to difficulties. Additional means of doing this are to control the conversation by asking closed questions so that the answers provide useful information;

“.... but no I try to ask questions where I’ll get the yes or the no. or one direct question......and I’ll always say to somebody did you say 28 pence? I don’t say did you say 28 or 38? I just give them one”. COPA 4/Interview 1/L392-396.

Manipulating the setting can also be employed as a means of keeping control. This can be done in various ways, for example, choosing to sit in quieter areas with less background noise so that more of the conversation is heard, or by choosing a particularly noisy area to sit so that everyone is disadvantaged and has to try harder
to communicate. Some individuals will go as far as to select or avoid particular venues where they know they cannot adequately compensate for background noise, often using ego defences to rationalize their decisions rather than blame this on hearing difficulties.

**Preserving the social identity** is dependent on the sub core category of **Evaluating the costs and benefits**. With each encounter the individual has to assess which course of action to take in order to preserve their identity. This is done by deciding which actions are likely to maintain the social identity i.e. to preserve the image that others presently have of the individual, and which actions will provide better communication (adapting the social identity) with least cost to the individual. As this is a binary choice, this part of the theory is represented in Fig 2 below.

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**Figure 2. Evaluating the costs and benefits**

The outcome of this evaluation determines whether the cost benefit analysis supports maintaining the current social identity, or taking on an adapted social identity. The arrows represent the two choices. This cost benefit analysis is carried out in relation to two important categories as shown below. The first of these is the **perceived threat of the social identity**, and the second is the **Level of confidence in any specific intervention**. Table 6.1 shows the substantive and theoretical codes in the model.

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**Table 6.1 Core and sub categories.**

<table>
<thead>
<tr>
<th>Core category</th>
<th>Preserving social identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub core category</td>
<td>Evaluating the costs and benefits</td>
</tr>
<tr>
<td>Properties of sub core category</td>
<td>Perceived threat.</td>
</tr>
<tr>
<td>Category</td>
<td>Maintaining the social identity</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Properties of category</td>
<td>Maintaining the status quo</td>
</tr>
<tr>
<td></td>
<td>Employing ego defences</td>
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<tr>
<td></td>
<td>Withdrawing</td>
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<tr>
<td></td>
<td>Minimising effects</td>
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<tr>
<td></td>
<td>Evaluating (mis)information</td>
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<tr>
<td></td>
<td>Controlling the environment</td>
</tr>
<tr>
<td>Category</td>
<td>Taking on the adapted identity</td>
</tr>
<tr>
<td>Properties of category</td>
<td>Exploring the new identity</td>
</tr>
<tr>
<td></td>
<td>Finding similarities</td>
</tr>
<tr>
<td></td>
<td>Building relationships</td>
</tr>
<tr>
<td></td>
<td>Facing fears.</td>
</tr>
<tr>
<td></td>
<td>Advocating</td>
</tr>
</tbody>
</table>

**Theoretical codes used**

Two theoretical codes were employed to create a model with both cyclical and binary properties. The present and adapted social identities are binary opposites with the individual moving between these categories depending on the outcome of each cost benefit analysis. This in turn is influenced by the perceived threat to identity and the confidence in the available intervention.

### 6.3 The binary concepts

#### 6.3.1 Introduction

The two binary concepts outlined in the model are **maintaining the present social identity** and **taking on the adapted social identity**. The individual will select one or other state depending on the situation he finds himself in and a range of factors...
that influence his choice. These two concepts and related categories are discussed in this chapter.

6.3.2 Maintaining the present identity.
In this state the individual tries to maintain the same social identity they experienced prior to the existence of the hearing impairment. The individual will employ coping strategies in order to prevent the social identity being affected. The strategies will change depending on the circumstances and communication partners therefore it is a cyclical process, with the individuals moving forward and back in order to match behaviour to settings. This is represented in Fig 3 below.

6.3.3 Maintaining the status quo
This relates to keeping interactions as normal as possible. In order to do so the individual will attempt to hide any communication breakdown by ignoring or excusing their errors. In some cases individuals will express surprise that a comment was directed at them, explaining that they had not been paying attention because they did not realise they were part of the conversation or by saying they were distracted;

“I say, I am writing on the flip chart and my back is to you I won’t hear really what you’re saying

Figure 3. Maintaining the present identity
because I am concentrating on what I’m writing, so wait until I turn around and face you, you know, so all these little tricks that we come up with but really they aren’t tricks they’re reasonable”

Dallas 2/Interview 1/L45-48.

This participant was at a stage where, having tried hearing aids, she could see the value of wearing them, but still chose to manage without and employ other strategies to hide the hearing impairment. She herself was unsure why this was the case and reflected:

“I think I keep thinking there has to be something stuck in my ear that someone could take out and I didn’t have to wear a hearing aid (laughs) like there was a cork in there?”

Dallas 2/Interview 1/329-332

In my notes I debated whether this was in fact procrastination, or lack of acceptance of the reality of the situation. There were frequent references to looking for a cure or looking for something better, and this suggested to me that some participants had not fully accepted the reality of their hearing impairment, but rather were waiting for an alternative solution. This particular participant referred to her means of understanding her position. Referring to the Kubler-Ross model of grief, she described herself as “being in denial and acceptance at the same time” which may explain her ambiguity. It does fit with the binary model proposed. She went to great lengths to conceal her hearing impairment in the workplace, disguising her inability to hear by using the tactics mentioned above while at the same time trying hearing aids out over a period of several months away from her workplace.

Many individuals will continue to take part in activities, even when they are not fully able to participate, by preparing for the event. This participant described how she coped with theatre visits;

“I go to plays and I’ve learned, you know, so if I don’t hear everything that’s said in the play… lot of times it’s a play that you’ve… ah its one that has been around and you’ve read the book or you can just tell by the actions and whatnot”

Dallas 2/ Interview 1/L73-75
A considerable amount of energy is expended in playing the role of the person who can still communicate effectively in company. Often this can be exhausting and any pleasure obtained from conversations in social situations can be diminished. Maintaining the level of concentration required to follow conversations, particularly complex conversations can have both a physical and psychological effect on the individual, leading to stress, headaches and muscular tension.

As time progresses and it becomes more difficult to maintain the status quo in meetings, many people reduce their social circle to situations where they feel they can manage conversations. This may be to a select number of friends and venues where there is no background noise. Acquaintances that are not aware that there are hearing difficulties may become concerned that the individual is suffering from depression or trying to withdraw from the friendship. This level of adaptation in an individual's social life can lead to friendships being neglected and people feeling isolated. In an attempt to prevent this happening, individuals with hearing impairment may feel the need to try harder to function in social situations.

One participant's coping strategies varied from completely avoiding situations to bluffing, which he admitted no longer worked for him, to being assertive. His choice of coping strategy varied depending on the circumstances and he seem to find it easier to be assertive with family and friends than with work colleagues. He explained,

“I used to listen to music but now it drives me crazy because I hear all those background noises so if someone turned on music I would want to move to a place where I can't hear it anymore and I have a lot of friends who would turn on music when I go over to their house and I just told them ‘basically you put me out of the conversation you know? I might as well go home!”

Dallas4/ Interview 1/L145-151

Having to cope with the background noise had caused him to withdraw from social events and he felt people viewed him differently because of this,

“I think people were beginning to see me as anti-social because I didn't participate in things and I got to the point where if I couldn't understand the conversation going on I would really tune out. Tune out to the point where I wouldn’t even listen to them anymore, I’d be doing or thinking something else.”
Another participant (Dallas 5/ Interview 1) explained that, twenty years on from the start of her hearing difficulties, she still had difficulty in company. She admitted that she sheltered herself, limiting her outings to a few settings where she knows the people and can have one to one conversations.

6.3.4 Employing ego defences.
Many of the ego defences identified by Freud (Dryden 1996) are evident in trying to preserve the social identity. The more common of these is denial, where the individual is unconsciously unable to face the reality of a problem and copes by denying its existence. In the early stages of hearing impairment, denial may play a part, although acquired hearing impairment is normally a slow process and there can be an initial lack of awareness from the individual. There is also a period of time for many where they are ambiguous about the hearing loss. Although they will describe instances that they can rationally see would be caused by an altered ability to hear they will still say that they do not think they are deaf, almost as though they are not ready to face the reality of this;

“I’ve actually got to look at them and say to them to speak up and stop mumbling. If I don’t see their mouths I don’t understand what they are saying. The guys must feel like parrots because they are saying things two or three times -and I don’t think I’m deaf.”

COPA 3/Interview 1/L7-16

Displacement is an ego defence that is often seen in clinical settings. This occurs where patients have been persuaded by a family member, more often a son or daughter, to have their hearing assessed. If the patient has not come to accept a hearing impairment they can be very angry with the family member for interfering with the status quo. This anger is often directed at the Audiologist rather than the family member. This means the consultation is tense and rapport is affected. Being the person to confirm the hearing impairment the family member suspected can also make the patient angry with the Audiologist, a position that makes a therapeutic alliance difficult to cultivate.
Many individuals rationalise their reasons for withdrawing or changing their routine rather than admit to difficulties in hearing. It is often more acceptable for many individuals to say, for example, that current films are of no interest to them rather than explain that they can no longer hear properly in the cinema. One of the most common rationalisations used is that “people mumble”. So rather than hearing impairment being the cause, the fact that people no longer spoke properly was the reason for poor communication. One participant explained that he had no difficulty with volume but the clarity of the speech was poor. Despite volunteering the information that his hearing was deteriorating he still rationalised his difficulties, explaining that people do not enunciate clearly any more as there is no pressure in school to develop clear speech. He also noted that he had difficulty hearing on the radio and telephone because presenters and call centre staff speak too quickly and have accents with which he is not familiar.

Another participant explained that part of the reason for not wearing a hearing aid seemed to be the fact that she had not yet decided whether she needed one. She felt she had difficulty hearing but explained that this could not be due to deafness but rather to poor communication skills in others.

6.3.5 Withdrawing

The desire to hide changes in communication abilities may eventually lead to individuals withdrawing from social events completely. Often, as mentioned previously, using ego defences to mask the real reason for withdrawal. This may happen when the individual has little or no control over the venue, leading to anxiety about how they will manage to disguise difficulties. Knowledge of the venue may also add to anxiety if the individual has had difficulty communicating there in the past. This can happen not only in social situations, but in more formal situations and can have a real impact on the individuals’ ability to communicate in meetings, leading to withdrawal from community life and also from the workforce.

Legislation allows for “reasonable adjustment in the workplace”. For example the “Access to work” scheme provides government funding to purchase advanced technology that supports those who have difficulties in the workplace. Part of the funding is provided directly by Access to Work but the rest comes from the employer. However many individuals are afraid to request these rights believing they will lead to them being seen as difficult or a burden on the company. Fear of
not being promoted or missing opportunities might lead to individuals deciding not to put themselves forward in the first instance, and often at interviews they will strive to hide difficulties, preferring to introduce this topic after the employment has been secured. This in turn can lead to conflict with management that could affect future development;

“…and in the US and Texas when a hearing impaired or disabled person goes to interview they are to be treated an equal to anyone else, so I would go to an interview……. Then I would get on the job and I would have to tell them I need a booster ……….. I am not required to tell them and so when I got hired and they discovered that I couldn’t…. they had not planned for that and they were not very happy to have to accommodate me,”

Dallas1/Interview1/L131-151

For some people, even the prospect of being seen as a person with hearing impairment outweighs the desire to continue attendance at social events. One participant admitted that if his hearing got worse he may be less likely to socialise and may withdraw rather than wear hearing aids.

6.3.6 Minimising effects

Individuals may use a combination of coping strategies, ego defences and withdrawal to minimise the effect of the hearing impairment, thereby attempting to maintain the status quo for as long as possible. As it becomes more difficult to hide the hearing impairment, the individual may become more proactive and attempt to minimise the effect by manipulating the listening situation without disclosing the true reason for this. One participant (Dallas 5) found that he had difficulty hearing when more than one conversation was taking place. In meetings he found that he could not follow conversation if there were “asides” going on at the same time. He would conceal the impact of the hearing impairment by asking individuals to take their conversations outside so that people could concentrate on the main topic. In this way he was seen to be acting as an assertive manager speaking on behalf of the team rather than admit to something he viewed as a weakness. This linked very strongly with controlling the environment.

6.3.7 Evaluating (mis)information

As the impact of the hearing impairment increases it becomes more difficult to hide the difficulties and at this stage individuals may start to consider the viability of
maintaining the status quo, considering whether there is a need to seek help. This is hampered to a large degree by the information and misinformation that is available. Most individuals will seek information about hearing aids in the first instance as there does not appear to be a great deal of knowledge about or availability of other rehabilitation services. This information tends to be obtained from three major sources, the NHS Audiology services, the private Hearing Aid Dispensing practice or the internet. For some individuals personal experience of communicating with a hearing aid wearer may have an impact on their decisions. Most individuals will look for information on the internet in the first instance. Information on the internet can be very contradictory and the individual is faced with a mass of information for and against private/NHS provision.

There is evidence that many individuals believe private practices are not to be trusted and these beliefs are reinforced by information from dissatisfied customers. There is a belief that private practices overcharge for services and use tactics to “grab” people by offering cheap hearing aids to “lure people in”;

“No I think it’s a big one I am getting. I like these wee ones you see advertised in the papers but I wouldn’t go privately it’s a con. They tell you the price in these adverts and then- it’s like going for glasses and the price is never the same once they get you in. There’s no need for the prices they charge.”

NHSF3/Interview 1/84-87

NHS services were also criticised for being too busy to allocate sufficient time, or too disinterested in the process to make the person feel wanted;

“And I thought oh forget it. And I was just so disgusted. As I said it’s about the hassle and I said no. I mean if it’s not going to. I mean the doctor more or less said well it’s not going to help you but we’ll give you this [Hearing aid] anyway.”

COPA 1/Interview 1/L69-72

Unfortunately in the absence of any specific information about rehabilitation in the NHS the public seem to believe that obtaining a hearing aid is a last resort and although they are now in a position where they may be considering moving towards seeking help, they will delay this as long as possible.
6.4 **Taking on the adapted social identity.**

![Cyclical movement representing the varying behaviour according to settings](image)

**Figure 4** Taking on the adapted social identity.

6.4.1 **Exploring the new identity**

For many individuals progression towards a new identity as a hearing impaired person is difficult. Participants were particularly anxious that others understood that they were still capable people despite their hearing impairment. Memo notes from an interview with NHF1 indicated that this man's work history seemed very important and it seemed really essential that he explain that he had an important position at work. I wondered if this was because he might be feeling marginalised now because of his hearing impairment. I noted in my memo that he seemed upset by the fact that his family were frustrated with him now that he could not hear. His behaviour and self-image seemed in conflict.

Another participant, a 71 year old male who had no history of noise exposure and had only recently been diagnosed with hearing impairment disclosed that he felt this was linked to a recent diagnosis of terminal cancer. In contrast to the first participant he had discussed hearing aids with friends and although he had received negative information he had still made the decision to go ahead. As with the first participant there was evidence that hearing impairment was perceived as something the individual had to deal with as described in the biomedical model. Both participants appeared to feel that they needed to wear hearing aids in order to communicate with others and seemed reluctant to cause others inconvenience.
Despite the fact that this participant was well informed and appeared very assertive, one comment seemed to suggest that he was compliant with the needs of the service rather than his own;

“The only minor thing was that the first appointment clashed with an event that I didn’t really want to miss, for personal reasons I didn’t want to miss it, and that meant there was another month before I had another appointment which surprised me a little because I phoned up immediately. Having said that I think the time I had to wait was perfectly reasonable. The problem with the NHS is that all these old people like us—there are quite a lot of us…” NHF2/Interview1/L170-175

Again this seemed to fit with the first participant’s desire not to be a problem to anyone. It would seem the original decision to explore the new identity may be more influenced by the individual’s need to relieve the burden on others rather than a desire to improve communication for personal reasons. This theme of pleasing others and not being a burden was noted repeatedly throughout the interviews. There appeared to be a shared belief that acquiring hearing impairment signalled a change in ability linked with deterioration and increased dependency which participants had to negotiate.

As previously discussed, participant NHF6 had a dual disability, being registered blind, and depended on her husband. Unlike the other participants she was keen to try a hearing aid and explained that her husband already had to read to her and now had to sit close so that she could hear what he was reading. She explained that she felt he “had an awfy lot to put up wae” and her main reason for getting a hearing aid was to relieve his burden. She was keen to have a hearing aid and felt that the only way to get one was to as she described it, “Answer the right questions in the right way”. This struck me as being more than pleasing the professionals and looking at this in conjunction with the comments made by a previous participant about her GP judging whether or not she needed help. I felt there was an element of “gate keeping” in which the participant had to act in a particular way in order to gain access to services. It seemed as though they were describing a selection process where they had to meet the criteria in order to be able to join the group.
6.4.2 Finding positive aspects...

Being able to find positive aspects to the hearing impairment was one element that helped participants move more towards the adapted identity. For one participant (Dallas 1) her hearing impairment helped to ease her anxiety, because she could not hear other people talk about her. She saw this as a blessing and explained how she viewed it;

“I didn't ask for this, this is something that came on me by the grace of god and I accept it.”

Dallas1/interview 1/L154-155

Another positive for this participant was that she was able to become more assertive in order to survive in the workplace and she freely admitted that she “had an attitude” and was not going to lose it, this meant she dealt quite assertively with others in communication. She related how she persuaded her husband to improve his communication skills. This attitude also gave her the confidence to deal with other relationships by handing over some of the responsibility for communication, which in turn helped her increase her self-esteem and value her own self-worth.

Seeing the positives certainly influenced another participant’s (Dallas 2) decision to move towards the newer identity. She explained that she had a great faith and a great sense of humour which she attributed to her Irish roots. This sense of humour helped her to see the funny side of miscommunication with her peers. She also saw the experience of losing her hearing as a source of personal development;

“It helped me to know myself better- how I cope with things and how I look at things and how there are some things I accept that isn't my doing, and I have to learn how to live with it.”

Dallas 2/interview 1/L304-307

In contrast, participants who had not had positive experiences were more likely to try and maintain the status quo. Dallas 5 described feelings of fear around participating in everyday activities, for example travelling on public transport and not being able to hear what was being said. She said she originally had concerns around hearing the telephone etc. but now that her hearing had deteriorated she had very real fears about communication with people. Despite this she did not see herself as someone who was disabled. Her self-image was of someone who was independent and
coped very well. Despite her concerns about missing vital information she still preferred not to volunteer information about her hearing impairment unless she absolutely had to. Despite being unable to see any positives in her hearing impairment she did consider herself fortunate. She believed that there needed to be more global awareness of the problem which she saw as the responsibility of the first world countries. She talked about having rehabilitation conferences on a larger scale and explained;

“You know what crosses my mind? I often wonder about doing something like this globally, because I am very fortunate to be in a first world country. I often think to myself ‘god what if I had been born in Egypt or Burma? I’d be sitting in a corner somewhere you know? -or in the street

Dallas 5 /Interview1/L366-377

6.4.3 Hearing aids

The provision of hearing aids forms the basis for rehabilitation in the UK, with the majority of referrals to Audiology departments being for an assessment for hearing aid fitting. Yet, as previously discussed many participants viewed hearing aids as something that was to be considered in the future for a variety of reasons.

One participant COPA 2 believed that he would happily wear a hearing aid when the need arose, but explained that because, of his particular circumstance at the present time, the hearing impairment was not impacting on his life. He explained that he had never been a particularly social person and now his wife’s disability meant that they had withdrawn from socialising completely. He did express great faith in the NHS and felt he would be happy to leave the decisions in the hands of experts.

Another participant (COPA 3) said that he would quite happily wear a hearing aid if he needed one, but admitted that vanity might influence his decision. Following the initial interview and subsequent assessment, this participant decided to have hearing aids fitted. He felt that the hearing aids did not necessarily make things better just “different”, but he had been told that it would take a while to adapt so he was willing to persevere as he had a goal to improve his social life. COPA 3/Interview 2/Sound file. For this participant his goal had been the motivating factor
but for many other participants there was awareness that hearing impairment was present but they did not feel, as one participant had put it, that it had yet “hit him” that changes in lifestyle were required to accommodate the impairment. Interestingly although he said that the hearing impairment had not affected his lifestyle he did allude to an increase in problems and on some level acknowledged that circumstances had changed;

“No I’m not making any changes, er I’m sceptical about what help would be available.”
COPA5/Interview 1/ L156

From these comments it would seem that the cost benefit analysis also applied directly to acquiring hearing aids. Where there was a desire or goal to hear better and a belief that amplification would help, the individual is more likely to move towards seeking help. Where the individual was sceptical about the efficacy of amplification or was concerned about wearing aids there was more likelihood that the individual would delay seeking help.

Participants also discussed ways in which hearing aids could be made more acceptable and therefore more widely used. COPA 6 thought this would only happen when they had a different image, although she remarked, “I don’t think anybody’s going to wear a hearing aid for fun, are they? She felt the image of hearing aids was poor, but did not see this image changing as there did not seem to be the will to explore this. The image of disability was raised by many of the participants. The image of the hearing aid as a large bulky object still exists but when explored further it seemed it was not the hearing aid per se that caused the stigma, but the meaning behind wearing a hearing aid. This was seen by the participants as giving the impression of being “old” or “slower”; as one participant put it, “a badge of decrepitude”. COPA 5/Interview 1/L296.

6.4.4 Finding similarities
Being able to find similarities with others helped the individual move towards taking on the adapted self-image. Those with significant others who had positive experience of hearing impairment were more likely to feel hearing aids were acceptable. If they could identify with others in their social circle who also struggled
to communicate they were more likely to take their advice than that of others, either professionals or family. If the individual could not see similarities with others this could become a source of stress, with the individual feeling isolated and less confident about managing their impairment. Despite an eighteen year history of coping with a hearing disorder, Dallas 5 did not relate to others with hearing impairment, frequently commenting that, for her, it was different. She did not see herself as deaf and did not seem to have come to terms with this. Although she appreciated that there had been a change, as she spoke of not being able to stand living in the real world and not hearing anyone. She wanting to be normal again although she realised this would probably not happen. Another participant did associate hearing loss with age which she admitted was a life stage with which she did not identify;

“Whether your knee is giving you jip today or something like that. And it’s just a constant reminder, don’t bother we’re aging. You know? So you end up without being able to do things absolutely spontaneously and automatically certainly I think it’s a cumulative thing as you get older It’s one of the things that you don’t realise is going to happen to you. Oh it happens to everybody else. But oh no, I’m not going to get old.”

COPA6/Interview1/L110-111

6.4.5 Building relationships
Taking on the adapted identity involves building relationships, particularly new relationships with professionals; it also means rebuilding and restructuring old relationships to accommodate the changes in communication. Participants in this study had many concerns about dealing with professionals. Some of these concerns have previously been discussed. These concerns were largely dependent on the individual’s locus of evaluation. Those participants with an external locus of evaluation wanted a relationship with an Audiologist where the Audiologist was the expert and gave advice on what they should do. For these participants the concerns were around pleasing the Audiologist or other professional by giving the right answers in order to obtain the service. While this would be acceptable at the start of rehabilitation it could lead to a dependency on the Audiologist which could lead to an inability to self-manage in the long run.
For those participants with an internal locus of evaluation, an Audiologist who was an “informed friend” was more acceptable. Here the concerns were around whether the Audiologist understood the individual’s experience of hearing impairment enough to know what they needed. This type of relationship was more likely to lead to self-management, but a strong relationship built on an equal footing strengthened this and made the outcome more successful. For example, Dallas 1 had been working with the same Audiologist for many years, during this time her hearing had deteriorated and rehabilitation sessions had been adapted to accommodate this. As previously discussed, when the Audiologist suggested a cochlear implant after a further deterioration in hearing was recorded this participant, after conducting her own research, questioned the Audiologist about the implications of this operation. Following this discussion she instructed the Audiologist to remove her name from the list as she was not interested in this option. She then took on the personal responsibility of learning to lip read in order to maximise communication and use her residual hearing, and subsequently approached her Audiologist and asked her what else was available to help her. This more collaborative partnership between herself and the Audiologist in which they shared information and debated the future management plans was more successful and the participant felt supported and valued.

Relationships with professionals were not always successful and this caused an emotional response from participants. Dallas 4 felt that he had not been given information from his Audiologist that might have been of use to him and that he had not been consulted in the rehabilitation process. The Audiologist had made recommendations on his behalf without consultation which effectively prevented him from accessing other sources of help. He was extremely upset about this and intended to speak to his Audiologist about it. I found it interesting that he said he wanted to ask her “why have you done this to me?” He felt he had not been consulted about decisions she had made that affected him and he felt this was something he needed to address.

COPA 1 did not feel her relationship with Audiology staff was particularly helpful and in fact had contributed to her decision not to go ahead with a hearing aid fitting. As previously described she attended a series of appointments. At the first appointment she had a consultation with the doctor and then a pure tone audiogram was
recorded. Following this she was advised by the doctor to come back in a year. This led to a series of appointments which the participant felt were unnecessary, badly organized and caused her inconvenience. She felt the doctor's attitude to the hearing aid did not inspire any confidence. Although it seemed this was not the only reason she had refused a hearing aid, as she made comment about “being so against the hearing aid to begin with” she clearly felt the attitude of the professionals was not conducive to rehabilitation.

One participant who was particularly influenced by the information from the professionals was embarrassed by her encounter. Prior to the assessment she was convinced that she had a hearing impairment and cited several examples of where this had affected her quality of life. Immediately following the assessment she expressed her embarrassment about being wrong and immediately disregarded her own opinion in this matter despite the fact that she continued during the second interview to offer examples of situations that she found problematic. She seemed disappointed in the results of the assessment and admitted that she was seeking solutions, she said she was "looking for a miracle". She expected the professionals would be able to tell her what was wrong and how to fix it and was now unsure how to proceed with the information she had been given. She continued to express her belief that she was not deaf but had difficulty communicating in certain circumstances. When asked whether she felt she had a hearing problem or a communication problem she said she felt the latter was a more appropriate description, and felt her problem was situational. If she was in a cinema for example she found the sounds “blaring” and impossible to understand, but if someone spoke softly or mumbled she could not understand that either. This made it difficult to decide whether or not she had a problem that could be helped. She seemed ambivalent about hearing aids; saying she would be prepared to wear them if they helped, but did not know if she was deaf and since the professionals had suggested she was not and told her that she just had to learn to live with it, she felt there was no reason to pursue this. She did say if there were any other means of help available she would be happy to accept - although she was not sure what would help her. Again, this indicated an external locus of evaluation and dependence on others to find solutions for her.
The role of the GP in the process of rehabilitation was discussed, in particular the provision of information in the surgery. One participant (COPA 6) raised the issue of the amount of information available in the surgery and whether anyone actually took notice of it but she did feel that identification of hearing impairment and appropriate information and advice needed to start before the hospital assessment and thought this should be partly in the domain of the GP. She believed the GP surgery was a good place to start the assessments, perhaps even in an informal way, in order to prevent unnecessary hospital appointments and felt the GP was in a position to do this as they had the role of “gatekeeper”. By providing an initial assessment the GP could then give advice on management of mild hearing loss without the need for further referral. She did however raise the issue of whether the GP would be sensitive to the impact of mild hearing impairment on the individual;

“I don't think it's going to be a huge amount of help to send everybody, to a specialist. But it might, at that point be worth saying something like if you are having a bit of difficulty you might just. You know. If you think it's a problem, acknowledge it's a problem to other people. We think in terms of disabilities and they tend to be rather exaggerated ends of the spectrum, rather than those which are maybe mild.”

COPA4/Interview1/L83-485

She felt strongly that there was a need for support in the early stages of hearing aid acclimatization to ensure that older people were able to access help and advice to deal with this new technology. She felt this needed to be carried out as a matter of course to allow the Audiologist to gauge the progress rather than rely on patients reports of their progress, she explained;

“It gets more difficult you know. Whatever they are like to look at or however good they are. If somebody doesn't really spend a lot of time.... or get a review or they're getting on with it or coming back for it. But it obviously needs a fair bit of input. Not just in the prescription and making sure the right one is being prescribed. But actually having you know usage of. Er sort of carrying on getting used to it. A wee time coming back and having a look at it and you've been getting on”

COPA6/Interview 1/Line341-353
Relationships with significant others also need to adapt to accommodate the changes in hearing and communication. While trying to maintain the status quo, individuals attempt to hide the changes from significant others and judge their ability to do this by evaluating how significant others interact with them. When the individual takes on the adapted role significant others need to adapt to the altered dynamics within the relationships and it is important to the individual that others do this in a supportive rather than a controlling way. Dallas 3 talked about how relationships had developed to cope with the loss of hearing and what was helpful to her and she was very clear that she preferred to have friends work with her to improve communication rather than take control of the situation and speak for her.

Dallas3/Interview1/ L254-255

6.4.6 Facing fears.
In order to move from the status quo to the adapted identity, individuals need to face many fears. For some this was the fear of others finding out they were, “less than perfect.” For others it was facing their own mortality and the fact that there was evidence that their body was “wearing out.” For many there was a fear around safety. Dallas 3 spoke about her fear of going out in public after the 9/11 terrorist attack because there might be an emergency and she might not hear warnings. Older participants talked about their fear of not hearing intruders and feeling unsafe in their own house. Another safety aspect was allowing access to their homes. Some participants were leaving doors open to allow deliveries because they did not always hear the doorbell. Participants also expressed fear about how they would be perceived by others once the hearing impairment was acknowledged. They feared that people would treat them as less capable, old, or disabled. There were also concerns about the impact on employment. In order to move on and seek help there was a need to face these fears and the ability to do this influenced the timing of seeking help.

6.4.7 Advocating
For many participants making sense of this experience involved using the experience to help other people through the journey. Dallas 1 felt that the purpose of her journey was to use her experience to help others. She had particular concerns for her sons, so that they did not damage their hearing and experience the same difficulties she had, and for other people who may be going through this same experience. She believed that there were not enough people who were willing to
speak openly about hearing impairment and she tried to do this whenever she could in order to educate individuals about their rights.

Dallas 4 talked about handicap being related to circumstances and as such a social construct, which could be influenced by society’s reaction to hearing impairment. For example she described going to a movie theatre and thinking how much better it would be to have listening devices advertised so that she could point to the poster and request one rather than having to explain what she needed to someone with no experience of the systems. In this way she felt deafness might become more “mainstream” and lose some of the stigma she felt was still attached to the condition. At present she feels it is still something that is hidden away or kept secret and consequently there is little genuine information or experience of dealing with this. A subsequent discussion about deaf awareness and how society could be more aware of the impact of hearing impairment and good communication revealed that this participant felt that hearing impairment was on a continuum rather than being hearing/non hearing, and everyone would benefit from a better understanding of how acquired hearing loss develops. She suggested that the best way to remove stigma was to educate children.

COPA 3 felt that there was a lack of services for people who had noticed a hearing impairment but were not yet ready to wear a hearing aid. He described this as a void and felt it would be more beneficial to have services for people that were not linked to hearing aid sales. He suggested that having the ability to go for a hearing test at a centre that was independent of hearing aid sales might encourage people to go for screening. He also felt this could more effectively be advertised using the media or the internet rather than information at a GP surgery. With regards to service he raised some points about adequate training and provision to carry out these test accurately. He realised that additional screening would have an impact on NHS services and wondered whether GPs had adequate training to screen and refer, and whether there would be enough trained Audiologists to support the referrals. With respect to professional relationships, he felt that the relationship between patient and professional was crucial and that those giving advice should be skilled and have up to date information and training in order to create trust between the patient and the Audiologist.
Although COPA 1 believed society had an important role to play she also felt that deafness is a disability that is not acknowledged and felt that individuals need to take control, ask for what they need and educate the public to provide this. She also felt that individuals with acquired hearing impairment should not rely on Audiology services alone to supply information. Participants expressed concerns that medical staff might not take patients seriously and this might undermine their confidence thus leading to poor rehabilitation. COPA 6 related this to her experience with medical staff during the episode of deafness she had experienced seven years ago and worried that doctors might not acknowledge individuals concerns. She stressed the importance of addressing hearing loss in the early stages rather than being dismissive of the problem, and felt that the GP did in fact have a role as “gatekeeper”. She believed this role that was important enough to influence patients’ decision to seek treatment;

“If you come to first port of call - might well be a GP or somebody if you are going. And if they are a bit dismissive or even that might be in a sense almost a block about whether you might bother to pursue it any longer”.

COPA6:Interview1/L213-214

Individuals carry out a cost benefit analysis in each situation in order to evaluate the most productive way to cope with hearing impairment. The elements considered by the individual in making this analysis have been identified, using previous and additional quotes to illustrate the data. The cost benefit analysis is related to two concepts; the perceived threat to the social identity and the level of confidence in the intervention.

6.5 Perceived threat to social identity and level of confidence in intervention

I will now discuss the concepts of Perceived threat to social identity and level of confidence in intervention with respect to the model. These two concepts influence the decision between maintaining the social identity and taking on the adapted identity. As such, these two concepts overarch the model and influence the cost benefit analysis.
6.6 **The perceived threat to the social identity.**

Where there is little perceived threat to the social identity, the individual may move towards maintaining the status quo. The threat may be viewed as low when interactions take place in favourable venues where there are optimal listening conditions, or where the interaction is a casual one with a stranger or with a person they are unlikely to have an ongoing relationship e.g. shop assistant. In cases like these the individual may use coping strategies to compensate for hearing impairment. These situations are less stressful for the individual because they are viewed as less important relationships. However, if the relationship concerned is more meaningful, the stress levels are higher and consequently the threat to the social identity is greater. This may be the case when communicating with friends and family or in a work situation. Where there is a risk that the hearing impairment is more likely to cause damage to the relationship, or more seriously to the individuals livelihood and promotion prospects, there is more likely to be a move towards taking on the adapted social identity.

6.7 **Level of confidence in interventions**

The level of confidence the individual has in any intervention will influence their decision to try the intervention and to continue its use. Where there is a high level of confidence in the intervention (normally amplification) the individual may be more inclined to try this as a means of preserving communication. A high level of confidence is acquired where the individual has had positive experiences of the intervention e.g. a friend or relative who is a positive role model for the intervention. Conversely negative information from others or from sources such the internet can influence the individual’s decision to move towards this option.

These two concepts are interrelated as the cost benefit analysis considers both concepts together. Consequently the level of risk and level of confidence combine to help the individual make decisions. Interestingly even when the individual has a high level of confidence in the intervention, they are unlike to proceed with the intervention if there is a low risk to the identity, suggesting that maintaining the status quo is more favourable until the threat reaches a point where the present identity can no longer be maintained and
the individual needs to move towards an adapted identity in order to maintain relationships. This is summarised in Table 6.1 below.

**Table 6.2 The relationship between perceived threat and level of confidence.**

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<tr>
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<th>High Confidence</th>
<th>Low confidence</th>
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<tr>
<td>High Risk</td>
<td>Move towards adapted identity</td>
<td>Maintain present identity</td>
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<tr>
<td>Low risk</td>
<td>Maintain present identity</td>
<td>Maintain present identity</td>
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6.8 **Summary.**

In this section I have discussed the model shown in figure 5 overleaf. This model outlines the binary and cyclical nature of acquiring hearing impairment. The individual will choose to maintain their present social identity or move to an adapted identity (binary) while experiencing hearing impairment. Their decision to choose one or other state is dependent on the perceived threat to their identity and their confidence in trying interventions associated with the adapted identity. Individuals will strive to maintain the status quo for as long as possible, and may only move towards the adapted identity when the threat is high and they have a high confidence in the intervention.
In the next section, I have set the data in the extant literature, giving a reflective account of the construction of this model using extracts from memos to identify key issues in the process.
6.9 Setting the data in the extant literature

6.9.1 Introduction

In this section I will discuss the data in relation to the extant literature, while providing a reflective account of the development of the model and core category using examples from the data. Chapter 2 gave a review of the background literature studied prior to the start of the data collection. In keeping with qualitative methods such as Phenomenology and Classic Grounded Theory, once data collection began no further reading in the area of research was undertaken until the core category had been identified, in order to avoid contamination of the data.

Following the establishment of the core category, a review of extant literature relevant to significant areas identified in the model was also undertaken, particularly for the core category of preserving the social identity. In Grounded Theory the literature can be used as a source of data and can therefore be used to add credibility to the theory (Birks. 2015). Prior to reading the literature relating to the components of the model, an updated search of the background audiology literature was carried out, in order to review the latest evidence base on acquired hearing impairment and aural rehabilitation. The second literature search identified a paucity of literature in the audiological domain therefore the search was widened to other disciplines such as nursing and sociology in order to make comparisons and identify knowledge that could be applied to audiology.

The core category and elements of the model are addressed with reference to health behaviour and social Identity frameworks. The influence of social identity theory and stigma on help seeking and rehabilitation are discussed. Finally the present limitations of aural rehabilitation are outlined and possible adjustments to practice are suggested. Examples from the data are used in discussing concepts. As before, the literature is discussed under the following topic headings; Impact of acquired hearing loss on the individual, significant others and society in general. The literature on aural rehabilitation is addressed later in the chapter in relation to the findings from the research.

Acquired hearing impairment has an impact on many aspects of the individual’s life; emotions, attitude, relationships, communication, life stages and self- image and
quality of life. Where possible these are discussed independently, although it is impossible to separate these in the individuals’ life and therefore the relationship between the aspects is also discussed.

6.9.2 Emotions.
In the preliminary literature review I noted that Danermark (1998) had suggested that addressing emotions should be given a higher priority in rehabilitation. He referred to the negative emotions that needed to be addressed to enhance adherence. Since then, work has also been done on the role of hope (Kent and La Grow 2007), and positive experiences in influencing adaptation and rehabilitation (Stephens et al. 2004). The purpose of this research was to look at the relationship, if any, between hope, personality and adjustment to acquired hearing impairment. Kent and LeGrow’s analysis found hope helped the adjustment to hearing loss and suggested CBT techniques might be used to instil hope and thus help the adjustment process. This would suggest that motivational interviewing could play a key part in the rehabilitation process but more work needs to be done to develop an evidence base. With regard to aural rehabilitation, Kent and LeGrow suggested that, since adjustment does not happen over time but rather because of intrapersonal qualities, we should ask whether any planned interventions raises the level of hope rather than raises the ability to hear. In keeping with Danermark (1998), Kent and LeGrow believed that psychosocial dimensions should be considered a priority in aural rehabilitation,

“...psychosocial factors, specifically hope, play key roles in adjustment. It also indicates the necessity of practitioners to consider psychosocial elements in hearing rehabilitation programmes because among those who have an acquired Hearing loss, hope mediates adjustment.”
Kent and Le Grow (2007) pg. 336

For many of the participants in the present study, hope was related to their belief systems. A belief in God helped participants accept their hearing impairment. One participant did admit that she was angry with God because she felt her hearing impairment was a judgement on her and she could not come to terms with it. It seemed as though she was expecting it to be taken away just as it had started and seemed stuck in this position. She admitted to being angry with God when she lost her hearing and she felt that she had brought this on herself. In her case she was
losing hope of God helping her and this was impacting on her ability to move forward. Therefore it would seem that it was not only hope but faith that played a part.

Kerr and Stephens (1997) had carried out a qualitative piece of research looking at the positives aspects of acquired hearing loss. They found that children and grandchildren were more likely to identify positive experiences than spouses or partners, perhaps because they were not under the strain of being the primary communication partner. One of the positive things noted in this study was that humour helped to get through awkward situations, and that was definitely so for participants in this study e.g. *Dallas 2/Interview1/L280-288*

A later study by Stephens and Kerr (2003) used a questionnaire designed from the responses obtained in their 1997 study. One of the findings from the correlation stated that understanding more about the non auditory elements of the experience from the individual's perspective could contribute to rehabilitation.

In conclusion, the literature and data both provide similar evidence that positive thoughts and attitudes have an impact on acceptance of hearing impairment. Where a positive belief in the ability to adapt is fostered there is more likely to be a successful outcome. This certainly supported the findings in the current data. Those who had experienced supportive contacts e.g. at the Callier conference were able to speak more openly about their hearing impairment and were more positive about being able to manage their communication needs.

6.9.3 Attitude.
This is closely linked to belief systems and positivity. The literature from 2003 did not produce any significant papers specifically focusing on attitude alone but, in keeping with the papers in the last section, on the impact of the person’s emotions on their attitude. This would suggest that researchers were widening research to look at not only at attitude but how attitude is influenced depending on circumstances. This links strongly with data quoted in the last section, and is important in terms of counselling patients.
6.9.4 Quality of life, Relationships and communication. Several studies looked at the effect of hearing impairment on quality of life. As part of the Blue Mountain hearing study in Australia, Chia et al (2007) used a self-administered short form health survey to evaluate quality of life. There was a small and insignificant association between self-reported hearing impairment and a reduction in quality of life, and between hearing aid use and increased quality of life. However this is not a causal relationship and many other aspects need to be taken into account. Chisolm et al (2007) carried out a systematic review on the impact of quality of life and hearing aid use. They found that wearing hearing aids had a medium to large effect on quality of life by reducing social, psychological and emotional effects of hearing impairment. Hallberg et al (2008) found that the men in their study had poorer hearing than the women and yet their quality of life was higher and Preminger (2010) suggested the patients’ frame of reference had an impact on perceived quality of life, with stress and mood affecting both the patient and their significant other. In this study it was found that where there was a congruent relationship with good communication between partners there was a better adjustment to hearing impairment whereas a negative mood affected both partners. It was also noted that when the patient judged their hearing impairment to be more severe than their partner estimated, and they took responsibility for managing situations there was more satisfaction in the relationship. Unfortunately, the number of participants in the study was insufficient to effectively explore any gender effect. What did emerge from these studies is that quality of life cannot be predicted by audiological findings alone and the individual’s psychosocial status needs to be explored.

In conclusion the literature since 2003 has recognised that the technological aspects of rehabilitation are not sufficient to address aural rehabilitation. The psychosocial aspects of hearing impairment are as, if indeed not more, important and need to be considered. This was also evident in the data from this project. The core category was “Preserving the social identity” indicating that dealing with the potential social impact of hearing impairment was a priority to those with hearing impairment and played a part in the individual’s decisions around seeking rehabilitation. In order to explore this further a second literature search was carried out using a combination of the following search terms; self-identity, social identity, identity theory, social
Since the literature suggests that aural rehabilitation needs to incorporate social and health aspects and shows that concentrating on the technological aspects of rehabilitation is insufficient to meet people’s needs, I decided to explore this further by looking at models of health behaviour in relation to aural rehabilitation. This is discussed in the next section.

6.9.5 The relationship between the present study and health behaviour theories.
In the previous literature review two models of health behaviour were discussed in relation to aural rehabilitation; The Health Belief model and the Theory of Reasoned Action. In this section these two theories are discussed in relation to the emerging data. A third model, the trans-theoretical model is also considered. The Health Belief model, created by Rosenstock et al (1974) can be used to predict participation in health prevention or screening programmes. A diagram of the model is shown below.

Saunders et al (2013) argued that hearing impairment shows overlap with other chronic conditions in terms of health behaviours. The emergent data reflects aspects of this model. In this study the authors focused on the health belief model despite the fact that it had only been used in one other study on hearing impairment. The rationale for this was because the concepts were considered to be more appropriate for exploring acquired hearing impairment, but no explanation is given to support this. This should be borne in mind when considering the findings. The data shows that where the individual had a high confidence level in rehabilitation, either

![Health Belief Model Diagram](source.png)
from personal experience or input from peers they were more likely to try wearing hearing aids than those who did not have previous experience or peer support. This thesis however, goes further, and shows that participants who had confidence in the effectiveness of hearing aids chose not to wear them until they felt they could no longer manage to preserve their social identity without them. Often the decision to go ahead with a trial of amplification was influenced by the amount of support available. This was also found in the present study;

“I am sure she [wife] will keep me in line, she wears hers okay”.

NHF3/Interview 1/ (Line 3)

The Health belief Model reflects the cost benefit aspects of the present model where individuals compare the perceived benefits with the perceived barriers. In this study the data showed benefits had to outweigh the barriers before the individual took action. In other words a cost benefit analysis took place. This health belief model looks at perceived threat, which was also evident in the present study. If the threat to maintaining the status quo increased, individuals reviewed their actions and moved towards seeking help. The other two aspects in the Health Belief model, self-efficacy and cues to action can also be seen in this data. However the model alone does not explain many of the aspects of this study. It suggests behaviour that resonates with the data but is not sensitive enough to explain the cognitive aspects behind these behaviours. This is explored further in the relation to the next model.

The second model, the theory of reasoned action Ajzen and Fishbein (1980), (latterly known as the Reasoned Action Approach) states that the most useful predictor of behaviour is the individuals’ intention to engage in a particular action or not. This intention was in turn affected by their personal attitudes and the subjective and cultural norms within which they operate. Noh et al (1994) stated that the individual is more likely to engage in the behaviour if it is viewed favourably and approved of by others. Therefore there is a social influence on decisions. This would suggest that engaging in the behaviour was more likely if the client has an external locus of evaluation as previously discussed, or if the behaviour is condoned by peers.
Again the Theory of Reasoned Action has aspects that confirm the data from the present study. Attitudes played a large part in influencing the individuals’ decision. If the individual believed the action was important and possible they are more likely to take action. For example a belief that acquiring a hearing aid was a positive thing, combined with a belief that maintaining communication is important would lead to action. In this study however, attitude to disclosure and hearing aids did affect decisions to seek help. As mentioned earlier, where the individual felt it more important to maintain the status quo and not disclose hearing difficulties, they chose not to wear a hearing aid, even if they did believe it would be of benefit. This would suggest that individuals would prefer to take no action until the point was reached where they felt they could not maintain communication and relationships without help. In other words, their priority was to maintain the status quo and preserve the present social identity.

The third model, the trans-theoretical model (or model of behavioural change) (Miller and Rollnick 2012) has been used in a limited way in aural rehabilitation to explain the stages an individual goes through in order to make a change (Ida Institute 2014). Using these stages combined with motivational interviewing it was hoped that the Audiologist could help the individual understand where they were on the cycle of change. The stages were; pre-awareness, contemplation, preparation, action, maintenance and relapse. This model was also limited in terms of looking at cognitive aspects of change. Although this was attempted by the addition of motivational interviewing, again it was not a sensitive enough model to explore the cognitive processes involved. Miller and Rollnick (2012) argued that people in the later stages of change were more likely to seek help and adhere to interventions. This was confirmed in the present study as all the participants were found to be at the action stage when they attended the clinic, hence ready to seek help. The average age of the participants was 70 years; again this confirmed earlier findings that older people are more likely to seek help.

One of the difficulties of using the trans-theoretical model is that often patients are not seen until they have reached the action state, and therefore Audiologists would only be able to use the earlier stages of the model when patients attended the clinic at the request of others; but at present there is no scope to offer other interventions other than providing hearing aids. LaPlante-Lévesque et al (2013) proposed that a
continuous model of change, as suggested in this thesis, rather than one with
discrete stages would be more compatible with the patient’s experience. This would
allow the cyclical elements of the emergent model to be considered. Although these
theories of health behaviour offer the opportunity to confirm some aspects of the
proposed model, they do not address all aspects that need to be considered and so
there is a need for a more comprehensive framework to explain the cognitive
processes involved. In order to look more carefully at the present model in relation
to other theoretical frameworks, I explored the literature relating to the core category
of **Preserving the Social Identity**, this provided a compatible framework for
explaining the model suggested in this study, and is discussed below.

### 6.10 Social identity Theory

In this section I will give a short outline of Social Identity Theory, and its relevance to
acquired hearing impairment. Social identity suggests that an individuals’ self-
concept is dependent on their perceived membership of groups. The social identity
is a means of explaining behaviour within groups, with social behaviour varying
along a continuum between personal needs and group requirements (Tajfel 1981).

In Identity theory there is an assumption that individuals are fundamentally driven to
achieve a level of positive distinctiveness within their group. In order to maintain a
positive self-concept the individual will attempt to maintain a positive social identity.

In an attempt to achieve this, the individual will gravitate towards the identity of the
“in-group” i.e. the group that has a higher status over the other group (the out
group), and those with lower status within the in-group will also strive to reach a
higher status within the in-group (Tajfel 1981). For those with acquired hearing
impairment, this may mean they must not acknowledge their impairment in order to
remain part of the group to which they have previously belonged. Within groups
there are three distinctive categories;

- **Individual mobility.** Where the individual disassociates from the group and
  pursues their own goals. This tends to happen when there is instability
  within the group. Instability may result as a consequence of the individual
developing hearing impairment. In these cases group promotion is less
important than maintaining one’s own position and the hearing impaired
individual’s priority is maintaining their own position within the group. This
would seem to be part of the experience of living with hearing impairment,
with the individual striving to maintain status by concealing and compensating for the hearing impairment, in order to “pass” as one of the group.

- Social creativity. Where the group is stable, the individual will endeavor to increase their personal status within the group without affecting the status quo or the relationship with the out group. A stable group e.g. a family group may be more conducive to developing stronger bonds within the group despite the impairment. Therefore the individual may be in a better position to disclose impairment and practice management strategies in a less threatening forum. However this may lead to loss of status in the group and may be the reason why individuals are reluctant to disclose the impairment. Participants in the study discussed their concerns about being seen differently, and I noted in my memos that some participants e.g. NHF1 went to great lengths to tell me how important his position had been at work as if to compensate for how his family viewed him now. As previously discussed this was also noticed by COPA 3/Interview 1/Lines 219-222. Although he owned the company, his employees were laughing at him because he was misunderstanding conversations and he felt a loss of position because of this, He also felt that the younger family members were not communicating effectively with him and he saw this as another loss of status. This adds another dimension to the cost benefit analysis; anticipation of negative perceptions, where the individual may decide not to make changes for fear of being discredited. This is based on the individual personal experiences and beliefs, and therefore may be an area where Cognitive Behavioural Therapy could help to give the individual the opportunity to explore the options and make decisions.

- Social competition. Where the in group strives to gain positive distinctiveness in direct competition with the out group. For example, this was evident in the earlier social attitudes of hearing individuals towards Deaf Individuals and Deaf culture, which sadly to some degree still continues. If the in-group is considered superior to the out-group it is difficult for the individual to demonstrate any characteristics of “other” which may undermine their identity with the in-group e.g. wearing visible hearing aids. This means the individual must conceal their hearing impairment in order to share more characteristics with the in-group than with any other group. If it can be
assumed that the individual has to deal not only with the stress of becoming "other" it could be assumed that they may be experiencing stress from separating from the original group. This was referred to by Dallas 2 when she said that she was in two different states of the grief process at the same time. *Dallas 2/Interview 1/L332-335*. She may have been trying to articulate the experience of having the two aspects of identity; denying the hearing impairment to remain in the in-group while accepting the need to move towards the other group. Moving involves not only having to project into a new group but having to separate from the familiar group, so there may be some aspects of a grief response in the process. Rehabilitation should therefore offer support in dealing with the loss in addition to providing tools and skills to move towards a new identity.

It should be noted that in-group members will favour their own members over those of the out-group, and that punishing the out-group benefits self-esteem more than rewarding the in-group (Tajfel and Turner 1979). This can also be an identity threat to those with hearing impairment as it reinforces for the individual the attitudes towards the out-group and the consequences of identifying with them. Burke and Stets (2009) stated that an individual’s identity is composed of their roles, (Mother, teacher), group associations (Scottish, member of the labour party), and their particular characteristics, (extrovert, moral). Identity theory seeks to; explain the meaning individuals’ give to these multiple identities, how these identities relate to each other and to other people, how these identities influence their behaviour, thoughts, feelings and emotions, and how these identities connect them with society overall. Individuals are clearly aligned with society, and therefore, although individuals have their own motivations, their behaviour, thoughts, feeling and emotions are dependent on the society in which they live. For this reason there needs to be an awareness of structural symbolic interaction.

In the early days of research into the self the findings reflected the beliefs assumptions and culture of the researchers. Since the researchers were predominantly European and North American it was assumed that the self was independent of external influences and autonomous. Over the last three decades the cultural influences have become more diverse. This is due in part to the

6.10.1 Multiple representations of the self.
There is a large body of work in psychology regarding the existence and implications of multiple representation of the self. For example between our inner (possibly more congruent) self and the self we show to the world in our various roles Baumeister (1986). However this work has not examined the relevance of culture to the expression and development of these roles (Cross et al. 2011). It has since been argued that cultural influences do have an impact on models of the self, with western societies favouring the individual over the group and consequently striving for independence and autonomy. In contrast, in eastern cultures the group takes precedence over the individual who strives to maintain harmony within the group. This further complicates group dynamics and has an impact on how individuals construe themselves.

All the participants in this study were from a western and therefore individualistic background and consequently it is not possible to comment on this particular aspect. Although there were some variations in attitude between North American and Scottish participants, insofar as the North Americans tended to be more assertive in obtaining their needs than the Scottish participants. However this may have been because they were attending a group rehabilitation programme and consequently felt a sense of identity with the group of hearing impaired individuals i.e. in this instance they became the stronger in-group and felt more confident as a group in expressing their position. This needs to be explored further in Audiology as this gives support to the idea that peer group rehabilitation may serve to strengthen the new identity. If this is the case further work needs to be done to develop group rehabilitation programmes, and encourage individuals to connect with these. It may also be that within larger cultures there are smaller areas of culture that influence behaviour, however further research would be required to investigate this particular aspect in more detail. Markus and Kitayama (1991) in Cross et al (2011) identified two specific self construals; independent and interdependent. Although they suggested there were many other construals their work has become synonymous with how individuals see themselves in relation to others
6.11 Integration of social identities

Most of the earlier work on self-construal and social identity looked at identities in isolation, but later work attempted to explain how these identities coexist and integrate within the individual. Amiot et al (2007) proposed a model of integration. She anticipated that this model would explain long term changes in the integration process, whereas earlier work has dealt only with short term situational changes.

The anticipatory categorisation involves a self-anchoring process during which the individual projects self-characteristics and attributes onto a novel group. This may lead to “trying out” the new identity in a limited way before committing to any changes. An example of this was Dallas 2 who attended the aural rehabilitation conference every year, wore hearing aids and communicated effectively with other members. She admitted that using the hearing aids and discussing her difficulties made conversation less stressful. Despite this, at the end of the conference she reverted to her “normal” state, regardless of the stress this caused her. She was not ready to take on this new identity, but each visit let her test it out to a greater extent and allowed her to move incrementally towards adopting the new identity. This was greatly assisted by the staff that let her try out various pieces of equipment without any pressure to commit to the new identity.

In the categorisation stage multiple social identities co-exist but one identity will predominate. At this point there is little or no overlap between the old and new identities. This is likely to be the point at which the individual will maintain their hearing identity where there is a greater threat, (for example, at work) while trying out the hearing impaired identity in situations where there is less risk of a negative outcome (e.g. with family and friends). Karlsson et al (2003) conducted a study in which a group of 7 men and 7 women aged 77-78 years with presbyacusis were asked about their experiences of participating in conversation. Ten categories emerged, the first of which was “conversation takes away or maintains identity”. This referred to the different situations in which conversations took place, and how they coped with and demonstrated the different identities used depending on the conversation partners and venues. In contrast to the present study all the participants were in their seventies and as stated earlier, previous research has shown that people are less affected by stigma as they get older, so this may have influenced the results. Despite this the findings supports the data in the present
study which had a wider age range. This would suggest that even when the impact of stigma is low, individuals still go through a process of “trying out” a new identity rather than embracing it easily. This employment of different identities may be in preparation for the next stage of the model; compartmentalisation, where multiple identities coexist without conflict with individuals using individual identities while not necessary owning them as a single entity.

Finally there is recognition and resolution of conflicts. Interrelations are established using commonalities and a dominant category is created to resolve conflict. At this point simultaneous identifications are integrated into the self (Amiot et al. 2007). This is the stage that many hearing impaired people do not effectively complete, possibly because they do not have a safe space in which develop ownership of the new social identity. One reason for this may be the long term attitudes to hearing impairment in society. Hogan (1998) outlines possible reasons for these deeply held views about the meaning of hearing impairment. He attributes these beliefs to 4 issues that came to the fore in the 19th century Although these have been adapted and diluted over the years there is still a legacy of being “less than” if you have a disability or defect. This needs to be contested, not only by the individual who has the hearing impairment, but by society itself in order to change attitudes, reduce stigma and promote inclusion. This is discussed further in “Society’s role”.

According to Amiot et al (2007), the notion of group membership is crucial to a renegotiation of identity after a major change. They propose that social changes lead to deep intra individual changes in social identities over time that are likely to be profound and require the reorganization of the entire self-concept to integrate these new social identities. Consequently, although social identities deal specifically with group memberships, they can also be conceived as one specific type of self-component comprising the entire self. Social identity can be defined as;

“That part of the individual’s self-concept which derives from his or her knowledge of membership to a social group (or groups) together with the value and the emotional significance attached to it”.


In order to understand how social identities develop and become integrated, it is necessary to look first at how they are organized cognitively within the self. Markus
(1977) viewed the self as a multifaceted cognitive structure. In line with these views, Amiot et al proposed that the self provides a core structure within which social identities can change, develop, and become integrated intra-individually. From a social cognitive point of view, integration is dependent on how the various components are organised within the self (Rafaeli-Mor and Steinberg 2002). Although distinct or unrelated components have positive effects, differentiation and linkages between the components are necessary for integration, and where components are organised in such a way that the components are simultaneously important the self will be coherent rather than conflicted (Sheldon and Kasser 1995). Hornsey and Hogg (2000) state that identities can be integrated in the self only when one's original social identity is secure, rather than threatened. Identity threat is likely to prevent comprehensive integration. This is problematic for those with acquired hearing impairment, as the identity is not secure or even definitively set, given that it is situational and can vary over time. If individuals feel threatened they may not be able to completely integrate this new identity into the whole. This is evidenced by the number of people with acquired hearing loss who never come to terms with the identity of hearing impaired, e.g. Dallas 3/Interview 1 /L223-236.

The distinction between “Deaf” and “acquired hearing impairment” is not always explicitly understood by the general public, (as discussed in chapter 1) and consequently it continues to impact on the individual’s perception of disability, and their alignment with certain groups.

Lack of value and identity of a hearing impaired out-group can influence the person’s attitude to choices. There is a very strong deaf culture with a clear identity, and a very strong hearing identity, but those with acquired hearing impairment often find themselves on the fringes. They are no longer hearing but not deaf, and therefore unable to strongly identify with either, while unable to find an in-group that reflects a strong identity. The choice seems to be to stay with the hearing group or to move towards the Deaf group and try to progress within a group that is culturally different. This would mean a greater integration of identities than staying in the hearing group, albeit at a lower status. Until attitudes to adults with acquired hearing impairment change so that a strong group identity can be constructed, it is likely that individuals will try to stay with the hearing group by any means possible.

6.11.1 The role of memory in social identity

In many cases individuals cannot remember when they first started to notice they
had a hearing loss, and often a significant other has had to suggest there might be a problem, or instigate the first appointment. Lack of detail about the onset or progression of hearing loss has often been attributed to the slow onset and progress of the hearing impairment. However another aspect of social theory may offer an alternative reason for this loss of memory about the impairment.

Dalton and Huang (2014) reported that people with social identity threat cope by suppressing the material they associate with the threat. The authors described the use of a defence response similar to Freud’s description of the ego defence, repression (Dryden, 2014) which they label motivated forgetting. This is linked by the authors’ framework to social identity threat. Individuals cope with this threat by suppressing the material. The extent to which this happens depends on how strongly the individual relates to the threat, and in specific cases even non-threatening linked materials can become suppressed. Similarly Jacoby (1991) argued that the individual may accidently retrieve the memory if they try to suppress it, particularly in the face of threat. Again this resonates with the concept of the “Freudian slip” (Dryden and Reeves 2014). The framework set out by Dalton and Huang supports the idea that motivated forgetting is more efficient when it is automatic. While admitting that motivated forgetting has been criticised widely, Dalton and Huang (2014), found that identity priming enhanced the forgetting of threatening material. This work was done in relation to consumer behaviour rather than in the field of audiology and to the best of my knowledge there is no research in this area specifically in relation to Audiology. This does have implications for rehabilitation and marketing. If, as suggested, priming the identity affects memory in threatening situations, it may be difficult to obtain accurate information about the patient as part of the assessment. This may explain the different narratives offered by the patient and their significant other. This will also be relevant for manufacturers who could be using a marketing strategy that impedes rather than promotes the sale of their products.

One area of identity threat identified by the participants was stigma. This was referred to throughout the interviews. Initially, it appeared that individuals were reluctant to wear hearing aids because of their appearance and indeed manufacturers have tried persistently over the years to develop and refine hearing aids in order to make them more acceptable. In fact the participants in this study felt
stigmatised, not by the appearance of the hearing aid itself but by the status it represented. The impact of stigma on social identity is discussed in more detail in the next section.

6.11.2 Stigma and social identity.

The term Stigma originated in ancient Greece. It originally meant a mark, often branded onto the individual to indicate something about the individual’s moral status. In early Christian times the term was developed to mean two things, firstly, a sign of grace (Stigmata), and secondly a bodily sign of physical disorder. In present terms the stigma is applied more to the disgrace itself rather than the mark, Goffman (1963).

As previously discussed individuals operate within group membership. The group categorises the person and draws attention to attributes. Using these methods we set up routines for interactions, to which we expect individuals from the group to conform without any adaptation. In this way we can use first appearances to identify the individual’s social identity. Our anticipations then form our expectations of normal interactions and become our “standard”. We now have an image of what Goffman (1963) termed a virtual social identity, however the actual attributes the individual has will form his actual social identity and these may not be consistent. We only become aware of these standards when they are called into question. When a new person enters the group, we obtain evidence of his attributes and any shortcomings from the virtual social identity will lead to the individual becoming seen as a tainted person rather than a whole person. The attribute that causes this discrediting effect is the stigma. It is possible that that the attributes can also make the person seem different or higher in the group than we anticipate, and attitudes can be creditable in one group and discrediting in another. Only attributes that are incongruous with our stereotype cause stigma, therefore Goffman (1963) argues that a stigma is a special relationship between attribute and stereotype.

The individual can view his attributes in two ways. If the other members of the group already know about the attribute, or it is evident, the person is discredited. If the individual believes that the others do not know or cannot see the attribute the individual is discreditable. In the case of the individual with acquired hearing impairment, there may be a further complication. For most of their life they may have been part of the “normals” Goffman (1963) in the in-group, later as the impairment develops they become discreditable but undetected. Then, gradually
they become less able to maintain this identity when they experience impairment sufficient to affect communication. By continuing to use coping strategies, some of which are maladaptive, they can conceal the changes to a certain degree and remain discreditable. Paradoxically, in order to maintain the connection with the in-group they reach a stage where they may need to have help to maintain communication, e.g. hearing aids, and at this point deciding to wear hearing aids, a physical symbol of their difference, they become discredited. The choice is therefore to maintain the status quo for as long as possible, or to accept help that will allow them to continue to function within their group but in doing so making them discredited. Further, the professionals they approach for help offer as a first line of management the very evidence that leads to them to be discredited; the hearing aid.

Goffman (1963) described 3 different types of stigma. Those who were not stigmatised, i.e. who fitted the stereotype, Goffman labelled “the normals”. He therefore argues that by definition, all those with a stigma are considered by the normals to be not quite human. How we act and interact in the company of the stigmatised depends on our beliefs and culture. The stigmatised person may not agree with this definition, believing he is a normal person who deserves the same chances as his peers. He can see that he is not treated on equal terms and this can lead to self-doubt and shame. This may be extended to personal hatred of the stigma and consequently the self. A stigmatised individual will attempt to respond to this situation by taking action to correct his failing, e.g. obtaining a hearing aid, but Goffmann (1963) contends that where a repair is possible often the person does not achieve normal status but a transformation of the self that contains a history of the stigma. Therefore the person with hearing impairment can only ever be a “spoiled” individual within any group. This may be compounded by the fact that hearing aids cannot correct sensorineural loss and therefore the individual has a constant reminder that they have not returned to normal.

A frequently cited barrier to hearing rehabilitation is hearing aid stigma (van den Brink et al. 1996) a multifaceted concept that was recently explored by Wallhagen (2010) in a longitudinal, qualitative study. People with Hearing impairment who did not wear hearing aids, and their communication partners participated in an interview at three time points over one year: Unfortunately the author does not clearly state whether the interview used structured, semi structured, or fully open interviews.
Topics are given but it is unclear whether the questions centred on preconceived topics, or these are the categories that emerged from the interviews. The participants reported stigmatising experiences associated with hearing aids that related to ‘altered self-perceptions’, ‘ageism’, and ‘vanity’. Participants commented that hearing aids would change the way in which the person with hearing aids would be viewed by themselves and others, and that a person with hearing aids would look old and less attractive. Wallhagen (2010) reported that hearing aid stigma influenced the participants’ acceptance of hearing aids, their decision to consult professionals about hearing aids and to obtain and wear hearing aids. This was also found in the present study where participants delayed seeking help because of their concerns about wearing hearing aids. This indicated one of the overarching concerns of the present model, “Level of confidence in intervention” covering not only concerns about the implications of wearing a hearing aid but also the concerns about whether or not the hearing aid would be advantageous. Concern about the effectiveness of the hearing aid was affected by the feelings about wearing the aid. Participants who felt the hearing aids would benefit them still preferred to have this intervention as “something they would have in the future”. Again this seemed to be a cost benefit analysis - will the benefit they bring outweigh the stigma of being discredited? It also suggests that the individual has not presently integrated hearing impairment into their identity and see this as something that happens outside of their present self.

The opinion of others is a real concern as people who display signs of hearing impairment are often perceived by others to be cognitively diminished, less able, and socially incompetent (Erler and Garstecki 2002). Although the participants in this study were varied in demographic terms, they were all reasonably affluent and well educated, and ethnic races were underrepresented with most participants being white, so it is not possible to extrapolate these findings to the general population. However, the study found that among young women there were more negative responses to stigma, whereas the effect was less in older woman. This reflects the findings in this study where hearing aids were seen as being acceptable for old age but not before. For younger woman, who are still competing in the workplace, the stigma of wearing hearing aids or admitting to hearing impairment needs to be considered in terms of promotion or indeed job security.
Erler and Garstecki (2002) predicted that, since women are not equally valued in society they may well be more vulnerable to being stigmatised, with hearing impairment being associated with lower intelligence, mental health problems, old age, disability and loss of femininity. If this is the case, women may find it harder than men to overcome their concerns about stigma as suggested by COPA 2,

“I er I er I don’t know I don’t know why I don’t. Come to think of it. It’s probably it’s probably something in the back of my mind that’s where it’s revealing a defect.

COPA2/Interview1/lines/239-240

This not only places rehabilitation of acquired hearing impairment firmly in the social agenda rather than the health agenda but raises the question of whether acquired hearing impairment is a feminist issue. Although this is out-with the remit of this thesis, there is scope for further research in this area.

Hetù (1996) developed a framework for understanding the psychosocial effects of hearing impairment in which he also explained that most individuals consider their hearing loss to be a "stigma." As a result of the stigma of hearing impairment, individuals may isolate themselves, avoid social interactions, and/or bluff their way through communication breakdowns. These behaviours and feelings can result in a change of one’s social identity and can lead to an enduring sense of social uncertainty. This is another area identified by participants. They were aware of avoiding settings or conversations with individuals that led to communication difficulties. Often another ego defence, rationalisation, was in evidence where they excused their non-attendance by reasons other than their hearing impairment. Blaming was also frequently used to shift the focus from their impairment to others, e.g. people mumble or the car noise drowned out what they were saying. These coping measures were also noted in this thesis and in Wänström et al (2014)

6.11.3 Changing identity and aural rehabilitation
There are many facets to coping with acquired hearing impairment that cannot be managed by technological solutions. The experience of negotiating the hearing impaired identity may be crucial to successful rehabilitation. Accessing rehabilitation means acknowledging the identity and for many people this is not acceptable until this option has become a last resort. I have discussed earlier the compulsion to stay
with the in-group, that passing as normal is a priority, and rehabilitation technology reveals information about the patient’s lifestyle (Hindhede 2012), this could lead to the person being discredited. Thomas and Herbst (1980) asked how we make a space for people to be self-actualised while we control normal and disabled body state. One method of rehabilitation that holds the individual to us is the technological method. Individuals are fitted with technology that is selected, programmed and adjusted by the Audiologists. Thus the individual takes on the dependent (disabled) role, having to access our expertise to enable him to cope with changes. This is not a person centred method of service delivery, although it is erroneous labelled so, as it does not see the individual as an equal in the process but rather as someone who has to be guided by the experts and agree with their choices of interventions. This in itself is disabling as the individual cannot select from a range of choices, and in fact may not even be aware of the choices available as demonstrated by Dallas 4 / Interview1/ Line 318-327.

The desire to avoid this contested identity may lead to help seeking being postponed for between 5-15 years (Hetù 1996). For some individuals this may mean a constant deterioration of hearing acuity that compounds the situation making rehabilitation more difficult. During this period individuals will start to withdraw from social situations and close their social circle so that only a few people, remain; those who can be confided in or managed with coping strategies. These associates can then become a support for the individual. However, there is a still a risk of isolation, loneliness and depression building during the intervening period before help seeking. This is caused, not by the hearing aid itself, but the stigma it represents, and the fear of society’s view on deafness and ageing. These aspects impact on the individuals choices in rehabilitation. If hearing aids transmit age related messages and having a hearing difficulty triggers a perception of deafness, the concern about stigma may mean the individual will minimise the risk of discovery by the in-group rather than maximise the advantages of the technology. This in turn can lead to an attack on the out-group, often represented by a remark frequently noted in the data, “I’m not deaf” in order to create distance from this group. In summary aural rehabilitation needs to be redesigned to address the pertinent issues and behaviours rather than focusing on technological solutions. It may be that health care professionals are not the most appropriate service providers. Individuals with acquired hearing impairment, in providing peer support and a possible new “in group” may be a useful resource in providing services.
6.11.4 The individual as expert.
Goffmann (1963) described one further stage of living with a spoiled personality that was also evident in this data; becoming a hero. This involves the individual becoming an authority in the area and advocating for others. In some cases the person becomes so involved in the role that they become a professional in the field and thus separate again from the group with whom they had now identified. Several of the participants discussed using their experiences to advocate for others. Dallas 1 talked about making sure her sons did not go through the same experiences she did, and admitted to becoming a spokesperson in her area, often volunteering to do talks that would raise awareness of peoples' rights. Dallas 1 /Interview1/Lines 304-311

6.11.5 Using personal experience.
A very strong theme was the participants’ desire to use their experience to help other people either avoid hearing impairment or deal with it in a positive way. This was an important role for many of the participants. It was felt that hearing impairment and hearing aids should be discussed more openly in society in order to project a more positive image. In one case participant COPA 1 went so far as to wear a badge, a symbol that announced her hearing impairment and immediately discredited her. In this way she could become an assertive hearing impaired person and educate those she met about providing adequate services. For these individuals there was a sense of coming to terms with the impairment, integrating it and then using it to help others. These individuals may have a lot to offer others in terms of support and similarities to allow individuals to begin to integrate this new identity as part of the rehabilitation process. By expanding the services to include knowledgeable peers we may be able to support more positive in-groups for hearing impaired individuals.

There have been some informal attempts to change protocols and include peers in service provision. One example of this was using peer support to coach and support those who are new to rehabilitation. This was a rehabilitation service offered by George Kirk, a former (now retired) Audiologist in Shropshire. Shared funding between Health and social work allowed Mr. Kirk to employ a coordinator for volunteers. The coordinator recruited suitably experienced candidates who had attended the Audiology department. Although it was indicated in the literature that using personal experience meant only one perception of the situation, the additional
training provided helped volunteers to rely not only on personal experiences, but also on evidence based techniques. Unfortunately, although there was positive anecdotal feedback, the service was never audited so there is no evidence of its effectiveness. However Brooks and Johnson (1981) did report on an assessment and counselling service provided in an area of Manchester. This was a very comprehensive service and would be difficult to provide in its entirety with the present demand for services. It is difficult to know the value of the initial visit or indeed any other aspects of the service as these were not evaluated independently, but there are aspects of this programme that could be incorporated into the current patient journey provided evaluation proved their usefulness. Despite the innovative approach, there was still evidence of a medical model of care and it was quite interesting that at the end of the rehabilitation period Brooks referred to releasing the patients from our care.

Having related acquired hearing impairment to the Social Identity framework, I will now look at how the theory and data relate to Aural Rehabilitation in terms of the current provision, and how the data can be used to develop services.

6.12 Development of Aural Rehabilitation.

In 1949, hearing aids became freely available in the UK, (Brooks 1981) and in North America the Veteran’s hospital instigated aural rehabilitation for military personnel to address hearing impairment caused by exposure to blasts during the war. Reed in (Brooks 1981) recognised in those early days that hearing aids should not be issued without support. He suggested that the patient must be handled in the early stages by someone who understood the difficulties sufficient to act as a Counsellor and friend. Sadly this did not happen as the demand for the service and the limited number of trained personnel made this impossible. Markides et al (1979) published guidance on aural rehabilitation in the British Journal of Audiology. They reported that the needs of the patients were not being met because of the lack of personnel. One of the recommendations of this report was that there should be more staff posts and training courses in rehabilitation. This led to the setting up of the hearing therapy profession. They suggested that clinical staff should have a minimum of an advanced Diploma or MSc. in aural rehabilitation in order to provide services. Now, in 2015, the same problems are reported, there is a shortage of trained staff, demand is increasing and there is no management commitment to continuing
professional development. Some attitudes have changed since the 1970s when Markides (1979) pg. 131 stated that the duty of the Audiologists was to;

"Try to alleviate as far as possible the handicapping effect of hearing loss, maximise the use of the residual hearing and to improve and preserve speech intelligibility"

We have moved on from such technological aspirations to a more holistic view of rehabilitation, in theory at least. Markides also states;

"Finally it must not be forgotten that hearing impaired adults do not substitute a subculture. They are members of the same social system and as such society at large needs more information and education about deafness. Individual needs cannot be determined solely on the degree of hearing impairment."

This is an opinion that has been expressed repeatedly by participants, but has not as yet become part of service provision.

It is evident from the data that, although acquired hearing impairment is caused by deterioration in bodily function, the main effects of the resulting communication problems stem from the wider psychosocial impact. Although technical solutions such as hearing aids and assistive listening devices can help towards improving input signals to the ear, they cannot restore hearing to its normal level and therefore the individual will always need to cope with an adapted form of hearing. Consequently each individual will have different needs from rehabilitation depending not only on the duration and level of hearing impairment, but also on their beliefs, culture, locus of evaluation and social identity. This means aural rehabilitation lies not only within the domain of Audiologist but also professionals in social care and the voluntary sector who can act as advocates and professional members of social groups, and with society itself.

Aural rehabilitation is often seen as an activity that takes place in the clinic, but rebuilding and integrating the social identity is an ongoing process and in fact rehabilitation take place throughout the individual’s life, not just in a consulting room. Therefore aural rehabilitation needs to evolve to provide a comprehensive service that addresses and supports the developing social identity in addition to offering
technological solutions. It should address service provision, staff education and training and providing education to help society integrate hearing impairment more effectively. In order to do this, professionals will need to adapt practice and work in a more multidisciplinary way. The role of the professions will be discussed in the next section.

6.12.1 The role of the Audiologist.
The role of the Audiologist is to assess hearing, balance and tinnitus, and provide person centred rehabilitation. The level of rehabilitation may differ depending on grade experience and education. As previously discussed, the profession has previously been split into Audiologists and Scientists, Hearing Therapists, Hearing Aid Dispensers and more recently Healthcare Assistants. In the main the roles differ in complexity but in terms of aural rehabilitation there is an overlap with Hearing Care Assistants programming and fitting hearing aids alongside Audiologists.

Providing services in a fractured service is difficult. Hearing Aid Dispensers, often working as health care assistants in the NHS, and Clinical Scientists are registered by the Health and Care Professions Council (HCPC) and have protected titles whereas the Audiologist sits on a voluntary Register for Clinical Physiologists (RCCP) and has no protected title. This leads to fragmentation in the service rather than a consolidated approach to rehabilitation. For example, in some areas Health Care assistants are not allowed to dispense hearing aids in the NHS clinic, in others they fit all the hearing aids and review the patients, only referring on to an Audiologist if there is a specific problem they cannot resolve. There are some areas where the hearing aids are fitted by the assistant and then the Audiologist sees the patient for further rehabilitation. This is not conducive to helping the individual integrate social identities as it fragments the process. The participants in this study expressed a need for a “learned friend” who could experience the journey with them, as described by Reed in 1949 (Brooks 1981). A fragmented service cannot provide such an individual and in this respect alone we are not meeting patients’ needs. A restructuring of services to include all resources in a holistic pattern of care, inclusive of a range of therapies and techniques would support the individual in coming to terms with the changes in a more person centred way. This is also discussed further in the final chapter. In order to maintain such services we must ensure that relevant education is provided for professionals.
6.12.2 Audiology education

Until the introduction of degree level training in Audiology in 2002, non graduate Audiologists training centred around providing technological solutions to hearing impairment with varying input on counselling techniques. To some degree this was addressed by the more in depth four year BSc. in Audiology, although the content of each programme varied across higher education institutions. With the launch of the Modernising Scientific Careers document (Managing Scientific Careers 2014) education in Audiology has now taken another path with students in England and Wales studying for a 3 year BSc. in Healthcare Science, encompassing learning in neurology, vision and audiology. This is known as the PTP path (Practitioner Training Programme). At present there is no undergraduate programme for Audiology in Scotland. Adopting the PTP with reduced hours and a more prescriptive curriculum brings the danger that the more therapeutic aspects that were becoming part of aural rehabilitation may be considered of less value and lost from the curriculum. These aspects need to be considered in planning and implementing future audiology education programmes, otherwise we cannot provide services that respond to patients’ needs.

6.12.3 The Audiologist as Counsellor.

Realistically, it would not be possible to train all Audiologists as Counsellors and it may not be appropriate for an Audiologist to counsel a patient and provide additional more directive services at the same time. Counselling as a profession in its own right has a strong ethical base and code of practice but is not yet regulated in the UK therefore caution needs to be used in selecting training programmes in counselling. It is however appropriate to train Audiologists to use counselling skills in practice, and it could be argued that this should be part of their education programme, providing there is an awareness of the limitations of their practice and the distinction between Counselling and using counselling skills.

In the first instance, Audiologists should allocate sufficient time to talk with the patient and explore their goals. It should not be assumed that everyone who attends for a hearing assessment wants to be fitted with hearing aids. As can be seen from the data, there are often different motives for coming to the clinic, such as proving relatives wrong. An assumption that hearing aids should be the first offer of help, rather than exploring the patient’s goals may prevent the development of a
good therapeutic alliance, leading to resistance and lack of adherence with this directive approach.

Aural rehabilitation need not be carried out in its entirety by the Audiologist. It may be more productive to have a range of facilities such as one to one sessions, group sessions, and peer led sessions. Making use of volunteers within the service may offer the individual the opportunity to meet others with acquired hearing impairment and test out this new social identity in a non-threatening way. In order to do this, ways in which individuals can be encouraged to connect with these groups need to be explored. Further investigation is needed to explore how the individual is empowered to make these connections. This may be more acceptable to the person than following instructions given by a professional, particularly one who has no personal experience of hearing impairment and possibly very restricted time schedules. Information technology could also contribute to equality in rehabilitation services in remote and rural areas.

Aural rehabilitation should not begin with the assessment of hearing when the patient has reached the end of his ability to cope without amplification. It should begin as soon as the individual starts to sense deterioration in their hearing, or notices that communication has become a little difficult in certain scenarios. Nor should it be based on the level of hearing acuity demonstrated in a pure tone audiogram. It has already been noted that hearing is a very complex sense and the impact varies for each individual, therefore an audiogram which shows the threshold level of hearing pure tones is inadequate to establish the impact on the individual’s life. At the earlier stages hearing aids may not be appropriate and other methods of rehabilitation may be required. Unfortunately present services are not configured to provide additional support. Therefore individuals describe waiting until they have to “face” getting a hearing aid with no help available to them before then. This is partly to do with how we “market” services and the profession. The participants in this study were unaware that there were any other solutions to their problems other than hearing aids. One participant pointed out that many middle aged people do not consult their GP often, so putting information in surgeries may be unproductive, and we need to find a way of making information more widely available. If individuals wanted to have their hearing tested to confirm or deny whether or not there was a problem they would chose to come to the NHS as there was no pressure to buy a
hearing aid, but this did mean they often had to resist the medical model of care. Developing services can be difficult, particularly in the current economic climate but combining resources with primary care and the private and voluntary sectors may facilitate more comprehensive services across a broader area, although further work needs to be done to pilot and evaluate the effectiveness of such a service in practice. This is discussed in more detail under the section on further research.

6.12.4 The role of other professionals in aural rehabilitation.
Participants described their feelings about accessing services and professional relationships. Positive and negative interactions were identified, and their impact on whether services continued to be used. Participants also identified areas where services could be developed or improved to meet the needs of people with acquired hearing impairment. As previously discussed, not everyone with hearing impairment requires hearing aids, but participants felt this was often their only option and only offered when professionals felt it was necessary. It was felt that services should focus on a wider range of helping techniques rather than just focus on hearing aids. Participants also felt that professionals needed to listen more to the individual and take their needs into account rather than make decisions about hearing aids on the basis of test results alone.

6.12.5 The role of primary care practitioners.
It would seem that general practitioners are in a position to educate and inform their patients about hearing impairment. The reality is that General Practitioners have minimal training in this area, even if they have a rotation in an ENT clinic, and few direct means of accessing continuing professional education in this area. Consequently some GPs still hold outdated opinions on rehabilitation based on experiences of unhappy patients. Many individuals complain that their GP has not considered their difficulties significant and offered limited help. It has also been said frequently that GP express low opinions of hearing aids and this in turn feeds into the individuals’ feelings about stigma and social identity. There were several examples of unsatisfactory consultations in the data. One participant gave a rather disturbing account of her experience, COPA 1\textit{/Interview 1/L55-72}. There is work to be done in bringing primary care and audiology services together in order to streamline services. Education for GPs should include deaf awareness training and updated information about rehabilitation options. This could be provided by the audiology team. GP surgeries could also be used as local drop in centres where
volunteers could hold informal information sessions. In a similar way Hearing Aids Dispensers, who are still erroneously treated with suspicion by GPs and patients, could work more closely with Audiologists and GPs to enhance the resources for rehabilitation.

6.12.6 The role of the voluntary sector in rehabilitation.
The voluntary sector already plays a part in publicising and advocating for individuals with hearing impairment. This role could be expanded to provide services such as; minor repair and maintenance clinics for those who use hearing aids, befriending services for newly diagnosed individuals, and peer led rehabilitation and self-help groups. Following the template used in the Shropshire service, a coordinator could be appointed to bring together all the services with responsibility for training and quality control, and a remit to reconfigure services to make best use of combined resources.

6.12.7 The role of screening in rehabilitation.
There has recently been a call for universal hearing screening to be implemented for adults, Davis (2007). However, screening for acquired hearing impairment was not supported by the participants in this study. It was felt to be a poor use of resources when the NHS is under financial stress. The participants felt they would not attend a screening appointment specifically for hearing impairment, unless they already suspected they had a problem. Although the participants thought they would have no objection to the screen if it were part of a larger screening appointment e.g. at a well man clinic, they were not convinced that they would act on the outcome, particularly if they did not already suspect a problem. In view of the model of social identity and hearing impairment, screening may not be an effective way of identifying and treating acquired hearing impairment if done in isolation. It may result in individuals being given an identity for which they are unprepared and may actually be detrimental in this respect. It has been noted that individuals may resist labels that are imposed on them without consultation. This may lead to non-compliance with follow up appointments and as such may be a poor use of resources. Screening may be more effective if linked to public education and information and offered specifically to those who request it. It would appear more work needs to be done in this area before universal programmes are implemented.
6.12.8 The role of society in rehabilitation.
Participants felt that acquired hearing impairment is a social not a health issue and society needed to be educated in order to reduce disability. Society has perhaps the biggest role of all in promoting rehabilitation and inclusion. As noted by Hogan (1999), some older attitudes based on 19th century experience and beliefs still infiltrate thinking about hearing impairment. This has led to the need to hide the impairment at all costs rather than acknowledge it and make use of the help available. Wearing hearing aids was described by participants as being “ageing”. It was also seen as lowering the person’s status in society and making women unattractive. One participant referred to the fact that people wear glasses now as a fashion accessory but thought that no one is ever going to make a sexy hearing aid which she thought would help:

“If you make something designer people are bound to…. It’s true, especially the younger generation”

COPA 8 /Interview 1/ lines 602-603

Hearing aid manufacturers have continued to produce smaller more discrete hearing aids in an attempt to hide the device but advertising may actually be sending the wrong message to the individual. A current TV advertisement for hearing aids shows a well groomed middle aged lady preparing for a night out. Just before she leaves she picks up her in the ear hearing aid and looks at it saying, “Let’s keep this between you and me” before putting it into her ear. This may reassure potential buyers that the hearing aid is small but it does perpetuate the belief that hearing impairment is something to be hidden. Marketing needs to address the source of the stigma rather than change the hearing aid itself.

In order to reduce stigma, hearing impairment needs a higher profile in society. At present assistance for individuals in public areas are few and far between and even when aids such as loop systems are available they are often not maintained or staff have no knowledge of how to use them. Deaf awareness training is not widely available in public sectors or only provided to frontline staff. Participants felt that this gave the impression that businesses were only paying lip service to addressing difficulties and described situations where they had to ask for assistive devices rather than them being readily available. This reminded me of an experience working in the NHS where I was given a type talk phone to allow Deaf patients to
phone the department. In this way management had “ticked the box” in provision for disabled patients. A lack of understanding was demonstrated when I realised they did not appreciate that this system only worked for the Audiology telephone extension. It had not occurred to them that Deaf people might want to make an appointment at another clinic. The solutions offered were that all Deaf people should have Audiology’s extension so that they could phone my department where staff would take a message, contact the appropriate department and then feed back to the patient. Alternatively the patients could fax the hospital, where the only fax machine was in the main finance office, and then receive a reply by fax within three days. There was no understanding of how discriminating this was to patients and this lack of deaf awareness is still common among the people who make strategic decisions about services. Part of the Audiologist’s remit is to educate others about Deafness and Hearing Impairment and the needs of each group in order to influence service development.

In general terms society needs to promote a change in perception through education of the public. Projects such as those suggested by Dallas 3 where deaf awareness and communication are part of the regular school curriculum could lead to an increase in understanding in the next generation, bringing hearing impairment into mainstream consciousness. Providing services at venues other than hospitals and health centres could also help in making hearing impairment more mainstream. As COPA 10 explained, many middle aged people who may be starting to experience early signs of hearing impairment, tend to be fit and active and therefore do not attend GP surgeries very often. Consequently they are not able to take advantage of any information provided there. If information were made available at social venues such as libraries, and leisure centres they may be more accessible to their intended audience. As previously discussed the participants did not view hearing impairment as a disability but rather a social difficulty. Therefore we should explore this further, it may be that aural rehabilitation does not sit well in medical facilities and should be more accessible to individual in a variety of settings.

6.13 **Relating the framework to other health care professions.**

The literature on social identity in Audiology was limited, and therefore I looked more widely at the health literature which shows that other health care professionals have used the framework of constructing and integrating the social self and biographical
processes in rehabilitation for treatment of chronic health problems. Many of the findings in other areas of health care reflected the finding in this thesis and therefore added credibility to the data. The findings indicate that use of the cognitive restructuring model could be applicable to Audiology and could be used to enhance aural rehabilitation.

The first theme common to these papers was that participants evaluated the present situation in terms of the past, Robertson (2013) conducted an in depth case study of a lady diagnosed with Alzheimer’s disease. She found that the ability to define the self and social identity was able to help the individual preserve a sense of social worth and give meaning to life after the onset of the disability. It was important to establish normality to help make sense of the impairment and reduce the social significance. This was similar to behaviour found in this study where participants talked about the normality of being hearing impaired at their age. Drawing on the work of Kelly and Field (1996) Robertson explained that individuals will constantly construct and reconstruct autobiographical accounts in order to preserve the self. Ageing and illness can create a tension in the self as explained by Goffman (1963) and it has been shown that people with dementia use narratives to construct identities that reposition them as capable active people who are valuable members of their community or family. It was important in cases of dementia that the individual maintained roles, and this was also evident in this study where participants were insistent on telling how capable they were and how they were still able to do things, regardless of what others thought.

Recent research has suggested that hearing impairment may be the first indicator of mild cognitive impairment (Kathleen Pichora-Fuller 2008) and therefore it can be difficult to separate the impact of these conditions in older clients. Alzheimer’s UK reported that Dementia affects 820,000 people in the UK, costing the economy £23 billion pounds. This number is forecast to rise rapidly in response to population growth. World wide a new case is diagnosed every 7 seconds. 40% of the UK population knows a close friend or family member with dementia. It is estimated that if scientists could delay the onset of dementia by 5 years, they could halve the number of people who die from the illness (Alzheimer’s Research UK 2015). The symptoms of dementia are memory loss, confusion, mood changes and difficulty with day to day tasks. Some of these symptoms can also be seen in individuals with
mild hearing impairment, and can make diagnosis more difficult. It is necessary to separate out the effects of dementia from the effects of hearing impairment, in order to provide effective services.

Cacace (2007) in an editorial for the American Journal of Audiology, suggested that Audiologists are in an ideal position to identify at risk people and include caregivers in educational counselling, as this is just as important as including the patient. He also suggested that Audiologists consider developing alliances with other services to contribute to diagnosis and management. Ulhmann et al (1989) looked at the relationship of hearing impairment to cognitive dysfunction in older adults. A case controlled study of 100 cases with Alzheimer like dementia was matched by age, sex and education to 100 controls who did not suffer from dementia. They found that the incidence of a hearing impairment of 30dB HL or more was significantly higher in those who had Alzheimer’s. Hearing impairment was also significantly and independently correlated with the severity of cognitive dysfunction measured using the mini mental state scale. This held true for both the cases with dementia and the control group. This would suggest that there is a relationship between hearing impairment and cognitive dysfunction. Although the study only used participants with Alzheimer’s type dementia, this is the most common form of dementia and is normally present in the same age group affected by acquired hearing impairment. It can be assumed that many of the individuals being assessed for the first time may be at risk of having both hearing impairment and Alzheimer’s disease. Since this may have an effect on the individual’s ability to participate fully in aural rehabilitation, both hearing and cognitive function should be evaluated in the assessment.

Ellis-Hill et al (2008) discussed the use of the life thread model to help stroke patients. This model is based on narrative theory and the purpose is to address the balance of power between professional and participant in order to take away the element of the expert telling the patient what to do. Failure to do this can mean the individual become a passive receiver of information. This shifting of power fosters a more equal relationship where the participant narrates his story and the professional works with them to “pick up the threads”. This method reinforces the importance of interpersonal relationships in rehabilitation, with the disability being viewed as a transition rather than a loss. Ellis-Hill et al (2008) contended that social reality is constructed through sharing of discourse in the social arena, and so rehabilitation
should take account of the individual’s personal preferences, and professionals need to bear in mind that individuals’ actions will be based on their social realities rather than professional expectations. They also found that professionals’ expert views can put individuals at a disadvantage with some professionals confirming the need to work in partnership while not allowing people to speak about their experience, or discounting their experience if it did not match medical expectations. This was demonstrated in the present study where one of the participants COPA 1 experienced difficulty hearing but was told that according to the test results her hearing was within normal limits. This did not facilitate discussion about her difficulties, and left her feeling embarrassed. This raises questions about whether present assessments are fit for purpose. This will be discussed in more detail in the next chapter.

At present the focus of aural rehabilitation is on correcting hearing impairment by technological means. This means the focus is on the body and what it can no longer do. Therefore rehabilitation is focused on limitations, problems or physical difficulties. However professionals in Audiology have limited training and knowledge in how to deal with emotional difficulties. In other disciplines, where psychological and emotional support is thought to be outside the remit of the healthcare professionals, this can lead to the psychological aspects of patients’ care being handed on to psychologists. In audiology this does not tend to happen. The profession of Hearing Therapy was created to help individuals deal with these areas but the numbers in the profession were very small and therefore only a percentage of the more “difficult” patients were referred for help. Ellis Hill-et al suggest that healthcare professionals need to practice “being” with the individual rather than just “doing” but many healthcare professionals will say they do not have time to do this, and time spent with each patient is likely to reduce as waiting time targets become more stringent. However Barry et al (2001) found that adapting practice did not necessarily mean taking a longer time with the patient. In their study it was the style of the consultation rather than the length that changed.

Many of the stroke patient’s interviewed in Ellis- Hill’s study expressed a feeling of being lost. This is an area in which those with acquired hearing impairment, which generally develops slowly, may be supported by addressing the emotional aspects in rehabilitation, but only if this is available at a much earlier stage of intervention.
To be able to stay with the in-group individuals need a positive sense of self and this needs to be fostered before the stage where technological help is needed. This is discussed further in the next chapter. Neuwirth (2002), in Ellis-Hill et al (2008) was concerned that;

“We may have forgotten that healthcare is primarily a humanistic endeavour that professionals are involved in healing rather than purely technological manipulation, that staff contribute more than just knowledge and the patient as a person is more important than the disease”. (Page 157).

I would suggest that in the search for better technology and faster fitting times, Audiology is losing its contribution to healing. While moving towards education and services that rely on more complex technical solutions the profession as a whole is losing interpersonal relationships and counselling skills, and therefore reducing the effectiveness of rehabilitation. This has an impact on services and patient satisfaction and is not in keeping with the progress made in other healthcare professions.

In this chapter I have discussed the data from this study in relation to the extant literature and identified possible areas that need to be addressed in order to develop rehabilitation services in the UK. In the next chapter I share my reflections on the construction of this theory followed by a final chapter discussing the implication of the findings for clinical practice and further research.
7 Reflective chapter

7.1 Introduction

This journey has been a long and rewarding one. I started the journey with an idea that I could help improve rehabilitation by finding out what people want, and ended the journey with a greater understanding of the impact of acquired hearing impairment on the individual, their families and friends, and the rest of society. Without the honesty and kindness of the participants I could never have completed this. They shared with me what I needed to know and more, and I believe they have enriched my life in the process.

This journey began many years ago when a friend and former colleague suggested I study part time for a BSc (Hons) in Health Studies at what was then Queen Margaret College in Edinburgh. At that time I was employed as an Audiologist. I loved working with patients but was becoming a little jaded as I felt frustrated by the lack of progress most of them made despite advances in hearing aid technology. It was as though each advance promised the ideal solution but did not deliver. I felt that I spent more of my time consoling rather than encouraging people. I have a memory of my first day in a clinic as a new student. The senior Audiologist was about to fit a hearing aid and her patient agreed that I could come in and observe. As she sat down the Audiologist told the lady she needed a hearing aid and produced a body worn aid at the same time. She put the mould in the lady’s ear and switched it on. The lady immediately dropped her head and began to sob. Anxious to reassure her, the Audiologist told her not to worry, that she would get used to it, and continued to give her instructions on how to change the battery while the lady tried unsuccessfully to control her tears. After the lady left I was told not to worry that I would get used to dealing with upset patients, it was best to ignore it and that they, “all come round in the end”. This incident happened in 1975 and years later in 1989 we were still telling patients they would, “get used to it”- although hopefully with more empathy as time progressed!

I decided to do the Health Studies degree, mainly to give me an interest, but was unprepared for the level of interest and commitment it provided! The first insight I had was that the people I met in the clinic were not patients, they were each individuals with varying degrees of difficulty in maintaining communication but they
were not sick and, with the exception of the very few who had conductive hearing problems, we were not setting out to “cure” them. What I felt was needed was a rapport with the person that would continue throughout their time attending the clinic, which is often from the date of their hearing aid fitting until the end of their life. As time progressed I was conscious that I was building long term relationships with people, often fitting children with hearing aids who later returned with their own children to be tested. I tried to adapt my practice to allow this relationship to develop and was successful to some extent but the sheer numbers of attendees at clinics and the shortage of qualified Audiologists made this difficult to implement on a large scale. At times I felt the throughput of patients meant that I could not take the time to develop a good relationship and always felt dissatisfied when I was working in what I referred to as a conveyor belt system of hearing aid fitting.

I obtained my BSc Hons in 1992 and immediately registered for my Masters in Audiology at University College London. This expanded my knowledge of diagnostic audiology immensely and although I enjoyed the “detective” aspect of diagnostic work I became aware that I actually preferred the human interaction of taking a history and discussing results more than the procedures themselves. I was also frustrated that I had not learned more about rehabilitation and seeing this as my niche in the profession I embarked upon seven years of counselling training. I still felt that as a profession we were not fully meeting the needs of individuals with acquired hearing impairment, and had a sense that this might be because we focused on the technology rather than on the counselling. I felt this was something that needed to be addressed and so I decided to concentrate on these missing elements for my PhD.

At the beginning I had little idea of where I was going or how I was going to get there, I had just the kernel of an idea and the drive to do something useful. Over the last few years I have grown as a person and as a researcher, and I am now confident in my ability to carry out appropriate qualitative research in order to increase our understanding of the psychosocial aspects of acquired hearing loss.

Having reached the end of this journey, everything has fallen into place and I understand now why it is so difficult to explain the process of constructing a Phenomenological Grounded Theory. It is indeed true that you have to, “just do it”
as so much of it is experiential and instinctive. The instincts and concepts do however have to be firmly grounded in the empirical data and this can be a difficult concept for the novice researcher to grasp. With this in mind I have reflected over the various stages of the journey, sharing my thoughts and memos as I put together the strands that finally became the theory. It is impossible to construct a Phenomenological Grounded Theory in a linear manner but in separating out some of the main stages I hope to share information with others that will be useful for their own research. It should be borne in mind that this is written from the perspective of a naïve researcher and some of the memos and discussions used in this chapter may seem simplistic, nevertheless they are relevant to the work and therefore presented in their original state.

7.1.1 Choosing the right Method.
As previously mentioned I had an area of interest but little knowledge of the best way to conduct the research. My previous training in research had been predominantly quantitative but I felt this would not give me the rich data I needed to explore this experience so I started to increase my knowledge of qualitative methods. I had previously undertaken a thematic analysis and looked at this method first but again felt it did not meet my needs as I did not feel it would add significantly to the body of knowledge. I finally decided Phenomenological Grounded Theory would be the best method for two reasons; firstly it would give me data on the individual experiences which I felt would help the professionals understand their patients, but secondly and more importantly it would provide a core of knowledge that could be used to advise policy decisions. Realistically, the NHS in particular is not going to be able to provide a service customized for each patient, but it may be possible to design services that address the core concerns and hence improve services.

At the beginning of this journey my experience of Grounded Theory at that time was purely theoretical and incomplete so I needed to do a lot of reading in order to understand the various strands as outlined at various times by Glaser, Corbin, Strauss and Charmian. I believe the first stage in carrying out Grounded Theory is deciding where your personal philosophy aligns with the method. I found it difficult to reconcile the fact that I was instinctively drawn towards Classic Grounded Theory, despite the fact that I consider myself to be forward thinking and open to understanding that theories adapt and refine over time. I reflected on this for a while
and became aware that I was trying to force myself into a method of working that actually frustrated me. Having reflected on this further I became aware that the idea of the researcher being part of the construction of the theory caused this unease. I felt that I would find it difficult to manage that interaction and I also realized that I felt some anger at the idea of the researcher, particularly if they have a vested interest in the subject, could contribute to the theory. I wanted this theory to be owned by the participants rather than influenced by the professionals. This may be because I was so close to the subject and walking the fine line between enhancing theoretical sensitivity and influencing the outcome. In addition to this I realized that I preferred the Classic approach because it was just that, Classic. I had obtained a bursary at the age of eleven to attend a high school. The school had a reputation for providing a sound classical education and a great deal of importance was placed on the values of tradition and reputation. I realized that I had introjected a lot of these beliefs in my formative years and subconsciously valued the Classic method more highly that the Constructivist. My main concern with the Constructivist method was that it seemed from my reading that a lot of adaptations were being made and I found it difficult to feel comfortable with a method that allowed such individual interpretation of “the rules”. I did have some alignment with Strauss' belief that there is more than one reality. However at that stage, following the structure of the Classic method gave me more confidence to undertake the research. I think it is important to feel comfortable and have confidence in your chosen method before starting the process of data collection.

Memo: Background reading

I feel as though I am making no progress with this reading. I read Glaser and Strauss and the classic method makes perfect sense to me but I cannot accept the fact that there is one reality. Perceptions and personal experience play such a part in the construction of reality and I believe that everyone’s reality is valuable and relevant. I can accept that there is a “core reality” which exists made up of a collective reality- although I know that comes from my allegiance to Jungian psychology! It does seem possible thought that I can reconcile these and use the classic method without subscribing totally to Glaser’s beliefs.

Strauss and Corbin, I find problematic because the “method” seems to rather concentrate on deconstruction rather than construction. Axial coding seems to be a layer of coding that re-links the concepts but I have concerns that this may prevent some of the creativity and intuition that was part of the former Classic method. –The
word classic keeps resonating with me. It brings back memories of school and support, I think there may be a lot of transference going on here as I am beginning to experience Glaser as a friendly trustworthy old fashioned school master- despite the fact I know very little about the man – and Strauss as the “betrayal” who moved away from the method and started his own path. – Again I think this is because of the relationship with Freud and Jung. Although I would describe my therapeutic position as Jungian, I still defer to Freud as the “master” of psychotherapy and see the schisms in the psychotherapeutic field as betrayals of his trust. Hmm deep rooted stuff!

I really struggle with Charmaz’ work. I understand the rationale for the researcher being a constructive part of the data, and this certainly gets round the idea of bracketing experience but it’s just too wide for me. I have a lot of experience of working with hearing impaired people but not with hearing impairment per se so while I think there may be times when it is better for the researcher to be part of the process, I don’t think this is one of them. I want to look at the lived experience through the participants’ voices not my preconceived ideas, so I have to distance myself as far as possible from my experience. It just does not feel right to risk doing otherwise.

Interestingly, this opinion changed as I continued to explore the project, and I realised that I was in fact not comfortable with the methodology of Classic Grounded Theory, rather I was looking for a “roadmap” to cling onto in my uncertainty. As my understanding grew and I reflected on my beliefs I realised that it was more natural for me to use a method than allowed interpretation drawn from experiences in addition to the data itself and consequently developed the analysis accordingly.

### 7.1.2 Sampling and data generation.

I found this aspect difficult to conceptualise but the process became clear very quickly when I started to collect data. My first interview was quite daunting and my first memo on interviewing (shown below) recorded my concerns about how I had conducted the interview.

<table>
<thead>
<tr>
<th>Memo: First participant’s 1st interview (NHF1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found this interview more difficult than I thought it would be. I felt as though I was trying to keep a fine balance between getting information and leading. At times I fell into the Counsellor role and felt comfortable with that but then I had to remember</td>
</tr>
</tbody>
</table>
As I progressed with the interviews I found I was less concerned about asking questions and as I reached the theoretical sampling stage it was much easier as I had a more defined area to explore. I became aware of when I was becoming interested in the individuals concerns more that obtaining the information and was able to bracket my professional interest while the interviews were being conducted.

7.1.3 Memos
My experience was that memos were an integral and core part of the process. I started by making memos on my background reading and preparation and always wrote at least one memo immediately after each interview. Initially, these were quite short and factual, but they developed over the course of time into longer more
meaningful pieces of writing. The course of qualitative research does not run smoothly and sometimes insight comes at inconvenient times, so although I started by typing memos that I filed in a folder on my computer. I often found that I would be talking to someone about my project and suddenly I would realize something about a piece of data. Therefore I started to carry a notebook with me so that I could make some notes wherever I found myself. I noticed that talking often helped me to understand the meaning of the data better than reading it, so I changed to a voice recorder, and would record myself mulling over areas I was working on. I soon found that discussing it out loud and finding answers in this way was the most productive method of memo taking. I did not have to think at the pace of my typing and consequently I made fuller notes that I could replay and add to on a regular basis. On reflection I could have started making more specific memos much earlier in the process, even before I started familiarizing myself with the details of the method however in my personal journal I had captured concerns and thoughts about my progress in the earlier stages of the study before I started to collect data so I was able to draw on these writings. In future studies I will start memo writing at a much earlier stage.

7.1.4 Constant comparison and writing up.
This stage was crucial to the project and the largest part of the process. To a certain extent writing goes on throughout the project, with memos at regular stages, but the formal writing up takes place once the core category is identified and theoretical sampling is underway. I found constant comparison was easier if I took the memos relating to the current participant and the previous participant and wrote a memo about them both, this helped to highlight the themes that needed to be explored and contributed to the final write up by providing a basis for the structure.

<table>
<thead>
<tr>
<th>Memo Constant comparison (following interview with COPA 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Again there was this concern about “must answer the professional’s questions. This gatekeeper theme keeps coming up. If I don’t play the game I don’t get what I need. Is this a form of people pleasing that influences the consultation? Do we need to take longer to develop rapport? There still seems to be the impression that the gatekeeper has the power. E.g. will they make me wear 2</td>
</tr>
</tbody>
</table>

Again there was a reference to “it bothers me” this seems to be the trigger for taking
Another aspect of the cost benefit analysis is how much trouble it is to do something. It is sometimes easier to maintain the status quo, and changes are often made to please others rather than self, but this can lead to resentment.

Again lack of knowledge causes concerns. Concerns can also be used as a passive aggressive means of not wearing an aid. It might be the case that when someone has a lot of contradictory concerns that more focus on counselling is needed.

Again, like the last interview, self-image and the implications of hearing aids were to the front of this interview. There seemed to be a time when the participant opened up and would have benefitted from some motivational interviewing or challenging to help her move on. This lady was not yet ready to wear a hearing aid and it is likely that without further input that she would have a negative experience of the process.

Looking back over the last interviews there have been some recurrent themes and despite people feeling different about their hearing aids there were some similarities. What struck me was that this cost benefit analysis seems to be the crux of whether or not people self-refer.

I thought at first that “When It bothers me” was the trigger but this latest participant admitted that it bothered her but still was resistant to taking action. I think perhaps it is not “when it bothers me” is not the trigger rather the trigger is when the CBA convinces the person that taking action is the lesser of two evils.

7.1.5 Core category.
The identification of the core category is pivotal to the whole process of Grounded Theory. Once this is established the rest of the data can be clearly constructed to support this category. I had some difficult establishing the core category at first, and consequently I felt I was forcing the data to fit into this category and into a model that did not fully describe that which emerged from the data. As I revisited the data and thought more conceptually, I realised that I was able to raise the data to a higher level and identifying the core category became more straightforward. This experience strengthened my agreement with Glaser’s belief that the data should not
be forced. In eagerness to find the core category it is hard not to try to make everything fit into a perspective with which one is familiar and comfortable. In the final analysis the core category came as rather a surprise to me initially, although I soon recognised that it did actually convey meaning that was grounded in the data and fit with observed experiences.

<table>
<thead>
<tr>
<th>Memo</th>
<th>Core category</th>
<th>September, 2013</th>
</tr>
</thead>
</table>
| I have been thinking the core category was **Acquiring hearing loss** and working on the premise that this process is predominantly a linear one- as in the patient journey devised at the Ida institute. I think now that that is not the case, I have been trying to force everything into that journey and on the surface it seemed to work, but the bit I struggled with was the end of the journey, where the person was “rehabilitated” or left the service. In the data this did not really happen. Even people who had been fitted with hearing aids etc. didn’t fit into this new category of “hearing impaired”. That is not how they described themselves and the acted differently in different situations so it was as though they were choosing the role that suited them best depending on the circumstances. So it’s not about becoming aware and accepting hearing loss, it is about **doing what it takes to preserve the life you have**. So if it is safe for you to say, act the part of a person with hearing impairment e.g. with family members who know about the problem, then individuals will do that. If, however the circumstances dictate that there is a threat e.g. in a job interview where hearing impairment may be held against you, it is more likely that the person will act as if there is no hearing impairment, as far as possible. In other words take measures to show that he is capable of functioning at the same level he always has. This isn’t linear; it isn’t even an increment on a pendulum. It is either/or depending on circumstances. It’s about preserving the identity others associate with the person. That would explain why individuals act incongruently in certain circumstances. This is not about how the person sees themselves, the self-identity can remain the same, but the person will act in such a manner as to **Preserve the social identity**. I think this is the core category and now everything else has fit. The trigger for asking for help isn’t “because it bothers me” It’s when the strategies for preserving the social identity cannot be maintained without external input e.g. amplification. The individual is trying to fix a “broken” hearing person rather than becoming a hearing impaired person. Rather than taking on a new social identity they adapt their current (spoiled) identity as far as possible to maintain the status...
quo. This reminds me of Goffman’s work on identity
This would explain why people keep saying “I’m not deaf” They see hearing impairment as something that may lead to them being seen as something with which they don’t identify and want to make it clear that they don’t identify with this. They don’t want to become a “deaf person” they want to be “fixed”. This lack of ownership of a new identity may explain why people will take on the role but never really accept the change in role.

7.1.6 Conclusions
Phenomenological Grounded Theory proved to be the best method for this project. It identified not only individual concerns that needed to be addressed, but also a structure that explained what was happening for the individual and how it could be incorporated into rehabilitation. In order to create a robust Grounded Theory great care needs to be taken at each stage (although the stages are concurrent rather than sequential) to produce and record evidence in a manner that allows critical evaluation and audit. In order to raise the data to the conceptual level required to construct the theory, the researcher needs to be able to use intuition to identify concepts and then ensure these concepts are firmly grounded in the data. It is a labour intensive method of research but one that produces the rich data required for research into the lived experience of acquiring hearing impairment.
8 Summary and implications for clinical practice, research and the profession.

8.1 Introduction.
The aims of this study were to develop a Phenomenological Grounded Theory that explored the essence of acquired hearing impairment and offered a model that may be of value to practice. The thesis also explored the impact of concerns on rehabilitation. The thesis met these aims by drawing on the principles of Phenomenology and Grounded Theory methodology to develop the emergent model in the substantive area of social identity, presenting the participants main concern of preserving the social identity.

It should be borne in mind that Phenomenological studies are undertaken with respect to human science criteria. Therefore the data cannot be presented in the same way as natural science projects. Human science has its own criteria for rigour exactness and precision (van Manen 1990), Phenomenology is not an empirical analytical science and therefore does not seek to prove hypothesis but rather to provide full descriptions and interpretations of human phenomena (van Manen 1990). Therefore it adds to the understanding of knowledge by making explicit the essence of lived experience and defines taken for granted knowledge. It does not necessarily seek to produce new knowledge but rather provide action sensitive knowledge.

This chapter summarises the contributions to knowledge of this thesis, and discusses theoretical and practical implications. Suggestions for service development are also offered.

8.2 Summary of the phenomenological Grounded Theory.
The Grounded Theory explains the methods used by individuals to address concerns about “Preserving the social identity” when experiencing acquired hearing impairment. Central to dealing with this is carrying out a situational cost benefit analysis of the level of threat in relation to the level of confidence in any available interventions.
When hearing impairment is first noticed, individuals will strive to maintain the present social identity in order to remain with the “normals” and will use a combination of coping mechanisms and ego defences to demonstrate that there has been no change in their ability to participate in activities. The extent to which they can do this without becoming discredited depends on the communication partners, relationships and setting. Individuals may be more comfortable with asking family members or close friends to repeat things but less likely to ask in formal situations such as work interviews. The higher the risk to their being able to remain with the in group the more likely they are to seek additional help to enable them to communicate. Again this is situational as they may prefer to wear hearing aids at home in family groups but not at work. Even if they have a high level of confidence in the intervention, the individual will still chose to maintain the status quo until they reach a point where they can no longer do so, when becoming discredited becomes less important that remaining with the in group even if in a “lower” status. The main concern was preserving status and stigma was not related to the physical dimensions or design of the hearing aids but rather the associated links between hearing aids and age/lack of competence.

8.3 Contribution to current theory and practice

Grounded Theory can be used for two purposes; the first is to create a substantive theory in areas that currently have little research, and the second is to look at situations in a new way. This thesis has achieved both of these. It has created a substantive theory within the frame work of social identity theory in relation to Audiology, an area that is presently under researched, and it has looked at barriers to compliance with aural rehabilitation from the individual’s perspective rather than concentrating on technological barriers. As previously stated in Constructive Grounded Theory and Phenomenological research the aim is to describe and further interpret the essence of a phenomena, and not necessarily to develop new theories (Charmaz 2006) and, although new information was in fact obtained, this description and interpretation were the main aims of this thesis.

Although the participants in this study were all individuals with acquired hearing impairment whose experience was of aural rehabilitation, the fact that the data resonates with empirical evidence outlined in social identity theory means that it is also relevant for individuals facing a range of acquired disability, and for the
practitioners who provide healthcare services. The key contributions from this thesis to current knowledge are in the areas of:

- Social identity theory
- Cognitive aspects of identity integration.
- Aural rehabilitation
- Service needs
- Professional education.

These will be discussed in the next section, and are summarised in table 8.1. This table shows where the thesis confirms, challenges or extends earlier findings and where new findings have emerged.

*Table 8.1 Summary of outcomes of thesis.*

<table>
<thead>
<tr>
<th>Thesis contributes to;</th>
<th>Thesis supported;</th>
<th>Thesis challenged;</th>
<th>Thesis added to;</th>
<th>New knowledge;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Robertson (2014) preserving a sense of social status to give meaning to life.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wänström(2014) Psychological approach form avoidance to acceptance in adults with</td>
<td></td>
<td>Knowledge of the process of moving from avoidance to acceptance</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>This thesis expanded on this work by including participants from different parts of the</td>
</tr>
<tr>
<td>Cognitive aspects of identity integration</td>
<td>Amiot et al (2007) and Gendreau (2013) work on integrating social identity</td>
<td>Knowledge of cognitive aspects of identity integration in the field of audiology</td>
<td>As above</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Design of Service provision</td>
<td>Multidisciplinary working in rehabilitation. Peer support in rehabilitation. Extension of rehabilitation skills and techniques</td>
<td>Use of screening programmes to encourage hearing aid uptake. Present levels of rehabilitative services The use of Pure tone Audiometry as the sole</td>
<td>Alternative approaches to aural rehabilitation.</td>
<td></td>
</tr>
</tbody>
</table>
8.4 **The core category and present service provision.**

Preserving the social identity was the core concern in this theory, and individuals will try to maintain their present social identity until they reach the point where they can no longer cope without additional help. This offers an explanation for why some patients wait for up to 14 years before seeking help. In order to provide a comprehensive person centred service, there should be time to discuss these concerns and establish where the individual is in terms of integrating this new identity into the self. Until health care professionals acknowledge and explore these concerns it is unlikely that we will be able to support individuals at an earlier stage in the journey of acquiring hearing impairment. At present there is pressure on government to fund screening programmes for older people, but the data from this study did not support the use of these programmes. Participants felt they might make use of screening sessions if they did not inconvenience them, but, regardless of the outcome, would still be reluctant to pursue hearing aid provision until they felt they needed to.

At the present time, there is a mismatch between the focus of the professional in audiology and the patients they serve. The Audiologist’s priorities are to provide the most appropriate technological solutions in the shortest waiting time possible. In this respect we meet the needs of patients who have reached a point where they have decided to seek technological help, however this is a small percentage of the population who could access aural rehabilitation. The priority of the patients is to
preserve their social identity by whatever means possible, and in this they feel there is no support, until they reach the stage of asking for amplification. This means that many consultations begin with different goals and until services adapt so that professional’s priorities match those of patients it is unlikely that we will make significant progress in the field of aural rehabilitation.

Part of the difficulty experienced by potential service users is the lack of appropriate information at appropriate venues, leading to lack of knowledge about services other than hearing aids. This means that the perception of the public is that Audiologists fit hearing aids, not that they offer a range of rehabilitation services. Unfortunately in many cases the situation is that only hearing aids are offered, and consequently although peer review of services suggests that Audiology clinics provide a high standard of service, it is centred on this one area of rehabilitation. Changes to services need to be made if we are to engage with individuals at an earlier stage and in a more meaningful way, in order to provide services that are accessible and acceptable. If aural rehabilitation starts at an earlier stage with counselling and information to support the individual in integrating this life event into the self, we may be able to reduce the isolation and depression associated with years of using maladaptive coping mechanisms and ego defences. In so doing we can also prepare individuals for the stage when they choose to wear personal amplification.

Aural rehabilitation programmes at present focus on communication skills and technology, but there needs to be provision of dealing with the emotional consequences of acquiring hearing impairment. For many practitioners this will mean development of different skill sets, and adaptation to clinical appointments. Many practitioners may be concerned about the time this will take, but it is possible to accommodate this by adapting and expanding services by means of multidisciplinary working and peer support. To provide truly patient centred services individuals concerns need to be addressed. In order to do this the following areas need to be considered:

1. Assessments,
2. Communication,
3. Society’s Role
4. Education
5. Resources.
These are discussed below.

8.4.1 Assessments
The present assessment normally includes a short medical and social history, examination of the ears followed by a pure tone audiogram and /or uncomfortable loudness level test. Following this an impression is made and the patient returns at a later date to have their hearing aid fitted. More recently improvements in hearing aid technology have meant that for most patients the hearing aid(s) can be fitted in the same day. This is an excellent solution for patients who have decided to have hearing aids, but it can mean that a patient who has come to confirm or deny a hearing impairment may go home from the hospital with a hearing aid before they are prepared to accept that they have a difficulty. Pure tone audiograms (PTA) have limited use in evaluating the impact of hearing impairment. A PTA will tell the Audiologist the quietest sound the patient hears at each frequency, but does not give any information about how the sounds are processed by the individual. Therefore although the PTA is a useful starting point for programming hearing aids, it is of limited value in finding out how the person’s life is affected by the impairment. In a time limited consultation it would be much more beneficial to use the assessments appointment to listen to the patient and establish his concerns and goals. Once these have been established, Audiologist and patient can explore and agree goals together and move forward in an equal relationship. These goals may include assessing the hearing and if this is the case this can be done using speech testing to demonstrate what if anything the patient is missing in everyday communication.

As mentioned previously, professionals are concerned about having sufficient time to carry out assessments but it has been shown that by changing the style of the consultation rather than the length of time taken, effective changes can be implemented. If these changes were made as part of a restructuring of audiology services, other professionals and volunteer involvement could reduce the number of patients seen at Audiology departments who are not yet ready or willing to wear hearing aids, and this in turn would produce time efficiency savings. Since patients would not feel pressured or obliged to take hearing aids, there would also be financial savings in terms of unused hearing aids being lost to the system. A further consideration is that if Audiologists have different goals from patients then much of the clinical time is being used in unnecessary assessments and hearing aid fitting.
This time could be freed up if practice were adapted so that the time could be used in a more person centred way.

8.4.2 Communication.
Communication between professionals and service users is important, but communication in the wider sense needs to be improved. Information needs to be available in a variety of venues and formats in order to reach all age groups (see table 8.2 below). Publications should cover all aspects of hearing impairment so that the public can access information about a variety of skills and how to access further training.

Manufacturers have a role to play here too. By portraying hearing impairment in a more positive light they can help to break down the stigma associated with losing hearing. Individuals do not relate to younger models in hearing aid advertising as this does not reflect the impressions they have of others with hearing impairment. Advertising using their own peer group may send a clearer message that people aged 50 + can lead useful competent lives.

8.4.3 Society’s role.
Until preconceptions about stereotyping of hearing impairment change, individuals will feel the need to postpone being discredited for as long as possible. Therefore not only the profession but society in general has a role to play in changing perceptions. There are several ways this can be done. Educating children in school about deaf awareness would help future generations grow up with an understanding of hearing impairment and foster better communication skills. Better access and information about assistive listening devices would help those with hearing impairment to integrate more easily and help to “normalise” hearing impairment. Finally using peer volunteers to support newly diagnosed individuals may help to portray a stronger in group for those with hearing impairment and offer them the choice of staying with their current in group at a lower status or identifying with an in group of individuals with hearing impairment.

Our society is predominantly phonocentric and consequently the large group of hearing individuals are part of a strong in group with a well-defined identity. We also have a group that is growing in strength and identity, the Deaf community. Both of these groups have clearly defined “criteria” for inclusion in the group, but in terms of
numbers the hearing group is larger and more influential. Those individuals who
acquire hearing impairment do not have a strong in group to represent them. They
will either stay with the hearing group, making adjustments to maintain their current
status until they have to accept that they can only continue with an altered status
within this group, or join the deaf community, a group with which they have no
common identity in terms of language and culture. Although there have been some
hard of hearing clubs in the UK in the past, their influence was limited, in part
because individuals felt membership would be discrediting, and thus there has been
little opportunity to develop a strong in group of individuals with hearing impairment.
Using peer support as a means of rehabilitation increases the chances of individuals
building and strengthening a group with common identity and could help to change
perceptions of hearing impairment in society.

8.4.4 Education
A BSc in Audiology is no longer routinely offered and England, Wales and Northern
Ireland have all adopted the managing Scientific Careers (MSC) Pathway. This is a
three year generic health care science degree that focusses on the scientific and
technical aspects of Audiology, i.e. diagnostic testing and hearing aid fitting. This
training does not provide the counselling and rehabilitation training required by
Audiologists to meet patients’ needs. At the present time Scotland has not yet
adopted the MSC pathway, and it would be prudent to consider the impact of this
pathway on providing the needs of the patients in Scotland. The professional bodies
in audiology have expressed their concerns about the curriculum, which is very
prescriptive, to MSC but at present the chief scientist has indicated there are no
plans to expand or adapt the curriculum. Retaining a four year BSc. in audiology in
Scotland would enable students to develop sufficient rehabilitation skills to perform
these tasks comprehensively.

8.4.5 Resources
It is accepted that there are limited resources for healthcare funding and any
changes need to be undertaken with consideration to present and additional costs.
Audiology is no different and providing a more comprehensive service would appear
to suggest an impact on resources. However not all services need to be provided
by Audiologists.
The Scottish government is committed to a service where health and social care are more closely aligned as evidenced in their 2020 vision report (Scottish Government 2011). This model could work effectively in conjunction with the third sector to provide a person-centred Audiology service. A proposed service is outlined in table 8.2 below, indicating the resources services and potential venues required for different stages of the patient journey.

Table 8.2. Proposed rehabilitation service.

<table>
<thead>
<tr>
<th>Stage in journey</th>
<th>Service required</th>
<th>Provided by</th>
<th>Possible venues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Access to screening on request</td>
<td>Health Care assistants</td>
<td></td>
</tr>
<tr>
<td>Comments from others about difficulties</td>
<td>Information available in public venues/internet. Information service from local clinic/ and GP</td>
<td>Action on Hearing Loss Scottish Council on Deafness Local service groups Local Audiology Department</td>
<td>Libraries Health Centres Social Centres Cinemas Health clubs Council offices Transport centres G.P surgery Local Audiology department Audiology departments Hearing aid dispensing offices Local clinics</td>
</tr>
<tr>
<td>Stage</td>
<td>Activity</td>
<td>Department/Role</td>
<td>Location</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Access to</td>
<td>screening on request</td>
<td>Health Care Assistants Practice nurses</td>
<td></td>
</tr>
<tr>
<td>Noticing</td>
<td>hearing impairment but not yet decided to take action</td>
<td>Information service from local audiology clinic GP and volunteers(with screening if requested)</td>
<td>G.P surgery, Local Audiology Department, Local clinics</td>
</tr>
<tr>
<td>Ready to take</td>
<td>action</td>
<td>Exploratory session Development and implementation of components of the agreed personal management plan</td>
<td>Local Audiology Department Community settings</td>
</tr>
<tr>
<td>Having</td>
<td>hearing aids fitted</td>
<td>Instruction and orientation to hearing aid. Volunteer support Access to rehabilitation sessions</td>
<td>Local Audiology Department Community settings Patient’s home</td>
</tr>
<tr>
<td>Ongoing review</td>
<td>Volunteer support Access to group rehabilitation sessions</td>
<td>Peer volunteers</td>
<td>Community venues</td>
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</table>
8.5 The proposed model in relation to current and proposed Health care Policies.

The conclusions and recommendations from this thesis fit with the recommendations of other health care providers and the Scottish Governments proposal for the future of health and social care provision. For example, Diabetes UK (Diabetes UK 2014) published a report in 2009 entitled “Improved supported self-management for people with Diabetes”. In this report they outlined the essential support systems that need to be in place for diabetics to self-manage their conditions. There are similarities between the services provided to diabetics in terms of length and number of consultations with medical staff to those provided in audiology. For most diabetic patients there is a routine check-up once a year and then individuals self-manage their condition with help from a range of individuals.

The report suggests the following support should be in place:

- Personalised care planning
- High quality tailored information
- Access to structured education
- Access to healthcare professionals and trained specialist advice when required.
- Emotional and psychological support
- Support from peers, family, friends and carers

These support systems are very similar to those required by individuals in this thesis. The personalised care planning could be undertaken at the first visit to the Audiologist resulting in a comprehensive individual management plan that addresses every aspect of rehabilitation. High quality customised information could be produced by support charities and local Audiology working groups and could be provided at a range of public and private venues throughout the catchment area. Access to structured education could be provided through rehabilitation programmes delivered directly or electronically through the use of the internet or smartphone apps. Emotional and psychological support has already been identified as a key theme and should be provided as part of rehabilitation and final support from peers, family, friends and carers could be facilitated by widening access to rehabilitation programmes and training peer volunteers. This report made some recommendations that also relate to audiology provision these include:
• Provision of and signposting to tailored information and awareness programmes in varying formats
• Improved access to emotional and psychological support including encouragement to access peer support
• Delivery of programmes and practices that empower and enable individuals to move from passive recipients to active partners in their own health and healthcare.
• All healthcare professionals should have access to skills-based training to support self-management and care planning, including group facilitation, active listening, goal setting and problem-solving skills.
• Health services, working with partners, should train and support people to influence and contribute to service improvement, redesign and monitoring, to advise on the self-management support services required.
• Development of better levers, systems and incentives that encourage healthcare professionals and services to prioritise support for self-management, for example the inclusion of structured education as a quality and outcomes framework indicator as part of a care plan.

The recommendations for working together to provide support for self-management are reflected in the Scottish Government’s 2020 vision report (Scottish Government 2011). In this report the government sets out its vision for combined health and social care by 2020. Priorities have been set in three domains; quality of care, health of the population, and value and financial sustainability.

One of the themes is independent living and Audiology services play a key role in maintaining independence by assisting communication skills and ensuring safety by providing assistive devices for individuals who cannot hear fire alarms or door bells. Promoting services that lead to self-management will enhance independence and help to meet this objective. One of the key deliverables put forward for 2013-14 was to integrate health and social care services to promote a seamless service to the public. This gives the opportunity for health and social services to work together to provide effective rehabilitative services for those with hearing impairment. Combining this with partnerships in the third sector will allow substantial changes in the range of services that can be offered to individuals. Two of the deliverables planned for 2013/14 are also relevant to this thesis.
8.5.1 People-powered health and care services.
The government intends to expand on the Patients' Rights Charter to give more power to individuals to shape and contribute to service quality. In addition it will promote greater personal responsibility for health and self-management. In order to do this, sufficient resources must be available to allow patients to make informed choices. The recommendations in this thesis fit with this aim, and are in keeping with the government's proposed developments in health care.

8.5.2 A review of national services to NHS Scotland to increase shared services.
In some areas audiology clinics provide hearing aids and social work departments provide assistive listening devices. Many elderly patients with hearing impairment that use both health and social services find it difficult to work between two agencies. By combining health and social care a more seamless service may be provided and the input from social services may help to change the public perception of hearing impairment from a disability to a social issue, which would be more aligned to the feelings and needs expressed in this thesis.

8.6 Summary.
The thesis has shown that the most important concern for the participants was preserving their social identity. Within the framework of social identity theory, the individual will integrate new elements into the self and this is evident in the journey individuals with acquired hearing impairment make. There is a mismatch between the needs of the individual at various stages of this process and the present system of rehabilitation. In fact Audiologists appear focused on technological solutions but individuals require a range of services at different stages. The main focus in the early stages of aural rehabilitation should be listening to the patients' concerns and helping them integrate the hearing impairment into the self in order to take ownership of this and move on.

Many of the services need not be provided by Audiologists per se but by other members of the community thus giving the opportunity to influence the perception of acquired hearing impairment. Professionals involved in aural rehabilitation should be adequately trained in active listening goals setting and counselling skills. The proposed model fits with the Scottish Government's policy of self-management and combined health and social care.

In the final chapter I will review the aims and outcomes of thesis and critique the thesis in terms of limitations, fit, relevance work and modifiability.
8.7 Conclusion

8.7.1 Introduction
In this final chapter I will discuss the aims of the thesis and how these aims were met by using the principles of Phenomenological Grounded Theory. I will then discuss the credibility of the thesis and its limitations. Finally I will discuss its contribution to knowledge and opportunities for future work.

8.8 Aims of the study
The aims of this study were to describe and interpret the lived experience of individuals with acquired hearing impairment in order to better understand their rehabilitation needs. A purposeful sample of adults aged 50 and over with acquired hearing impairment was obtained from the United Kingdom and North America. Participants contributed to open interviews, focus groups and Audiological assessments. The interviews were transcribed and checked for accuracy and the data was coded according to the constant comparison method used in Grounded Theory. A core category was identified, “Preserving the social identity”, and a model was constructed to explain the lived experience of this phenomenon. Although the sample in this study was small, this is in keeping with Phenomenology and Grounded Theory, where the aim is to obtain rich data from a small number of participants. The core category emerged from the data and was repeatedly referred to across the participants. This can be seen in the transcriptions provided in Appendix D. The findings were interpreted with respect to Health belief models, Goffman’s (1983) work on stigma and Social Identity theory (Tajfel 1981).

8.9 Credibility of the thesis.
Grounded Theory is evaluated in terms of fit, work, relevance and modifiability Glaser (1978). “Fit” relates to the validity of the study. This is measured by the extent to which the theory is representative of the behaviour under investigation. Validity was achieved through use of the constant comparison method to ensure the theory was not forced. It was also achieved by the use of negative cases to explore the data further and refine the codes, and finally by viewing the theory in relation to the extant literature to ensure fit.

Work relates to how individuals work through their concerns, this is clearly evidenced across the participants. Constant comparison and coding confirmed a
common goal that related to all participants and a method for working through these problems that was consistent across the data.

Relevance is related to the importance of the core concern. A combination of memo writing and reflection helped to conceptualise this core concern from the raw data. Using the constant comparison method the core concern emerged without forcing and reference to the extant literature demonstrated that this concern is expressed in other settings.

Modifiability relates to how the theory can be altered in response to new data or literature. The aim of Grounded Theory is not to prove theory but rather to provide a way of knowing that can be refined by further sampling. Further sampling in other areas may lead to modification of the theory, and indeed this will ensure that the theory retains ongoing relevance, but at the present time having met the criteria for fit, work, relevance and Modifiability, I believe that the thesis as it stands is theoretically complete.

8.10 Contribution to Knowledge.
Although the aims were primarily to describe and interpret the experience, new findings did emerge that can be used to inform practice. This thesis contributes to the knowledge about how acquired hearing impairment is viewed by those who experience it, and how this differs from the participants' perception of the professionals who provide the services. Despite the fact that professionals believe they are offering person centred care, the data suggests that in fact the services are profession driven rather than patient centred and as such do not always meet the expectations and needs of the service users. The data contributes to the knowledge about the psychosocial aspects of acquired hearing impairment and how the differing goals of patient and professional can hamper rehabilitation.

Finally the data suggests that the present technical method of rehabilitation is not conducive to good rehabilitation. The data suggests that hearing impairment is not viewed by the service users as a disability but an inevitable stage of life, one that should be embraced by the whole of society rather than seen a medical problem and as such, not manageable by trying to correct hearing impairment. The time spent on technological solutions rather than psychosocial solutions is disproportionate and in itself may not be a good use of public resources.
8.11 Limitations of the study.

Every study has its limitations, but Birks and Mills (Birks. 2015) refer to PhD theses in particular as apprenticeships, therefore the limitations should also be discussed in terms of personal learning experiences and development. These will be addressed in this section. Phenomenology and Constructive Grounded Theory allows the researcher to use instinct and conceptualization and is therefore dependent on the skills of the researcher. While every effort was made to keep closely to the criteria for producing a Grounded Theory it has to be accepted that naivety will have influenced the thesis. As previously mentioned in one of my memos I am aware that the early memos were very simplistic, none the less they led me to a theory that was grounded in data and emerged without being forced. Therefore I am confident that the theory is robust. Indeed lack of experience enhanced data collection and analysis as I was concerned about ensuring everything had fit and that I had reached saturation and, with hindsight, believe I continued to sample long after I had reached the point where no new findings emerged. The extra data did not contradict or modify the model and consequently I believe that the theory was not compromised by the continued data collection. Grounded Theory is experiential and the new researcher has to experience the process in order to use it effectively. Reading about saturation and how it is identified is useful, but having the confidence to stop in practice takes confidence and experience!

My experience of interviewing was the most enlightening experience in terms of developing research skills. In the early stages of interviewing I was confident that my experience as a Counsellor would enable me to be non directive and objective in the interviews. In fact this was much more difficult than I thought and there were times when I became so engrossed in the discussion that I was unaware at first when the conversation went off track. This concerned me as I felt I had moved from interview to conversation; however this is addressed by Brinkmann and Kvale (2015). They explain that interviews are actually views between two people in conversation (dialogue) and that it is appropriate to challenge and contribute to the discussion. This is also appropriate in Constructive Grounded Theory where the researcher constructs the data with the participants. I had also decided to use completely open interviews to ensure I did not direct the topic, however with hindsight I believe it may be helpful in some cases to make an interview schedule around topics rather than specific questions to keep the interviews consistent.
In this thesis, I chose to present the description, interpretation and coding together to present a comprehensive analysis. However I took the view as discussed previously that as a naïve researcher I should discuss the extant literature separately to provide clarity. Having completed the writing, I now feel it would be more concise to present the thesis with the extant data woven into theory. This would be my preference for future work.

This theory has been proven to have generalizability; however it is a substantive theory and not a formal one. In order to develop a formal theory and ensure the theory can be widely applied additional sampling and analysis would need to be undertaken in a broad range of disciplines. This theory describes the concerns the individual experiences when trying to preserve the social identity and as such relates to one aspect of being. It is not intended to suggest that this is the only process an individual goes through in acquiring hearing impairment and this should be borne in mind when planning and delivering services.

8.12 Further research
Several areas for further research were identified; Preserving the social identity was the core category of this study, and for Audiologists this suggests a potentially different way of approaching rehabilitation. In order to explore this further, an investigation into how individuals experience the impact of hearing impairment on integration of the social identity would add to the knowledge base, and help develop services that support them through this process.

Screening programmes may help to identify physiological changes in hearing but there is evidence that this in itself is not enough for individuals to take action. An investigation into the cost effectiveness of a screening programme as opposed to an educational programme leading to targeted screening needs to be undertaken.

A pilot should be carried out to establish ways of combining resources in order to provide a comprehensive rehabilitation service that deals with psychosocial aspects in addition to technological solutions. A first step in this could be a larger evaluation of how individuals experience services at present. The outcome of rehabilitation is presently evaluated using the Glasgow Hearing Aid Benefit Profile. (Gatehouse 1999) While this measures the reduction in residual disability it is designed for use in evaluating hearing aid fittings and is not sensitive enough to evaluate other
aspects of satisfaction. A questionnaire could be developed to capture information about additional aspects of the individuals' life experience.

8.13 Dissemination of Data
The findings from the study should be disseminated through professional journals and conferences in Audiology in order to inform Audiologists about the wider aspects of rehabilitation. Other bodies e.g. General practitioners, Social Workers, and third sector organisations would also benefit from this knowledge in relation to the provision of multidisciplinary delivery of services.

Education of Audiologists needs to adapt to ensure rehabilitation techniques such as counselling skills are robustly and reflectively taught in order to guarantee we produce new professionals who are confident in their ability to provide comprehensive services. In this respect the findings need to be disseminated to Professional and Government bodies in order to influence policy.

8.14 Final thoughts.
In summary, this thesis argues that the role of Audiologists is much more varied than providing hearing aids. We have the potential to change people’s lives and participants have indicated that they want professionals who will work with them to help them through this journey. We can provide excellent technology and copious instruction, but our service users want more than that, they want an “educated friend” who can support them and help them through all the aspects of this life change. It is an opportunity we should not waste. Perhaps we, as professionals, should bear in mind the words of the late Maya Angelou,

“People will forget what you did to them, they will forget what you said to them, but they will never forget how you made them feel”
8.15 References


FRANKL, V.E., 2014. The will to meaning; Foundations and applications of logotherapy. Plume books.


