The biopsychosocial impact of hearing loss on people with hearing loss and their communication partners

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DEDICATION

For Mamai.

ABSTRACT

Hearing loss is a prevalent condition that can have negative implications on the day-to-day lives of those with hearing loss, and their communication partners. Several reviews have identified numerous questionnaires that explore the impact of hearing loss, with little consensus among researchers as to their preference. One reason for this is a lack of an agreed framework concerning exactly what is the impact of hearing loss, and what is important to those who live with the condition. To address this gap in understanding, the experiences of those living with hearing loss or with someone that has hearing loss was investigated using various systematic research methods and tools.

A comprehensive review of published studies exploring the impact of hearing loss on those with hearing loss and/or their communication partner was conducted. An inductive (data-driven) synthesis of the research evidence led to the development of two frameworks; one for each perspective. Each framework comprised of three higher-level 'supra-domains' (i.e. Auditory, Social and Self) which capture the broader implications of hearing loss, and numerous lower-level 'domains' and 'subdomains' that tap into distinct aspects of life. The frameworks were evaluated for face-validity in focus groups with hearing aid users, communication partners and audiologists. Hearing aid users and communication partners were then asked to rank the domains in order of importance based on their experience of living with hearing loss. The domain 'communicating' was ranked most important from both perspectives.

A subdomain mutual to both frameworks, 'raising the volume of the television/radio' was explored further in a case-control study. The preferred TV volume across 42 couples where one partner was a hearing aid user and the other was a non-hearing aid user was measured. A mean difference in volume preference of 6.3dB was

observed between groups across the TV programmes viewed by all participants. The hearing aid prescription of hearing aid users was not verified.

Future research should explore how domains in the frameworks are currently being measured and addressed in clinic. Also, data-driven methods should be applied to identify coping mechanisms adopted by people with hearing loss and their partner to accommodate for the diverse range of hearing-related difficulties depicted in the frameworks.

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Venessa Vas

DECLARATION

I certify that this is my own work, except where indicated by referencing. No part of this thesis has been submitted elsewhere for any other degree or qualification.

Venessa Vas 13th October 2017

Venessa Vas Date

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LIST OF ABBREVIATIONS

AoHL	Action on Hearing Loss
APHAB	Abbreviated Profile of Hearing Aid Benefit
BRC	Biomedical Research Centre
BSA	British Society of Audiology
CPHI	Communication Profile for the Hearing Impaired
CSOA	Communication Scale for Older Adults
DAH	Deborah Anne Hall
dB	Decibel
DoHL-CP	Domains of Hearing Loss framework - Communication Partner
DoHL-P	Domains of Hearing Loss framework- Person with hearing loss
dB	decibels
dB HL	decibels Hearing Level
dB SPL	decibels Sound Pressure Level
GBI	Glasgow Benefit Inventory
GHABP	Glasgow Hearing Aid Benefit Profile
HARQ	Hearing Attitudes in Rehabilitation Questionnaire
HDHS	Hearing Disabilities and Handicap Scale
HHIA	Hearing Handicap Inventory for Adults
HHIE	Hearing Handicap Inventory for the Elderly
ICF	International Classification of Functioning, Disability, and Health
IHR	Institute of Hearing Research
Hz	Hertz
kHz	Kilohertz
MAA	Michael A Akeroyd
MMPI	Minnesota Multiphasic Personality Inventory
MRC	Medical Research Council
NHS	National Health Service
NIHR	National Institute for Health Research
PIS	Participant Information Sheet
PPI	Patient and Public Involvement
PRO	Patient-Reported Outcome
PROM	Patient-Reported Outcome Measure
PTA	Pure-tone Audiometry
SD	Standard Deviation
SLM	Sound Level Meter

SOP-HEAR	Significant Other Scale for Hearing Disability
SPL	Sound Pressure Level
SRM	Self-regulatory model
SSQ	Speech, Spatial, and Qualities of Hearing Scale
ULL	Uncomfortable Loudness Level
UoN	University of Nottingham
VV	Venessa Vas
WHO	World Health Organisation

CHAPTER 1. LITERATURE REVIEW

1.1. INTRODUCTION

Hearing loss is a chronic health condition that affects an estimated 300 million people worldwide (WHO, 2015). Hearing loss is currently estimated to be the 13th most common disease burden worldwide, and it is predicted to be the seventh leading disease burden by 2030 (AOHL, 2015). In the UK alone, around 11 million people have hearing loss. Given the aging demographic of the UK, this figure is expected to increase to 15.6 million people by 2035 (AOHL, 2015). The most common type of hearing loss is age-related hearing loss, and subsequently the prevalence of hearing loss is much higher in older adults than in younger or middle aged adults.

In this introduction of the thesis, the current evidence for adult aural rehabilitation and the diagnostic measures used to capture the impact of hearing loss will be described. Those outcome measures used to assess the effectiveness of an intervention will also be discussed. This literature review identifies gaps in clinical practice concerning patient-reported measures and patient-centred care.

1.2. HEARING LOSS

There are two main forms of hearing loss: conductive and sensorineural. Conductive hearing loss occurs where there is damage or blockage to the outer and/or middle ear (Katz, 2002). Common causes of conductive hearing loss in adults include a perforation to the tympanic membrane (Ibekwe et al., 2009) and infection. The underlying causes for some cases of conductive hearing loss are treated medically (Raz, 2004). Sensorineural hearing loss is caused by damage to the inner ear. Age-related hearing loss, otherwise known as presbycusis, is the most common form of sensorineural hearing loss. It is a

complex multifactorial condition characterised by symmetrical progressive loss of hearing over that can occur over several decades (Gates and Mills, 2005).

Ear infections, excessive noise exposure, head trauma, ototoxic medication are examples of factors that can cause hearing loss (Katz, 2002). Age-related hearing loss can occur in some people and arises due to a loss of hair cell function in the hearing organ, the cochlea (Schmiedt, 2010). Such deficits may be compounded by effects of auditory deprivation (Boothroyd, 2007). This may be particularly true for people who do not seek help or who are not aware of their hearing loss immediately. Hearing loss can also be accompanied by vertigo and/or bothersome tinnitus (Schreiber et al., 2010).

1.2.1. Diagnosis

In the UK, patients with suspected hearing loss undergo a clinical history and formal audiometric testing (pure-tone audiometry) to confirm the diagnosis, determine severity, and direct management for their hearing loss (BSA, 2011a). The aim of pure-tone audiometry is to measure the least intense sound someone can hear, known as hearing thresholds (dB HL) across a frequency spectrum (0.25-8 kHz). Other specialised audiologic testing may also be conducted if required (Katz, 2002). The hearing thresholds of an individual ear are typically described using audiometric descriptors rather than the numeric hearing thresholds at each frequency (BSA, 2011a). For example, hearing thresholds that are 20 dB HL and below across the frequency spectrum is classified as ‘normal’ hearing. An individual who presents with hearing thresholds above this level is categorised as having some level of hearing loss, and the severity of the hearing loss is based on the hearing thresholds. A hearing threshold between 20-40 dB HL is classed as ‘mild’ hearing loss, 41-70 dB HL is classed as moderate hearing loss and 71-95 HL is categorised as ‘severe’ hearing loss. Thresholds above this range fall into the ‘profound’

category (BSA, 2011a). It is typical for a hearing-impaired individual to present with hearing thresholds that fall into multiple hearing loss severity categories across the frequency spectrum. For example, the hearing acuity of an individual with age-related hearing loss is typically worse in the high-frequency region compared to the low-frequency region. Thus, they may present with milder hearing thresholds across the low frequencies and more severe thresholds across the high frequencies. Therefore, their classification of hearing loss may be 'mild-moderate' or 'moderate-severe' (BSA, 2011a). An individual with an ear infection on the other hand, is more likely to present with normal hearing thresholds across the mid-high frequencies, and elevated thresholds in the low frequencies. Hearing loss can also be categorised according to whether there is a hearing loss in one ear only (known as unilateral hearing loss), or where there is hearing loss in both ears (known as bilateral hearing loss).

The audiometric profile of a patient can give some indication as to the likely difficulties that individual may experience as a result of their hearing loss. It does not however, dictate the degree of difficulty and impact on a person's day-to-day life as two individuals with a similar audiometric configuration may manifest very different problems as a result of their hearing loss. Therefore, the audiogram alone cannot predict the extent of these difficulties (Cox et al., 2007, Dawes et al., 2014b).

1.2.2. Impact of hearing loss

The onset of age-related hearing loss has been suggested to have two main effects on the person's auditory perception. The first, is the change in relationship between the sound stimuli (what goes into the ear) and the sensation of sound (what the listener experiences) (Boothroyd, 2010). The second, is a change in the amount of information made available by peripheral auditory mechanisms to central auditory and linguistic mechanisms (Boothroyd,

2010). With hearing loss, the amount of information received is centrally reduced. The subsequent impact of hearing loss on speech perception is widely acknowledged (Schneider et al., 2005, Lavie et al., 2014).

There is a general consensus that hearing loss can also have a negative impact on various other aspects of an individual's life, such as quality of life (Kochkin and Rogin, 2000, Ciorba et al., 2012). This impact is known to extend beyond the degraded auditory capabilities such as listening and speech perception (Boothroyd, 2007). The potentially wider scope of difficulties attributed to hearing loss has been shown in numerous studies that have investigated its effects (Ng and Loke, 2015). Some studies have investigated the impact of hearing loss specifically on speech understanding (Lorenzi et al., 2006) or other aspects of life, such as work (Hetu et al., 1995) or social life (Mick et al., 2014). Other studies have explored the day-to-day impact of hearing loss more generally (Solheim et al., 2011). These impacts are known to vary considerably from person to person and the degree of difficulties correlates poorly with audiometric profiles (Gatehouse and Noble, 2004). The negative implications of hearing loss are explored further in CHAPTER 2.

1.2.3. Third-party disability

Some of the implications of hearing loss on the hearing-impaired individual can extend to those who are in regular contact with the hearing-impaired individual, such as family and friends. The World Health Organisation (WHO) has branded this phenomenon as "third party disability" (Hickson and Scarinci, 2007, Scarinci et al., 2009c). Third-party disability refers to the effect of hearing impairment on the unimpaired spouse (Scarinci et al., 2012). For example, whilst an individual may not have a hearing loss themselves, this concept proposes that they still may experience difficulties or problems as a result of their spouse's hearing loss. In this case, hearing loss creates an environmental factor which forms the

spouse's third-party disability. The term communication partner has been used to refer to these individuals, who may include the hearing impaired person's spouse, siblings, children, friends, relatives, colleagues, and carers (Lunner, 2013). Further information regarding the impact of hearing loss on communication partners is explored in CHAPTER 2.

The progressive onset of age-related hearing loss means that it can often be years, or even decades before help is sought. As a result, the individual with hearing loss may not always be aware of all the effects that hearing loss has had on his/her life. Communication partners may also find themselves having to repeat themselves more often to the hearing-impaired person, or to constantly put in greater effort to achieve effective communication such as speaking with a louder voice, speaking with precise articulation, facing the individual with hearing loss when speaking, or being in closer proximity to be heard rather than from a nearby room (Manchaiah and Stephens, 2013b). These increased demands may exert pressure on the communication partner which may in turn negatively affect their relationship with the hearing-impaired individual (Preminger and Meeks, 2010). It is therefore common for communication partners to play a role in encouraging the individual to seek help for their hearing loss as a result of the impact they perceive it to have on their relationship.

1.3. ADULT AURAL REHABILITATION

Currently, there is no single treatment that can be offered to patients that will cure them of age-related hearing loss, as damage to the cochlea over time is irreversible (Sindhusake et al., 2001). Adult aural rehabilitation has been defined as:

"the reduction of hearing-loss-induced deficits of function, activity, participation, and quality of life through a combination of sensory management, instruction, perceptual training, and counselling" (Boothroyd, 2007).

Hearing loss is typically addressed with the provision of hearing aid(s). It is common for hearing aids to serve as the primary (and in some cases the only) intervention for age-related hearing loss. Hearing aids serve to provide frequency-specific amplification to make sounds audible, while preserving comfort and perceived sound quality. Hearing aids cannot however, restore hearing back to normal (Gates and Mills, 2005, Picou et al., 2014). Other interventions for age-related hearing loss do exist such as communication programs that aim to augment speech perception and communication by training patients to utilise communication strategies and speechreading cues, but are not widely adopted in routine clinical practice (Gagné et al., 2009).

There have been milestone advances in hearing aid technology over the last three decades. For example, in 1996, digital signal processing was introduced into hearing aid processing algorithms (Kerckhoff et al., 2008). This technology has enabled algorithms for noise reduction systems, directional microphones, real-ear measures and wireless technology for hearing aids. Prior to the advent of digital signal processing, analogue hearing aids comprised microphones with fixed directionality only (i.e. the microphone could only amplify sound from all directions – 'Omni-directional'), or from a specific direction. Today, hearing aid microphones include numerous options for directionality as well as those that are adaptive to the listening environment. Despite such advances however, uptake of hearing aids is low, with just 20% of people with hearing loss in the UK owning them (AOHL, 2015). Furthermore, it is reported that of those who do own hearing aids, between 15% and 20% do not wear them regularly (AOHL, 2015).

The optimal benefit gained from hearing aids may not always be instant, it develops over time as the user gets used to processing and interpreting the amplified auditory input (Dawes et al., 2014a, Ng and Loke, 2015). Auditory acclimatisation has been defined as a process of perceptual learning, whereby an individual learns to utilise the change in acoustic information provided by the hearing aid (Dawes and Munro, 2017). However, the research evidence for auditory acclimatisation is mixed (Dawes et al., 2014b, Dawes and Munro, 2017). A recurrent finding in research and in clinical practice in the case of hearing aids is the comparatively low correlation between improved function of performance and self-reported hearing aid benefit and satisfaction (Taylor, 2007). It has been suggested that these findings are due to a lack of consideration of the psychosocial and functional impact of hearing loss since the carryover of hearing aid benefit to other aspects of life, such as social participation and quality of life, is not necessary implicit or automatic. These gaps in understanding of the type and extent of problems the patient experiences may result in the audiologist being ill-equipped to instruct the patient on how to obtain optimal benefit from their hearing aid(s). It is therefore essential to understand the types of factors that can contribute to self-perceived disability of hearing loss, such as environmental, situational and psychosocial factors (Heine and Browning, 2002).

Reviews by Barker et al. (2015) and Henshaw and Ferguson (2013) have shown that the evidence for aural rehabilitation is sparse. The disparity between what hearing aids can (and cannot) address and what patients consider to be the most burdening consequences of their hearing loss, may provide some rationale for the low-reported benefit and satisfaction with hearing aids. There is further uncertainty as to how well current rehabilitation plans adequately

address issues arising due to hearing loss, particularly those that extend beyond the auditory impairment (Boymans and Dreschler, 2012).

The need to adopt a holistic approach to aural rehabilitation has been suggested by several researchers (Boothroyd, 2007, Falkenberg, 2007, Wong and Hickson, 2012). These researchers have suggested the role of non-audiological factors such as perceived self-efficacy and support from communication partners in rehabilitation. For example, Manchaiah and Stephens (2013a) reviewed the application of different models of disability in relation to hearing loss. The authors stated that consideration of hearing loss within a biomedical model would focus on the understanding of the pathophysiology of the ear and auditory function using audiological tests only. Whilst this would identify hearing loss before the individual reports hearing difficulties, this approach may be too crude for explaining the other effects of hearing loss due to the complex interaction of hearing loss and its consequences. A social model on the other hand would focus on understanding activity limitations and participation restrictions of the hearing impaired individual. For example, the psychosocial factors relating to intervention uptake and adherence have been explored using health behaviour models (Ferguson et al., 2016). Schulz et al. (2016) used the health belief model to describe the role of communication partners in hearing aid uptake. The authors found that the health belief model construct ‘cues to action’ was a significant predictor for individuals to pursue clinical assessment for hearing loss, and the perceived burden of hearing loss on communication partners was significant. Given there are potential advantages to both types of models, biological and social paradigms have been merged to describe health conditions by the World Health Organisation (section 1.4).

Greater patient involvement in rehabilitation has been repeatedly advocated in recent years (Laplante-Lévesque et al., 2012a, Laplante-Lévesque et al., 2012b, Laplante-Levesque et al., 2013, Grenness et al., 2014a). Understanding the processes that underpin rehabilitation decisions for older adults with hearing loss has been considered essential for audiologists managing patients with hearing loss (Laplante-Lévesque et al., 2010). Boothroyd's definition of adult auditory rehabilitation suggests that the provision of hearing aids (sensory management) should form just one component of a multifactor rehabilitation programme. Laplante-Lévesque et al. (2012b) have since also emphasised the need for audiologists to adopt a patient-centred care approach (see section 1.3.1) and account for the contextual and personal factors of each patient in order to optimise success with hearing aid interventions. Current rehabilitation plans address the auditory effects of hearing loss to improve listening and speech understanding, i.e. hearing aids. However, the approach suggested by Laplante-Lévesque et al. (2012b) considers the audiological factors to form just partial components of aural rehabilitation only.

Successful rehabilitation has also been suggested to be based on identifying the individuals need of the patient, making shared informed decisions and supporting self-management (BSA, 2016). Boothroyd (2007) suggests that perceptual training (i.e. instructing patients how to obtain maximum benefit and acclimatise to their hearing aid), as well as talking to patients about the impact of hearing loss on their day-to-day life (counselling), should also be integrated into rehabilitation (Abrams and Chisolm, 2013). That is, clinicians may need to consider interventions that are additional or alternative to the provision of hearing aids. This is not currently considered in routine clinical practice. A national report conducted by Action on Hearing Loss reported that nearly a

quarter (24%) of NHS services do not signpost patients to counselling and hearing therapy (Lowe, 2015).

1.3.1. Patient-centred care

Patient-centred care (also known as client-centred care) is referenced frequently as a well-established component of the delivery of many health and rehabilitation interventions (Mead and Bower, 2000). Grenness and colleagues have defined the term patient-centred care as "*where patients should be encouraged to be active participants in their health care through the creation of a power balance and, therapeutic relationship with their health professionals"* S61 (Grenness et al., 2014a). Patient-centred care has been adopted by health professionals for the management of various chronic health conditions. For adult aural rehabilitation, a model of patient-centred care has been suggested, but not yet adopted (Laplante-Lévesque et al., 2012a, Grenness et al., 2014a, Grenness et al., 2014b). For example, Grenness et al. (2014b) conducted in-depth interviews with patients who had undergone adult aural rehabilitation to gain their perspectives on their experience with rehabilitation, their thoughts and feelings, and preferences about the nature of patient-centred audiological rehabilitation. Following a thematic analysis of the qualitative data, three dimensions of patient-centred audiological rehabilitation emerged. These three dimensions are based on what older adults with hearing loss consider to be important elements of patient-centred audiological rehabilitation (Grenness et al., 2014a). The first dimension, is the 'therapeutic relationship' which describes the value and relationship patients expect to develop with their audiologist. The authors explain that the participants described the value they place on developing a relationship with their audiologist. The second dimension, the 'players: audiologist and patient' highlights that the audiologist and patient are both critical to forming the therapeutic relationship. Whilst participants who were

interviewed in the study acknowledged their own role in their rehabilitation, they also placed particular emphasis on the technical and interpersonal skills of the audiologist. This simultaneously facilitates the third dimension of patient-centred audiological rehabilitation, the 'clinical processes'. All participants explained their preference and experience of giving and receiving information and feeling informed during all appointments (Grenness et al., 2014b). The authors also emphasised the importance of information exchange expressed by participants. Participants described the need to be given the opportunity to express their perspectives and preference. The overarching theme of the three dimensions was 'individualised care' which depicts the importance of flexibility across all rehabilitation plans to meet and adapt to the specific needs of each patient (Grenness et al., 2014b). An understanding of the individual impact of hearing loss on every patient and being prepared to take a multidimensional approach therefore, is of paramount importance.

Poost-Foroosh et al. (2011) used the concept of process mapping to identify factors of clinician-patient interaction that may influence hearing aid adoption. This process required a group of participants to voice their ideas and then represent the idea in a visual map. In their study, Poost-Foroosh et al. (2011) invited audiologists and patients with hearing loss to map factors in patient-clinicians interaction that were perceived by participants to influence hearing aid adoption. Two main themes were identified from this exercise: "client-centred interaction" and "client-empowerment". The authors highlighted that an important component of patient-centred care that emerged is that the patient feels that his or her concerns have been considered and factored into the rehabilitation. These findings conform to those found in the interview study by Grenness et al. (2014b). Poost-Foroosh et al. (2011) also advocate that such

components should not be considered as additional components of aural rehabilitation but rather as components to integrate into conventional practices.

1.3.2. Questionnaires for clinical assessment

Researchers are now acknowledging the importance of patient report as the most reliable source of information for clinical assessment (Barker et al., 2015). For example, self-reported hearing loss has been noted to be the only robust predictor of hearing help-seeking, hearing aid uptake, use and satisfaction (Carson, 2005).

Several recent reviews of the audiological literature have shown that numerous standardised self-report questionnaires have been developed to explore the impact of hearing loss. In their comprehensive survey of hearing questionnaires, Akeroyd and colleagues 2015 collated copies of all published hearing difficulty questionnaires. The text of each questionnaire was mapped onto a set of categories to obtain the questionnaire topics. The authors found 139 hearing-specific questionnaires. Across the items of these questionnaires, the authors identified that a third were concerned about the person's own hearing, another third was the impact of it, and a quarter were regarding hearing aids (Akeroyd et al., 2015). A systematic review of audiological research by Granberg and colleagues (Granberg et al., 2014a) identified 39 different patient-reported measurement instruments in use. The Hearing Handicap Inventory for the Elderly (HHIE) (Ventry and Weinstein, 1982) was the most common questionnaire but appeared just seven times out of a total of 122 articles, and the Abbreviated Profile of Hearing Aid Benefit (APHAB) (Cox and Alexander, 1995) was the second most common, appearing just four times. The frequency of usage of individual instruments is therefore low. This pattern of "many questionnaires in use, yet little consensus" has been confirmed more recently by a scoping review (Barker et al., 2015). These issues demonstrate that

presently there is no questionnaire that is accepted as a gold standard measure to assess the impact of hearing loss (Akeroyd et al., 2015). There is also further debate as to whether questionnaires are the correct medium to be used for capturing the lived experiences of hearing loss in aural rehabilitation (Barker et al., 2015).

Cox and colleagues highlighted aspects of life affected by hearing loss, such as personality, that cannot be measured using performance-based technical measures (Cox, 2003). Similarly, other effects that individuals with hearing loss may experience are in activity limitations or participation restrictions (Helvik et al., 2006) and these cannot be measured directly in the clinic. Subsequently, patient-report has been recommended as the most appropriate measure for capturing a wide-ranging and representative account of hearing-related complaints (Macefield et al., 2014).

For clinical assessment, it is desirable to ask questions that comprehensively capture a diverse range of complaints (Kirshner and Guyatt, 1985) and those could span both generic and hearing-specific complaints such as hearing disability, hearing handicap, quality of life, hearing aid benefit, communication and psychological difficulties (Barker et al., 2015). Yet, how the items in the questionnaires identified by Granberg et al. (2014a) were selected to meet this requirement is not always reported clearly in terms of either stakeholder input (professionals, patients or both) or methods used to collect potential content information. Without this knowledge, it is not certain that examining questionnaire items or subscales in isolation will give the *full* range of patient-reported complaints relating to the everyday impact of hearing loss. Table 1.1 summarises information about how items were developed for the most common hearing-specific questionnaires identified by Granberg et al. (2014b).

Throughout this thesis the term "*domain*" is used to refer to a broad area of life that is negatively affected by hearing loss (e.g. communicating). Domains are presented within a hierarchical framework (CHAPTER 2) with supra-domain, domain and subdomain groupings. A "*subdomain*" refers to a distinct aspect of life that is affected by hearing loss such as a particular listening situation or scenario (e.g. A subdomain of communicating could be conversing on the telephone). A "*supra-domain*" aims to broadly encapsulate the relevant domains and subdomains (such as "Auditory" to categorise all complaints associated with the domains hearing, listening and communicating). To bring different areas of research together, common terminology is used to describe those supra-domain, domain and subdomain groupings.

Table 1.1 Summary of level of patient/clinician-input in development of those hearing-related questionnaires identified in Granberg et al. (2014).

Questionnaire Instrument	Professional input (e.g. Academic, clinical)	Patient Input	Methods for item development	Hearing health status assessed
Measure of the impact of hearing loss				
Hearing Handicap Inventory for the Elderly (HHIE) (Ventry and Weinstein, 1982)	✓	×	Literature review & generation of questions by experienced audiologists	Hearing handicap
Abbreviated Profile of Hearing Aid Benefit (APHAB) (Cox and Alexander, 1995)	✓	✓	Modification of the Profile of Hearing Aid Benefit (PHAB)	Hearing disability Hearing aid benefit
Hearing Disability and Handicap Scale (HDHS) (Hétu, 1994)	Unclear	Unclear	Unclear	Hearing disability Hearing handicap
Hearing Handicap Inventory for the adults (HHIA) (Newman et al., 1990)	✓	×	Item substitution of the HHIE	Same as HHIE
Communication Profile for the Hearing Impaired (CPHI) (Demorest and Erdman, 1987)	✓	✓	Patient interviews	Communication problems
Communication Scale for Older Adults (CSOA) (Kaplan et al., 1997)	✓	×	Item consistency reliability and test-retest reliability	Communication strategies Communication attitudes
Hearing Handicap and Disability Inventory (HHDI) (Van den Brink et al., 1996)	✓	Unclear	Revised version of the health belief version	Hearing disability Hearing handicap
Performance Inventory for Profound and Severe Loss (PIPSL) (Owens and Raggio, 1988)	✓	✓	Patient interviews	Hearing disability
The Speech, Spatial and Qualities of Hearing Scale (SSQ) (Gatehouse and Noble, 2004)	✓	×	Unclear	Hearing disability

Of the nine questionnaires developed to measure the impact of hearing loss, only five explicitly involved patient involvement using qualitative methods (Communication Profile for the Hearing Impaired (Demorest and Erdman, 1987), Performance Inventory for Profound and Severe Loss (Owens and

Raggio, 1988), Satisfaction with Amplification in Daily Life (SADL) (Cox and Alexander, 1999), the Speech, Spatial and Qualities of Hearing Scale (Gatehouse and Noble, 2004), and the International Outcome Inventory for Hearing Aids (IOI-HA) (Cox and Alexander, 2002). The remainder reported that clinicians generated questions based on clinical experience; (HHIE) and Hearing Aid Performance Inventory (HAPI) (Walden et al., 1984), or modified existing questionnaires, the Abbreviated Profile of Hearing Aid Benefit (APHAB) and Glasgow Benefit Inventory (GBI) (Robinson et al., 1996). Thus, we cannot simply learn about the range of patient-reported domains relating to the everyday impact of hearing loss by examining questionnaire items or subscales in isolation.

1.3.3. Patient-reported outcome measures

A patient-reported outcome (PRO) is defined as being *"directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment"* (Weldring and Smith, 2013). For example, PROs can be used to report changes following an intervention. In relation to aural rehabilitation, patients with hearing aids could demonstrate good clinical outcomes such better speech-recognition scores or hearing aid usage, while PROs may identify that the patient complains of background noise or loudness discomfort. The effectiveness of hearing aids therefore comprises many dimensions, including clinical measures of hearing aid benefit as well as the benefit perceived by patients as a direct result of the intervention. The patient experience with hearing aids has played a part in aural rehabilitation research for some time, and continues to increase with the recognition that a patient-centred approach is essential for comprehensively assessing and treating hearing loss (Grenness et al., 2014a). Weldring and Smith (2013)

suggests that PROs can also be used in clinical trials in conditions where there is no objective measurement. In the case of hearing loss, a lack of consensus of outcome measurement for hearing aids has led to the suggestion for the use of PROs in aural rehabilitation (Barker et al., 2015).

In order to address the growing pressures on audiology services, there is a need within healthcare for clinical practices to audit performance and demonstrate that they provide benefit and use resources efficiently. PROs in chronic health conditions are typically assessed using patient-reported outcome measures (PROMs) such as self-report questionnaires (Macefield et al., 2014). However, there are few PROMs that exist within aural rehabilitation. Due to the potentially large number and broad scope of dimensions associated with the impact of hearing loss, identifying appropriate PROs and PROMs for clinical practice and research is challenging. As a result, there is an inconsistency as to how change or benefit is measured overtime following a hearing aid intervention across clinical practice and clinical research (Barker et al., 2015).

Generic health questionnaires capture more commonly experienced health-related outcomes that allow comparison to normative populations. However, these questionnaires may not be sensitive to changes in disease-specific health-related outcomes over time (Snyder et al., 2012). Disease-specific questionnaire on the other hand, may be more sensitive to specific symptoms experienced by patients, but may miss more generic health outcomes (Snyder et al., 2012). Disease-specific PROMs have greater face-validity than generic PROMs i.e. disease-specific questionnaires identify specific conditions and measure the impact of those specific conditions (Weldring and Smith, 2013). Ambiguity surrounding what are the important aspects of hearing loss to be measured, and what types of measures should be used, raises questions as to

whether the hearing-related questionnaires currently available are adequate for capturing the effectiveness of a specific intervention.

The importance of PROs has gained attention in the hearing and general health field of research (Grenness et al., 2014b, Macefield et al., 2014). Evidence has shown that integration of PROs in clinical practice improves patient-clinician communication (Snyder et al., 2012). It has also been shown to enhance patient care and outcomes. At the patient level, PROs can be used monitor intervention-related changes overtime and facilitate patient-centred care. PRO data can also be used to analyse health data over time, such as monitoring satisfaction with hearing aids, to evaluate which interventions are effective (Snyder et al., 2012).

When assessing the effectiveness of a particular intervention, such as hearing aids, the choice of outcome measures must reflect the goals of that intervention (Boothroyd, 2007). The range of various issues that occur as a result of hearing loss have been measured in different ways. Difficulty understanding speech for example is typically measured objectively using speech-perception tests (Akeroyd, 2008). These measures are important in evaluating the effectiveness of an intervention (hearing aids) from a technical perspective, because they are repeatable and objective (Tysome et al., 2015). However, the ability to hear sounds in a clinic room that is typically a sound booth or quiet office does not represent the overall impact that hearing loss can have on an individual's life. Speech recognition tests have been used as outcome measures in several hearing aid acclimatisation studies. Numerous studies have demonstrated evidence for acclimatisation in relation to improved speech recognition scores over time (Cox and Alexander, 1992, Gatehouse, 1992, Gatehouse, 1993, Cox, 2003). However, fewer studies have demonstrated evidence for auditory acclimatisation by measuring other perceptual or physiological changes with

hearing aid use over time (Dawes and Munro, 2017). Furthermore, these studies have shown that there is a disparity been perceptual measures of hearing aid benefit such as speech recognition tests, and self-report measures such as questionnaires. Hearing aid users report ‘getting used’ to their hearing aids with very little outcome measurement aside from self-report data, to align with this perceived change (Barker et al., 2015). The authors identified a restricted range of health status outcomes in hearing loss: hearing handicap, auditory disability, quality of life, hearing aid benefit, communication, and psychological outcome. A prominent weakness found by Barker et al. (2015) was that given the chronic nature of adult onset hearing loss and interventions prescribed to lessen its effects, long-term benefit by measuring outcomes months and years after intervention was rare (Barker et al., 2015).

In addition to the uncertainties regarding which outcomes are to be selected and what outcome instruments are to be used, the more fundamental concepts of what aspects of adult functioning with hearing loss are considered important to people with hearing loss also remain ambiguous (Danermark et al., 2010), since these questionnaires have been developed with varying level of input from patients (Table 1.2).

Table 1.2 Summary of level of patient input into development of those frequently used outcome measurement questionnaires reported in Granberg et al. (2014).

Questionnaire Instrument	Professional input (e.g. Academic, clinical)	Patient Input	Methods for item development	Hearing health status assessed
Measure of treatment-related benefit				
Satisfaction with Amplification in Daily Life (SADL) (Cox and Alexander, 1999)	✓	✓	Focus groups	Hearing aid benefit
Glasgow Benefit Inventory (GBI) (Robinson et al., 1996)	✓	✓	Modification of GHABP	Effect of a hearing intervention on hearing-related quality of life
Hearing Aid Performance Inventory (HAPI) (Walden et al., 1984)	✓	✓	Areas that were hypothesised to be relevant to success with amplification were represented in questionnaire	Hearing aid benefit
International Outcome Inventory for Hearing Aids (IOI-HA) (Cox and Alexander, 2002)	✓	✓	Patient interviews	Hearing aid benefit

As shown in Table 1.2, these questionnaires have been developed by different groups and disciplines (such as researcher and/or clinician). Such questionnaires, are formed of several scales and single items are often used together in clinical trials to assess a range of relevant health domains.

Very few instruments have been developed specifically for measuring outcomes associated with aural rehabilitation. An example of one of the few outcome measurement instruments developed for aural rehabilitation is the Glasgow Hearing Aid Benefit Profile (GHABP) (Gatehouse, 1999). This was derived as a candidate outcome measurement instrument for application in routine service

context for the assessment of aspects of disability, handicap, and hearing aid benefit. The GHABP requires patients to consider four scenarios involving speech and asks them to rate their perceived initial hearing disability, initial handicap, aided benefit aided handicap, hearing aid use and hearing aid satisfaction on a five-point scale. The GHABP has played a significant role in the UK-modernisation of the hearing aid service (Davis et al., 2007). The validation of any outcome measurement instrument depends on the criteria against which its performance can be judged. During the development of the GHABP, Gatehouse (1999) suggested that these criteria should be validity, clinical utility, and that the instrument should be relatively quick and easy to administer. The components of a clinical instrument should be a useful part of diagnostic assessment, management and rehabilitation from the perspective of the patient and the audiologist (Gatehouse, 1999). Several researchers have also since advocated that outcome measurement instruments should also represent a form of good clinical practice rather than an additional element to rehabilitation (Grenness et al., 2014a, Grenness et al., 2014b, Barker et al., 2015).

Currently it is difficult to compare hearing loss interventions because randomised controlled trials (RCTs) are rarely feasible (Tysome et al., 2015), the quality of those RCTs is low and the outcomes reported are highly heterogeneous (Barker et al., 2015). In other health conditions, standardisation of outcome measures by developing a core set of patient-centred outcomes have facilitated comparison of trials and allow clinicians to monitor outcomes of rehabilitations over time. Here a core outcome set is defined as a minimum set of outcomes agreed by the clinical community to be measured and reported in all RCTs. For example, an international, informally organised network initiated in 1992 (OMERACT) was created with the aim of improving outcome

measurement in rheumatology (Tugwell et al., 2007). OMERACT employed the use of a majority consensus across relevant stakeholder groups to determine relevant health outcome domains in patients with musculoskeletal conditions. There were several stages to achieve this. First, the experts and opinion leaders generated interest in the topic and formed a committee to coordinate the process. Then, candidate domains were nominated for the topic at hand from general domains of health status. The committee used the general domains of health status defined by *Discomfort, Disability, Dollar Cost,* and *Death,* specific domains to the question of interest are developed. These domains were formed during workshops (and further group sessions) with experts in the research agenda, using research studies are presented that inform the creation and selection of the domains through agreement and prioritisation. Thus the domains and the measures chosen through the data-driven methods form the basis for the consensus methods (Tugwell et al., 2007). Currently, a core outcome set for hearing loss does not yet exist.

1.4. ICF CORE SET FOR HEARING LOSS

In 2001, the World Health Assembly endorsed the International Classification of Functioning, Disability and Health (ICF) for use as an international standard for describing and measuring health and disability (Granberg et al., 2014a, Granberg et al., 2014b, Granberg et al., 2014c, Granberg et al., 2014d, WHO, 2002). The ICF offers a model that integrates biological, psychological, and social aspects of human functioning. This project has integrated patient and professional perspectives to create a comprehensive list of categories relevant to adult hearing loss (Danermark et al., 2013). It was developed to provide an assessment of an individual's functioning with hearing loss. The ICF is a framework for conceptualising hearing loss with a holistic approach. Other frameworks have that applied health psychology to hearing loss have been

developed, such as the transtheoretical model (Prochaska and DiClemente, 1983). However, the ICF is the only framework that is based on an approach that integrates a biological and social paradigm to create a biopsychosocial approach to a health condition (Dalton et al., 2003). The ICF framework also provides a common language for describing health and health-related states. Various terminology has been used to refer to dimensions measured by self-report. For example, 'disability' and 'handicap' have often been used interchangeably (Granberg et al., 2014a). The ICF was previously defined using the terms impairment, disability and handicap which denoted more focus on the individual's *in*abilities and *dys*functional status. The revised definition on the other hand places a more positive emphasis on the individual's abilities and functional status. This definition endorses the terminology developed by the WHO to classify the impact of disease (Granberg et al., 2014b).

Researchers have recently used the ICF to develop a "Core Set" which consists of a comprehensive list of categories that are of particular relevance to a specific condition. In 2008, an international working group supported by WHO generated a core set for adult hearing loss (Danermark et al., 2013). It provides a framework that aims to capture the far-reaching effects of hearing loss on the individuals with hearing loss. The development of the framework followed a prescriptive methodology with the first phase comprising four preparatory studies (Granberg et al., 2014a, Granberg et al., 2014b, Granberg et al., 2014c, Granberg et al., 2014d). Each of these studies involved gaining various perspectives from those affiliated with hearing loss including researchers, experts in the field of hearing loss and patients themselves.

The second preparatory study involved focus groups. The aim was to identify which areas of functioning; disability and the environment were

considered important, from the perspective of adult persons with hearing loss, using seven open-format questions. The questions used to elicit information from patients were developed to specifically address the different components of the ICF framework describing a person's level of functioning with hearing loss rather than just the negative implications of a health condition. The Comprehensive ICF Core Set comprises 117 categories. It has four overarching components: body functions, body structures, activity and participation, and environmental factors, that each contain several sub-categories. The 'body structures' (anatomical parts of the body) and 'body functions' (physiological functioning of body systems) components describes a person's functioning in terms of the person's body. The remaining components are 'activities' (execution of a task) and 'participation' (involvement in real situations). The ICF also considers that the person's functioning maybe influenced by 'contextual factors' (environmental and personal factors). The term disability is an umbrella term for all impairments, activity limitations and participation restrictions described in the framework (Granberg et al., 2014b). A shorter version of the Comprehensive ICF Core Set was also developed, called the Brief ICF Core Set (Table 1.3). The Brief ICF Core Set contains the same four overarching components, but with a reduced set of 27 categories. This version of the framework was developed using voting inputs from the same stakeholders as the Comprehensive ICF Core Set (Danermark et al., 2013).

The Comprehensive and Brief ICF Core Sets were both developed for clinical purposes. However, widespread adoption of the ICF in audiological clinical practice has not yet occurred. This could be due to the relatively large number of items within the four components, even for the brief version.

As Granberg and colleagues explained, any patient-reported complaints that fell outside of the Comprehensive ICF Core Set could not be assigned to any ICF category and were excluded from further consideration (Granberg et al., 2014c). This suggests some ambiguity as to how well the ICF framework captures the entire scope of complaints of hearing loss. Excluded responses were not reported in the publication (Granberg et al., 2014c) and it is possible that essential complaints may therefore not be reflected in either the Comprehensive or the Brief ICF Core Sets for hearing loss.

Table 1.3 Brief ICF Core Set for hearing loss

ICF category (numeric code)	ICF category (label)
	Body Function
b126	Temperament and personality functions
b140	Attention functions
b144	Memory functions
b152	Emotional functions
b210	Seeing functions
b230	Hearing functions
b240	Sensations associated with hearing and vestibular function
	Body Structure
s110	Structure of brain
s240	Structure of external ear
s250	Structure of middle ear
s260	Structure of inner ear
s115	Listening
	Participation
d240	Handling stress and other psychological demands
d310	Communicating with-receiving- spoken messages
d350	Conversation
d360	Using communication devices and techniques
d760	Family relationships
d820	School education
d850	Remunerative employment
d910	Community life
	Environment
e125	Products and technology for communication
e250	Sound
e310	Immediate family
e355	Health professionals
e410	Individual attitudes of immediate family members
e460	Societal attitudes
e580	Health services, systems, and policies

1.5. CONCLUSIONS

Achieving better rehabilitative outcomes for hearing loss involves alleviating the effects of hearing loss on communication and general well-being. Hence, adult aural rehabilitation cannot focus solely on addressing auditory impairment, but also on optimising the broader aspects of communication and functioning with hearing loss. In order to achieve this, it is imperative researchers and clinicians appreciate and fully understand the patient's concerns with their hearing loss using a multidimensional rehabilitative approach.

1.6. STRUCTURE OF THESIS

The first study outlined in Chapter 2 is a comprehensive review of the current research evidence domains of hearing loss from the perspective of adults with hearing loss and communication partners (Table 1.4). This review was conducted using systematic methods and the data analysis approach was meta-ethnography. The study in Chapter 3 is a qualitative study that assesses the domains derived in Study 1 for face-validity. A series of focus groups were conducted with key stakeholders and the results were analysed using thematic analysis. These domains are then explored further in Chapter 4 in a survey study that required adults with hearing loss and communication partners to rank the domains in order of importance to them based on their experience of living with hearing loss. A domain mutual to hearing aid users and communication partners derived from the comprehensive review, 'raising the volume of the television/radio' was then investigated in a case-cohort design study outlined in Chapter 5. The aim of the study was to measure the preferred volume of hearing aid users and their significant other whilst watching television. Chapter 6 presents the final study which is another survey study that explored the general television habits and difficulties experienced by hearing aid users and communication partners. Chapter 7 provides a summary of the thesis and discussion of the main findings.

Table 1.4 Summary of thesis structure

Chapter	Primary objective	Study design	Participants	Analysis
1	To provide an overview of the literature relevant to the thesis	Literature review	-	-
2	**Study 1:** To collect and synthesise generic and hearing-specific complaints in everyday life that are reported by people with hearing loss, and by communication partners	Comprehensive review	Research evidence where adult with hearing loss and/or communication partners are the populations of interest	Meta-ethnography (inductive)
3	**Study 2:** To explore comments made by hearing aid users and communication partners on the domains of hearing loss frameworks, with respect to their own personal experience of understanding the construct	Focus groupx3	13 participants: five hearing aid users, five communication partners and three audiologists	Thematic analysis (deductive)
4	**Study 3:** To identify those domains relating to the most important patient- and communication partner aspects of hearing loss	Online/paper questionnaire-survey	255 respondents: 207 hearing aid users and 48 communication partners	Ranking analysis and thematic analysis (deductive)
5	**Study 4:** To measure and relate the television volume set by participants across couples one of whom is a hearing aid user and the other is a partner	Prospective case-control	84 participants: 42 hearing aid users and 42 partners	General linear model
6	**Study 5:** To report on those TV viewing difficulties of hearing aid users and communication partners	Online/paper questionnaire-survey	329 respondents: 307 hearing aid users and 22 communication partners	Descriptive statics
7	To provide an overall summary and discussion of the key findings from the thesis	-	-	-

CHAPTER 2. A META-ETHNOGRAPHIC SYNTHESIS OF RESEARCH EVIDENCE FOR DOMAINS OF HEARING LOSS, AS REPORTED BY PATIENTS OR THEIR COMMUNICATION PARTNER

2.1. INTRODUCTION

Given the high prevalence of hearing loss, there is a greater need to improve treatment outcomes in order to capacitate for the growing pressure on hearing health services (AOHL, 2015). In a similar way to other chronic health conditions that typically occur in later adulthood, tackling the direct effects (i.e. auditory impairment) as well as resolving the patients concerns of their hearing loss is challenging. There has not been, thus far, any comprehensive synthesis of evidence for the impact of hearing loss on both the patient and their communication partner (usually the spouse or live-in partner).

While there is a growing body of literature on the impact of hearing loss on the communication partner, this is a relatively new field of research. Nevertheless, a recent systematic review identified 24 studies relating to the impact of hearing loss on the communication partner only (Kamil and Lin, 2015). The review included observational clinical studies, randomised clinical trials, and epidemiologic studies and so the focus of data synthesis was based on outcome metrics and study findings, more so than on self-reported experiences. The authors identified social life, burden of communication, and quality of life as emerging dimensions of generic and hearing-specific complaint and they also identified a gap in knowledge about effects of hearing loss on the communication partner's mental health. However, the authors did not

synthesise studies that explored the impact on those experiencing or diagnosed with hearing loss.

There has been no such synthesis of the impacts of hearing loss on the person with the hearing loss themselves. The present review is therefore novel in that its primary objective is to collect and synthesise generic and hearing-specific complaints in everyday life that are reported by people with hearing loss, *and* by communication partners. The term "*domain*" is used to refer to a broad area of life that is negatively affected by hearing loss such as communicating. Domains are presented within a hierarchical framework with supra-domain, domain and subdomain groupings, using inductive (data-driven) methods. Definitions are the same as given in Chapter 1. A "*subdomain*" refers to a distinct aspect of life that is affected by hearing loss such as a particular situation or scenario such as conversing on the telephone. A "*supra-domain*" aims to broadly categorise these lower-level domains and subdomains such as auditory. To bring different areas of research together, common terminology is used to describe those supra-domain, domain and subdomain groupings across the two groups. This process generates two perspectives about living with hearing loss: (i) the personal impact of hearing loss from the perspective of the person with hearing loss, and (ii) the personal impact of hearing loss from the perspective of the communication partner.

Secondary objectives then sought to (i) identify similarities and differences in the evidence collected from people with hearing loss and from communication partner(s), (ii) compare the data-driven framework of domain groupings with the Brief ICF Core Set for hearing loss, (iii) assess the quality of research methods and findings of included studies and, (iv) investigate whether any domains or subdomains vary as a function of hearing loss severity (data permitting).

2.2. MATERIALS AND METHODS

Methods were guided by the Preferred Reporting Items for Systematic reviews and Meta-analysis (PRISMA) (Liberati et al., 2009). This statement offered guidance on all components of review reporting. The details of the study eligibility criteria, information sources, search strategy, selection and data collection process and the data synthesis methods have been published as a protocol in advance of completing the data collection (Vas et al., 2016). There were no modifications to the published protocol or subsequent changes in methods.

2.2.1. Inclusion criteria

To be eligible for inclusion in the review, studies must have included adults (men and women) ≥18 years old who had been diagnosed with mild-to-profound hearing loss as the primary condition of interest, and/or communication partner(s) who could be of any age or hearing status. Participants of included studies were required to use oral communication as their primary mode of communication, but there was no restriction to those people using hearing aids or other assistive listening devices. Any studies that investigated the perspective of professionals on the impact of hearing loss were excluded because it was not in the scope of the research question.

Eligible publications were journal articles, book chapters and conference proceedings that reported interventions, observational or cross-sectional studies and that employed questionnaires, interviews or focus groups to collect data relating to the primary question, but case reports, articles for professional magazines, and web-based discussion forums were excluded. Published systematic reviews were not subject to the data collection process itself, but their reference lists were manually searched to identify any additional eligible studies. There were no restrictions on research settings.

Given the large number of closed-set questionnaires in use, eligible study designs spanned quantitative, as well as qualitative methodologies. Intervention studies were included where data in these studies was obtained and reported at the initial assessment, as well as non-intervention studies. There was no restriction on the type of study design. Resource and language limitations within the team led us to limit studies to those published in the English language. The search was limited to publications on or after 1st May 1982, chosen because the HHIE questionnaire (Ventry and Weinstein, 1982) was published then.

2.2.2. Information sources

To support an exhaustive literature search, published studies were identified through numerous electronic databases: Cos Conference Papers Index (ProQuest), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, PubMed (including MEDLINE) (Table 2.1), Web of Science. Google Scholar was also searched page by page until one page contained no relevant studies. All electronic searches were conducted on 31st August 2015.

To ensure that the review was up-to-date, a manual search was conducted of the top four journals in which eligible studies had been sourced (i.e. Ear and Hearing, International Journal of Audiology, Audiology and Journal of the American Academy of Audiology,) from August 2015 to April 2017. This final search was conducted on 3rd May 2017.

In addition, charitable associations representing people with hearing loss (Action on Hearing Loss, The Ear Foundation, the IDA Institute, and Hearing Loss Association of America) were contacted once, without reminder, on 22nd

January 2016 to enquire about commissioned reports. None of the organisations responded.

Table 2.1 Summary of scope of databases searched

Database	Scope of archive
Cos Conference Papers Index (ProQuest)	Major areas of coverage include clinical medicine.
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	Allied health, biomedicine, healthcare and nursing journal database.
Excerpta Medical Database (EMBASE)	Biomedical and pharmacological journal literature.
PubMed	Biomedical and life sciences journal literature at the U.S National Institutes of Health's Library of Medicine's search service. MEDLINE is directly searchable within PubMed.
Web of Science	Comprises of seven online databases consisting of cross-disciplinary research including sciences, social sciences and arts.

2.2.3. Search Strategy

Search terms were informed by the PICO (Participants, Interventions, Comparators, and Outcomes) elements and by the primary review objective (Table 2.2). For qualitative research, the PICO approach aims to facilitate the development of a research question (Liberati et al., 2009).

Table 2.2 Components of research question according to PICO criteria

Participant	Person with hearing loss
Intervention	Everyday biopsychosocial impact of hearing loss
Comparison	Communication partner
Outcomes	Meta-ethnography

The electronic database search required “hearing” in the title, in conjunction with additional relevant search times in the title or abstract. This was because the condition of interest was hearing loss, and therefore studies only met eligibility if hearing-related difficulties in those studies were defined as being due to ‘hearing loss’. The search strategy was reported in the protocol (Vas et al., 2016), the search terms were: 1) hearing AND problem OR complain* OR symptom OR impairment OR difficult* OR concern* OR impact AND 2) patient OR communication partner OR partner OR spouse OR significant (other) OR famil* (Table 2.3).

The search strategy was modified to accommodate to the settings of each database and where possible was limited to human study participants, adult, English language and studies published post-May 1982 (Figure 2.1). The search strategies for each database were designed to be highly sensitive in order to capture as many potentially relevant studies as possible, but not too restrictive that studies that could have been included are missed.

Table 2.3 Matrix of the search terms for PubMed, EMBASE, and CINAHL.

First category AND	Second category AND	Third category
hearing	problem	patient
	complain*	communication partner
	symptom	partner
	impairment	spouse
	difficult*	significant (other)
	concern*	family
	impact	

(((((((hearing[Title]) AND ("1982/05/01"[Date - Publication] : "3000"[Date - Publication]))) AND ((((((((((((((((problem[Title/Abstract]) OR complain*[Title/Abstract]) OR symptom[Title/Abstract]) OR impairment[Title/Abstract]) OR difficult*[Title/Abstract]) OR concern*[Title/Abstract]) OR impact[Title/Abstract]) NOT child*) NOT p*ediatric) NOT hearing screening) NOT hearing protection) NOT hearing conservation) NOT hearing prevalence) NOT hearing incidence) NOT hidden hearing) NOT "hidden" hearing loss) NOT dementia))) AND Humans[Mesh] AND English[lang] AND adult[MeSH])) OR ((((((hearing[Title]) AND ("1982/05/01"[Date - Publication] : "3000"[Date - Publication]))) AND ((((((((((((((((patient[Title/Abstract]) OR communication partner[Title/Abstract]) OR partner[Title/Abstract]) OR significant other [Title/Abstract]) OR famil*[Title/Abstract]) OR spouse[Title/Abstract]) NOT child*) NOT p*ediatric) NOT hearing screening) NOT hearing protection) NOT hearing conservation) NOT hearing prevalence) NOT hearing incidence) NOT hidden hearing) NOT "hidden" hearing loss) NOT dementia))) AND Humans[Mesh] AND English[lang] AND adult[MeSH])

Figure 2.1 An example of the search syntax from PUBMED

Given that the first and second category search terms were very broad, it was important to modify the search strategy to minimise irrelevant studies. Therefore, the search strategy comprised terms that the databases excluded from the search results if contained within the title of the study e.g. NOT hidden hearing.

2.2.4. Study selection

Study selection commenced once the searches of the pre-selected databases were conducted, and consisted of three stages: title screening, abstract screening, and full-text review.

2.2.4.1 Title Screening

The first selection step considered the title information and determine inclusion according to the PICO search strategy and study eligibility criteria. The terminology used in the title of each search result was screened to determine whether the potential scope of the study was relevant for inclusion in the review. Studies that were deemed not relevant to the review at this stage were excluded. Studies that were deemed as potentially relevant or where there was

insufficient information in the title to assure inclusion were taken forward to the abstract screening stage. This stage was conducted by one research (VV). An additional research (DAH) independently screened 10% of the titles.

2.2.4.2 Abstract Screening

Abstracts of studies that passed the title screening stage were independently screened by two members of the research team (VV and DAH). During the abstract screening stage, the authors assessed potential eligibility of the studies against a purpose-designed screening tool. Studies were taken forward to full-text review if one or both the researchers deemed the study to be potentially relevant based on whether there was insufficient information in the abstract to suggest inclusion. Disagreements between reviewers were resolved through discussion between the reviewers.

2.2.4.3 Full-text review

The third and final stage of the screening process considered the full text of studies that met abstract screening or where there was uncertainty in eligibility. The full-text of studies were then independently screened by the same two reviewers (VV and DAH) according to the research eligibility criteria. If it could be determined that the study did not meet inclusion then it was excluded straight away. Specifically this was those studies that were clearly not relevant and those that addressed the outcome of interest but failed on another criteria, such as age of study sample. For those in this latter category, reason for exclusion was noted. Where there was disagreement over full-text inclusion between the two researchers, the researchers consolidated on their reasoning for inclusion/exclusion until a mutual decision was made. Those that met eligibility were retained for data collection.

2.2.5. Data collection process

For every full-text study, data collection was conducted using a pre-specified electronic data collection form (an excel spreadsheet). The data collection form was developed during the protocol write-up at the inception of the review process. To minimise observer bias, guidance material was created prior to the data collection process (Appendix 8.1.1). The data collection form and guidance material were both piloted and revised across two iterations by two reviewers (VV and DAH). The guidance material contained a short description of each data item. Final data collection was conducted by one researcher (VV). Given the large time period of the search citation (34 years), the lead author of the included studies was not contacted by email to seek clarification for any missing data. Missing data was marked as “not stated”.

2.2.6. Data items

The list of data items is give in Table 2.4. For each included study, the researcher performing data collection was recorded along with study authors, title, year of publication, type of publication (e.g. journal article, book chapter, or conference paper), and country of origin. For the data items relating to the study design was recorded along with whether or not hearing loss was the primary condition of interest, the wording of questions (open, closed, or open and closed), sample size, and reference to a theoretical framework reported by authors (if any).

Table 2.4 Data items of data collection form

Data item group	Data item
General information	• Researcher performing data extraction (Initials) • Study number (to uniquely identify study) • Author (Last name, first name) • Study title • Year of publication • Type of publication (e.g. journal article, , report, conference paper, book chapter) • Country of origin
Study characteristics	• Study design (e.g. treatment studies, observational, other) • Is hearing the primary condition of interest? (e.g. yes, no, unclear) • Primary method for collecting individual hearing loss complaints (e.g. questionnaire, interview, focus group, other) • Type of questions (e.g. open, closed, open and closed) • Sample size (total number of participants) • Theoretical framework (if stated)
Participant characteristics	• Mean age • Gender • Ethnicity • Socio-economic status • Setting (e.g. academic, clinical) • Hearing status • Co-morbidities • Patient-reported complaints • Measure (e.g. interview, focus group) • Examples of patient-reported complaints • Perspective (e.g. perspective refers to self, perspective refers to communication partner) • Communication partner-reported complaints • Measure (e.g. interview, focus group) • Examples of communication partner-reported complaints • Perspective (e.g. perspective refers to self, perspective refers to communication partner) • Free-field text (any relevant information that is not stated in the study)

For the data items relating to participant characteristics, the mean age was recorded along with, gender, setting (e.g. academic, clinical), and hearing

status (including mean audiometric thresholds, description of hearing loss severity, or aetiology of hearing loss).

For complaints reported by both the person with hearing loss and their communication partner, the measure used to obtain each hearing loss complaint or domain (questionnaire, interview, or focus group) was recorded. The domain as described in the text, author examples or participant quotes describing their complaints, and perspective (referring to self or to other) was also extracted. For studies using closed-set questionnaires to assess the impact of hearing loss, only data only for those subscales or questionnaire items that had been highlighted by the study findings or conclusions as reflecting experienced complaints were extracted (i.e. data collection did not simply extract information indiscriminately for all subscales or items of a questionnaire). For intervention studies, data pertaining to the research question was extracted only at the initial assessment. Data pertaining to the effectiveness of treatments was not collected. Given that the primary research question was to identify what are the reported problems in everyday life experienced by adults with hearing loss as well as their communication partners, the data collection process carefully considered those domains, examples and quotes given by each party in terms of how hearing loss affected them personally. The terminology used by study authors, in the form of reported examples or quotes, was important to assist with understanding each authors' epistemological frame and hence to interpret their concept of each domain (Table 2.4).

2.2.7. Data management

VV was responsible for data management and maintained editorial rights of the study documents. The bibliographic software EndNote was used to manage references. All identified studies were saved into a Microsoft Excel master file

where studies were tracked through the screening and data collection steps by a unique study identification code. A simple system of study annotation was implemented to study reasons for exclusion at the abstract screen and full-text stage. Once data collection was completed and the file had been further checked and formatted, an excel sheet of the master file was saved as a locked document to avoid amendments to the file in error (1st December 2015).

2.2.8. Outcomes and prioritisation

The primary research question was to identify what are the reported problems in everyday life experienced by adults with hearing loss as well as communication partners. Therefore, the priorities for data synthesis and reporting of findings focused on those domains, examples and quotes given by each party in terms of how hearing loss affected them personally. This approach gives two perspectives: (i) the personal impact of hearing loss from the perspective of the person with hearing loss, and (ii) the personal impact of hearing loss from the perspective of the communication partner. Any problems reported by people with hearing loss that referred to how they perceived their communication partner to be affected (and vice-versa) were collected and grouped into domains, but are simply reported in a table because they are "second-hand" complaints.

2.3. PLAN OF ANALYSES

The following pre-specified subgroup analyses were carried out:

1. Main findings from included studies that contain evidence from the perspective of patients that report the everyday impact of hearing loss were presented in a summary table.

2. Main findings from included studies of the impact of hearing loss reported from communication partners were presented in a summary table.
3. To approach the secondary objective about whether there are any similarities in the evidence collected from patients and their communication partner(s), the reported domains of hearing loss were directly compared between study populations.
4. To address the secondary objective about reported complaints in relation to severity of hearing loss, a table was devised that presents the reported domains of hearing loss-related complaints corresponding to hearing loss severity (mild, moderate and severe).

2.3.1. Synthesis of results

Reported domains, examples and quotes associated with hearing loss typically referred to the negative functional impact on hearing ability or other psychosocial consequences of hearing loss, but examples were wide ranging. The aim of the data synthesis was to identify and group together similar data characteristics into domains using a meta-ethnographic approach (Noblit, 1988, Campbell et al., 2011). Data synthesis was guided by the seven steps of Noblit's meta-ethnography (Noblit and Hare, 1988).

1. Getting started

The specific research question that data synthesis aimed to address was to collect and synthesise generic and hearing-specific complaints in everyday life that are reported by people with hearing loss, and by communication partners. Meta-ethnography aims to identify commonality across studies allowing for themes to emerge from the qualitative data thus utilising an inductive (data-driven) approach, resulting in a re-conceptualisation of the data. This approach

provided an appropriate method of synthesising the qualitative data extracted from the included publications.

2. *Deciding what is relevant to the initial interest*

The scope of the synthesis was to focus on what studies had reported the personal impact of hearing loss on individuals with hearing loss, and the personal impact of hearing loss on communication partners. Quality assessments of the included studies were conducted and reported in section 2.4.7.

3. *Reading the studies*

Familiarisation of the studies was first conducted in the study screening stage of the abstracts and full-text of the studies and later by reading the data collected in the excel spreadsheet.

4. *Determining how the studies are related*

The first step required searching for and grouping the domain data under descriptive labels that contained recurring keywords, such as “stigma” and “withdrawal”. All of the extracted complaints and domains were printed onto card for analysis by the research team (VV, DAH and MAA). To clearly identify which complaints were comparable, the printed cards were sorted into groups. To do this, VV, DAH and MAA looked through the cards for common and recurring themes (Figure 2.2).



Figure 2.2 Stage 4 of domain grouping exercise

The extracted qualitative data was synthesised at domain level in the first instance. Preliminary domain groupings emerged from the given words, phrases and sentences taken directly from the full texts (without any abstraction). Complaints that appeared to be non-specific (e.g. “background noise” or “domestic life”) or contained limited information (e.g. “public incidents” or “dependence”) were temporarily placed in a “miscellaneous” group and carried forward to further review.

5. Translating the studies into one another

The preliminary groupings were then thoroughly reviewed by the research team. The descriptive labels used to name each grouping was also reviewed based on the revised domain keywords. Suggestions were shared among all three researchers leading to a harmonisation of the domain classification (Saldaña, 2015).

6. Synthesising translations

At this stage, not only were the domain groupings and their descriptive labels reviewed and revised, but supra-domains were also created at a higher level of

abstraction (Campbell et al., 2003), and subdomains at a higher-level of specificity. Supra-domains were “Auditory”, “Social” and “Self”. “Auditory” refers to domains relating to perception of sound and speech. “Social” refers to domains that represent the impact of hearing loss on activities with friends and family, as well as attitudes to hearing loss. “Self” refers to domains relating to self-perception and personality. Following the development of the domains, data grouped within each domain was then categorised into more specific groups (VV and DAH), known as subdomains. Subdomains captured the richness of the dataset and enabled greater distinction between complaints within each domain grouping.

The domain groupings were analysed using a more interpretative level of scrutiny, rather than simply relying on the linguistic terms of the dataset alone. This stage involved paying meticulous attention to the corresponding examples and quotes for each domain in order to interpret the underlying concepts and semantics intended by the original investigator. For example, the extracted quote *“I can’t interpret where sounds are coming from and what causes them”* contains two separate constructs. The participant makes reference to having difficult localising sounds as well as detecting what the sound is.

The data coded with in each subdomain was checked several times to ensure this data was representative of the subdomain. This required moving back and forth between the data to ensure the data was placed appropriately within the subdomains and to identify any overlap or differences in the emerging domain and subdomain groupings. Again, subdomain labels were created using representative words or phrases from within the dataset, thus adopting a bottom-up approach. At this point, it was observed that some of the subdomain items combined several aspects of complaint and could therefore potentially be allocated to more than one subdomain. This was particularly true for examples

or quotes that stated a theoretical construct with an underlying emotional construct; for example, “frustration in communicating at work” or “upset to know others are aware of hearing problem”. In these cases, the individual complaint or example was assigned to multiple subdomains. All domains and subdomains were not based on the number of data items reporting that particular subdomain, rather on the uniqueness of the construct contained within the data. For example, a subdomain could have emerged from data contained within one data item if that item could not be consolidated with another subdomain.

7. Expressing the synthesis

The domain groupings from the two perspectives were used to create two frameworks, one for the person with hearing loss and one for the communication partner. The domains derived from this review sit within a very broad scope of hearing loss complaints, ranging from listening-related complaints to emotional consequences. Therefore, it seemed prudent to structure the framework in a hierarchical manner with supra-domains, domains and subdomains.

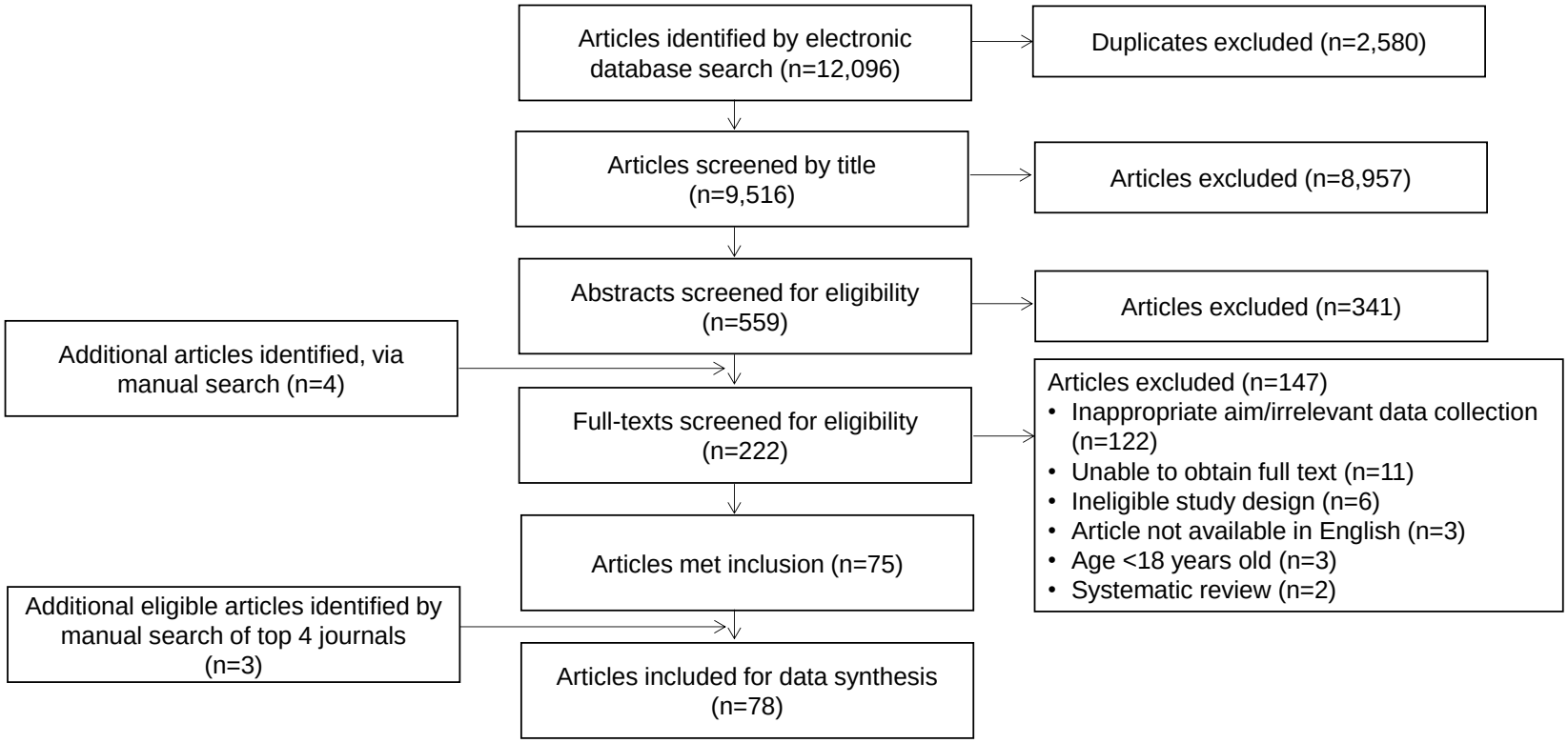


Figure 2.3 Flow diagram of study publications following the PRIMSA guidelines

2.4. RESULTS

2.4.1. Study selection

The electronic search identified 12,096 studies in total: Cos Conference Papers Index (n=231), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (n=753), EMBASE (n=4,484), PubMed (n=1,697, Web of Science (n=4,906), and Google Scholar (n=25). The flow of studies through the review process is illustrated in Figure 2.3. There were 2,580 duplicates, leaving 9,516 studies for title screening. Title screening conducted by one reviewer (VV) removed a further 8,957 studies leaving 559 studies for abstract screening by two reviewers (VV and DAH). At this stage, any study judged as potentially relevant by either author, or any study with no abstract was taken forward to full-text review. Abstract screening removed 341 studies. In total, 222 studies were nominated for full-text review, with this number including three studies identified by the manual search of reference lists. Eight studies subsequently had to be excluded as the research team was unable to obtain a full text, and two were excluded because they were not available in English (Sebastian et al., 2015, Badran, 2001). Full-text screening was also conducted by two reviewers independently (VV and DAH) for the remaining 214 full texts against the inclusion criteria. A total of 75 studies met inclusion at this point. A further three relevant studies were identified following the updated manual search and were added for data collection. Therefore, a total of 78 studies met inclusion, with the remaining reasons for exclusion agreed between VV and DAH and reported in Figure 2.3.

2.4.2. Study characteristics

Most of the included studies focused on the impact of hearing loss on the person with hearing loss only (n=49). Fewer studies investigated its effects on the communication partner only (n=11). Another 18 publications explored both

perspectives as part of the same study. All communication partner studies were conducted with the spouse or partner of the person with hearing loss. The age of all participants ranged from 18 to 92. Sixty-four studies reflected the views of both men and women; two publications recruited men only (Hetu et al.,1990; Jonsson and Hedelin, 2012), one recruited women only (Magilvy, 1985); and 11 studies did not report gender. Sample sizes ranged from n=9 (Jonsson and Hedelin, 2012) to n=4266 (Stephens et al., 1990). In terms of data collection methods, 44 studies used questionnaires and 34 used qualitative methods such as interview and focus group methods. Of those 34 studies, only 11 reported the questions used to elicit complaints, and of those only nine that used open-worded questions; six with people with hearing loss (Hetu et al., 1988, Stephens et al., 1990, Yorgason et al., 2007, Wallhagen and Strawbridge, 2009, Kelly and Atcherson, 2011, Jonsson and Hedelin, 2012) and three with communication partners (Lormore and Stephens, 1994, Stephens et al., 1995, Yorgason et al., 2007). A total number of 1015 complaints were extracted and synthesised across the full dataset (628 patient-reported complaints and 387 communication partner reported complaints).

Included studies in the present review employed a diverse range of outcome measures comprising both quantitative and qualitative approaches to assess the impact of hearing loss. Questionnaires and interviews were amongst the most commonly cited method of obtaining patient complaints. The Hearing Handicap Inventory for the Elderly (Ventry and Weinstein, 1982) was the most common questionnaire used in the included studies; with seven studies (Magilvy, 1985, Newman and Weinstein, 1986, Garstecki, 1987, Mulrow et al., 1990, Saunders and Forsline, 2006, Vuorialho et al., 2006b, Govender et al., 2014). Other questionnaires included The Hearing Dependent Daily Activities Scale (Hidalgo et al., 2008), The Minnesota Multiphasic Personality Inventory

(MMPI) (Hathaway and McKinley, 1951), The Hearing Disabilities and Handicap Scale (HDHS) (Hallam and Brooks, 1996), Your Hearing (Slawinski et al., 1993), The Hearing Attitudes in Rehabilitation Questionnaire (HARQ-F) (Hallam and Brooks, 1996), The Self-Evaluation of Life Function (SELF) (Linn and Linn, 1984), The McCarthy-Alpiner Scale of Hearing Handicap (McCarthy and Alpiner, 1983) and The Glasgow Hearing Aid Benefit Profile (GHABP)(Gatehouse, 1999) (Table 2.5). Each one of these was reported in only one study.

Table 2.5 Summary of the frequency questionnaires used in included studies

Questionnaire	Number of studies
The Hearing Handicap Inventory for the Elderly (HHIE). (Ventry & Weinstein, 1982)	7
Hearing disabilities and handicap scale (HDHS) (Hétu, 1994)	1
Minnesota Multiphasic Personality Inventory (MMPI) (Butcher, 2001)	1
Hearing-Dependent Daily Activities Scale. (Hidalgo et al., 2008)	1
Your Hearing (Slawinski & Kline, 1989)	1
Hearing Attitudes In rehabilitation Questionnaire HARQ (Hallam and Brooks, 1996)	1
Self-Evaluation of life-function (SELF) (Linn and Linn, 1984)	1
McCarthy-Alpiner Scale of Hearing Handicap (McCarthy and Alpiner, 1983)	1
Glasgow Hearing Aid Benefit Profile (Gatehouse, 1999)	1

Eight communication partner studies employed at least one questionnaire to obtain complaints, (Newman and Weinstein, 1986, Robinson and Hames, 2004, Scarinci et al., 2008, McNeil et al., 2011, Preminger and Meeks, 2012, Govender et al., 2014, Schulz et al., 2016, Schulz et al., 2017). Across these studies, five questionnaires were identified: a modified version of The Significant Other Scale for Hearing Disability (Govender et al., 2014), The Significant Other Perception of Hearing (SOPH) questionnaire (Scarinci et al.,

2009a), The Hearing Impairment Impact-Significant Other Profile (Preminger, 2012), The Hearing Handicap Inventory for Adult Screening (HHIA-S) (Newman and Weinstein, 1986), The Hearing Handicap Inventory for the Elderly- Spouse (HHIE-SP) (Newman and Weinstein, 1986) (Table 2.6).

Table 2.6 Summary of questionnaires used in communication partner studies.

Questionnaire	Number of studies
Subscale adapted from The Significant Other Scale for Hearing Disability (Hull, 2010)	5
The Significant Other Perception of Hearing (SOPH) Questionnaire (Robinson and Hames, 2004)	1
Hearing Impairment Impact-Significant Other Profile (Preminger and Meeks, 2012)	1
Hearing Handicap Inventory for Adult screening (HHIA-S question)	1
HHIE-Spouse (HHIE-SP) (Ventry and Weinstein, 1982)	3

2.4.3. Synthesis of extracted data

The primary objective of this review was to synthesise the research evidence for person with hearing loss- and communication partner-reported complaints of hearing loss. In the following section, main findings are presented separately for the two perspectives (person with hearing loss and communication partner). Using the domain groupings, two frameworks were developed, ‘Domains of hearing loss-Person with hearing loss’ (DoHL-P) (version 1.0) and ‘Domains of hearing loss – Communication partner’ (DoHL-CP) (version 1.0). Included studies typically reported a mixture of domains and illustrative examples, either in terms of individual questionnaire items or participant quotes. For this reason, the data items supported in the primary data synthesis were considered to be equivalent, irrespective of the study design or analysis methodology.

Each framework comprises of three overarching supra-domains, Auditory, Social and Self (see section 2.3.1). “Auditory” had four domains and 35

subdomains (Table 2.7). “Social” had five domains and 18 subdomains (Table 2.8), and “Self” had five domains and 28 subdomains (Table 2.9). Many of the domain-level complaints were shared across both perspectives, and this was true for the subdomain complaints associated with communicating (“Auditory”) and the perceived role of the communication partner (“Self”), but not for other subdomains.

When describing the results, the domains reported by patients only are reported first, followed by the communication partner domains, and then the domains reported from both perspectives. The “Auditory” supra-domain contained the highest number of subdomains. None of the included studies reported at the supra-domain level only. In total 58 subdomains were derived for DoHL-P and 38 for DoHL-CP. Each domain is described in turn, and the amount of data used to form each domain is detailed.

Table 2.7 List of identified domains and subdomains that were classified within the "Auditory" supra-domain.

Domain	DoHL-P	Both	DoHL-CP
Hearing			
	• Hearing warning sounds • Hearing telephone ring • Hearing the doorbell • Hearing television and radio sounds • Hearing distant sounds • Hearing environmental sounds • Hearing speech sounds		
Listening			
	• Listening to speech on the telephone • Listening to speech in noisy environments • Listening to birdsong • Listening to music • Pleasure of listening to music • Listening to quiet speech (whispering) • Listening to speech (at work) • Listening to speech (speech in general) • Listening to speech in a group of talkers • Listening to speech in a travelling vehicle • Listening to speech in public places • Listening to speech in quiet environments	• Raising the volume of the television/radio	
Communicating			
	• Asking people to repeat • Communicating at work • Communicating, general conversation • Communicating, speech in quiet • Conversing on the telephone • Reduced communication	• Conversing in a group of talkers • Conversing in noisy environments • Conversing one to one • Having to speak on behalf of partner with hearing loss • Reduced spontaneous conversation	• Having to repeat
Speech production			
		• Speech production	

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

Table 2.8 List of identified domains and subdomains that were classified within the "Social" supra-domain.

Domain	DoHL-P	Both	DoHL-CP
Interventions			
	• Expectations of rehabilitation • Technical problems with hearing aid		
Social Life			
	• Social withdrawal • Altered social interactions		• Goes out alone • Reduced enjoyment of social activities
Isolation			
	• Sense of isolation		• Don't go out much as a couple • Isolated as a couple at social events
Occupational			
	• Fear for loss of employment • Reduced employment prospects		
Relationships			
	• Relationship with family members	• Relationship with spouse/partner	• Effects on intimate relationship • Misunderstandings • Relationship conflicts • Threat to relationship

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

Table 2.9 List of identified domains and subdomains that were classified within the "Self" supra-domain.

Domain	DoHL-P	Both	DoHL-CP
Role of CP			
			• Having to answer the telephone • Having to say that phone is ringing • Accommodating to the hearing loss • Having to act as an interpreter • Speech production by partner
Emotions			
	• Embarrassment • Rejection • Worry	• Frustration • Anger • Upset	• Burden of adjustment • Having to raise the TV/radio volume • Emotional consequences on relationship • Guilt • Stress
Effort and Fatigue			
	• Listening effort	• Feelings of fatigue	• Effort and fatigue of having to accommodate • Effort involved in communication • Effort of having to act as an interpreter • Effort of having to repeat
Identity			
	• Feelings of inadequacy/self-esteem	• Self-image	
Stigma			
	• Stigma of hearing aids • Pretending to understand speech	• Denial • Stigma of hearing loss	

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

2.4.4. Patient-reported domains uniquely reported by people with hearing loss alone (DoHL-P)

2.4.4.1 Auditory: Hearing sounds

This domain corresponds to the passive function of hearing, the ability to access sound, but not always in the context of listening to speech. Subdomains describe difficulties in hearing various types of sounds. The most commonly reported problem was hearing warning sounds (n=8 complaints) such as fire alarms. Specific problematic situations included hearing the telephone ring (n=7 complaints), television/radio sounds (n=5 complaints) and the doorbell (n=4 complaints). Whilst these problems were not directly reported in the context of hearing in DoHL-CP, communication partners did observe the increase in the volume of the television and constantly having to answer the telephone.

2.4.4.2 Social: Interventions

This domain focuses primarily on the issues associated with any intervention an individual receives for their hearing loss. In particular, this domain covers the limitations of some interventions and unrealistic expectations of hearing aids leading to varying rehabilitation outcomes (n=3 complaints). For example, "...a hearing aid would be wonderful if they could solve the problem…" (Claesen and Pryce, 2012, pp 282).

2.4.4.3 Social: Occupational impact

This domain refers to problems experienced in hearing-impaired person's place of work as a result of their hearing difficulties. Subdomains describe the impact of hearing loss on everyday work-life, and particularly in relation to potential implications of their hearing loss on job security (n=4 complaints); for example, "Originally I was told that I would lose my job if I needed to use interpreters" (Punch et al., 2007, pp.511).

2.4.5. Communication Partner-reported domains uniquely by communication partners only

2.4.5.1 Self: Role of Communication Partner

This domain refers to any additional responsibilities or roles the communication partner has had to take on as a result of the limitations hearing loss has imposed on their hearing impaired partner that prevents them from carrying out certain tasks. Subdomains described roles relating to listening and communication in the home and social settings. The most commonly reported task was having to answer the telephone (n=7 complaints) as well as having to tell the person with hearing loss the phone is ringing (n=2 complaints); “having to answer the telephone seemed to be a source of annoyance because it's never for me… and I have to take the call and then I have to go through the oh yeah, I'm well thanks, How are you?” (Scarinci et al., 2009a, pp.2092). This complaint represents difficulties whereby hearing-impaired individuals avoided having to answer the phone due to difficulty hearing the telephone ring, as well as listening to conversation whilst on the phone.

Another reported subdomain, having to act as an interpreter (n=3 complaints), refers to communication partners having to speak on behalf of the hearing-impaired individual, particularly in social situations, “…by the time you’ve tried telling him what they have said, they’ve moved on…” (Morgan-Jones, 1998, pp.68). Communication strategies or tactics employed by the partner to aid were also explicitly reported (n=2 complaints). These more generally capture the accommodations by communication partners to the hearing-impaired individual. One explicitly reported strategy, ‘speech production by partner’ (n=4 complaints), represents the communication partner having to raise their voice in order to facilitate effective communication with the hearing-impaired individual.

Most of the difficulties encountered by the person with hearing loss were also noticed by the partner, and vice versa. For example, communication partners acknowledged that the person with hearing loss often did not often hear the telephone while the person with hearing loss acknowledged that they were more reliant on the communication partner to answer the telephone. Communication partners acknowledged the person with hearing loss withdrawal from social situations as well as their own compensation to engage on behalf of the person with hearing loss in response the withdrawal.

2.4.6. Domains reported by both patients and communication partner

2.4.6.1 Auditory: Listening

This domain refers to difficulties experienced when hearing is purposefully engaged, implying some degree of attentional effort, especially but not always in the context of listening to speech. The 14 subdomains (Table 2.7) within this domain describe listening problems experienced in everyday situations both in the home environment and in public spaces. For people with hearing loss, the most commonly reported problem was listening to speech in noisy environments (n=17 complaints).The subdomain “raising the volume of the television/radio” appears in both perspectives. From the point of view of individuals with hearing loss, this was in relation to the difficulty in hearing the dialogue on the television and thus having to raise the television volume. Communication partners subsequently reported their annoyance of their partner setting television volume too loud. Another common subdomain was listening to speech on the telephone (n=10 complaints) to the extent that several examples reported individuals with hearing loss avoiding taking phone calls (Hetu et al., 1988, Hetu et al., 1993, Hetu et al., 1990, Miyakita et al., 2002). The corollary of that was observed in one communication partner domain, “Role of the communication partner”, where taking responsibility for answering the

telephone was very common (n=7 complaints) across the 29 studies that questioned partners.

2.4.6.2 Auditory: Communicating

This domain refers to difficulties experienced when actively participating in conversation, where there is a mutual exchange of spoken information between at least two people. All of the 12 subdomains describe problems experienced in conversational settings and these can be in the home, as well as in public places. For people with hearing loss, the most commonly reported problems were participating in general conversation and in conversation with a group of talkers (n=13 and n=12 complaints, respectively). Next concerned asking people to repeat things (n=11 complaints). The result of that for communication partners was having to repeat to their partner which was mentioned seven times. The second most frequently reported challenge for communication partners was conversing on a one-to-one basis (n=5 complaints). Examples and quotes indicate that this subdomain predominantly refers to conversations with the hearing impaired spouse: “When you've spent forty years able to converse easily and then one goes deaf it’s very difficult to adjust…” (Morgan-Jones, 1998, pp.65); “my husband sometimes gets annoyed because I can’t hear and he has to keep repeating” (Hass-Slavin et al., 2005, pp.331)

2.4.6.3 Auditory: Speech production

This domain refers to changes in the loudness of one’s speaking voice that can occur as a result of hearing loss. There was just one subdomain, “speech production” that appears in both frameworks. For people with hearing loss, this related to increases in the volume in their voice since the onset of hearing loss (n=2 complaints). For communication partners, speaking problems also related to an increase in loudness of their own voice when talking to their hearing-

impaired partner (n=3 complaints). For example, “I have to raise my voice” (Govender et al., 2014, pp.52).

2.4.6.4 Social: Social life

Social withdrawal was the most frequently reported subdomain overall (n=42 complaints). Quotes given by people with hearing loss made reference to the inability to fully engage in a social event or social gathering, and physically removing themselves from the situation due to experienced difficulties. For example, "I find myself avoiding company because conversation is too much effort” (Hallam and Brooks, 1996, pp.205) and “…there was a party I end up in the kitchen because it is quiet there. If two or three are talking I can’t hear. Then I left” (Wanstrom et al., 2014, pp.32). There were 14 mentions of the changes and quality of social interaction e.g. “I do communicate socially but I find, I suppose because I am deaf, I don’t like conversations to be so long...that one has to think ‘Now what exactly is that person saying?’” (Morgan-Jones, 1998, pp.78).

Communication partners made similar complaints. Reduced enjoyment of social activities due to their partner’s hearing loss was most common (n=7 complaints). For example, “…he's not participating in the actual conversation and there's just all this noise going on around him he just switches off" (Scarinci et al., 2008, pp.146). Indeed, one communication partner complained that such difficulties had resulted in him or her attending social events alone, "He might accept a social invitation initially but he could also pull out” (Scarinci et al., 2008, pp.146).

2.4.6.5 Social: Sense of isolation

The subdomain ‘sense of isolation’ encompassed feelings of separation and exclusion from interactions with others, especially in relationships or during

social gatherings. Again, there was no overlap in the subdomains across frameworks. For people with hearing loss, the perception of isolation was very much in the context of themselves in certain social situations (n=26 complaints). For example, "My hearing loss makes me feel isolated from other people" (Hallam and Brooks, 1996, pp.205) and "I feel a bit left-out" (Morgan-Jones, 2001, pp.45). For communication partners, complaints referred to their general sense of being part of a couple (n=8 complaints). For example, "We don't go along to our senior's group anymore…isolated at parties" (Scarinci et al., 2009b, pp.2092). Furthermore, they reported feeling isolated as a couple at social events (n=3 complaints).

2.4.6.6 Social: Relationships

People with hearing loss and communication partners both acknowledged that hearing loss can have negative effects on personal relationships. The subdomain "relationship with spouse/partner' is present within both frameworks. For people with hearing loss, changes in their relationship with family members and their spouse or partner were often attributed to their hearing loss (n=8 and n=5, respectively). Spouses or partners were often identified as the primary motivator for seeking an audiological appointment usually as a result of the strain on communication: "My wife threatened me with divorce" (Claesen and Pryce, 2012, pp.283). People with hearing loss also attributed communication breakdown in their relationship to their hearing difficulties: "acknowledge responsibility in communication breakdown." (Claesen and Pryce, 2012, pp.283).

The negative effects of hearing loss on relationships were more prominent with communication partners than those complaints reported by people with hearing loss. In particular, effects on the intimate aspects of the relationship were frequent (n=8 complaints). For example, "My partner's hearing difficulties has

an effect on our intimate relationship" (Govender et al., 2014, pp.53), "I withdraw from my partner and we do things alone" (Govender et al., 2014, pp.53).

Hearing loss sometimes also results in greater conflict, threat and misunderstanding in relationships (n=3, n=2 and n=1, respectively). For example, “there is no use in discussing the problem with him…it does not work, it always ends up in a conflict” (Hallberg, 1999, pp.53), and “I've threatened to leave him to fend for himself, if he didn't toe the line” (Scarinci et al., 2009b, pp.2092). Misunderstandings within couples were frequently reported. This was in relation to individuals with hearing loss mishearing what is said and responding inappropriately. In other cases it was because individuals with hearing loss did not feel their partner fully understood or were not patient with their hearing difficulties; *“sometimes I just don’t bother” [Female C2].*

2.4.6.7 Self: Emotions

Several emotional responses to hearing loss, and to the secondary problems caused by hearing loss were reported across both frameworks (Table 2.9). There were a higher number of emotional domains reported by the communication partner literature. Within the communication partner domains, feelings of frustration at their partner for having hearing loss was the highest-reported emotional subdomain (n=14 complaints). For example, "I understand she's got a problem but it doesn't stop me from getting frustrated as hell sometimes” (Scarinci et al., 2009b, pp.2092). For those with hearing loss, negative emotional domains were typically in response to limitations imposed by their hearing loss (n=11 complaints*);* “just can’t hear what they’re saying to me it’s just awful” (Claesen and Pryce, 2012, pp.279).

Another reported subdomain was the burden of adjustment to hearing loss (n=4 complaints) experienced by communication partners, ″I feel that it's actually the

other people who are with him who suffer more than him because I think they've got to adapt their living style rather than him" (Scarinci et al., 2009b, pp.2092).

The emotional consequences of having to raise the volume of the television/radio was also reported (n=6 complaints); for example "What I find is when it gets up too high, it aggravates me. I don't get any pleasure out of it...I'm not having a happy time" (Scarinci et al., 2009b, pp.2092) .

2.4.6.8 Self: Stigma

In this domain, subdomains reflect the personal stigma that is associated with hearing loss and/or hearing aids, and the behaviours resulting from those societal beliefs. The subdomains "denial" and "stigma of hearing loss" appeared across perspectives. People with hearing loss particularly identified complaints of stigma either of hearing loss (n=9 complaints) or hearing aids (n=7 complaints). For example, "having been diagnosed, I feel I have labelled myself" (Morgan-Jones, 2001, pp.88) and stigma of hearing aids, "I think that if you wear a hearing aid, people tend to ignore you" (Hallam and Brooks, 1996, pp.206). Admitting denial was a recurring complaint (n=11 complaints). For example, "When I became conscious of it the hearing loss I kept trying to deny [it]" (Yorgason et al., 2007, pp.219). Wanting to conceal hearing loss or minimise the effort of participating in conversation was also frequently reported (n=7 complaints). For example, "Lots of times it is useful if you tell somebody something and they say, "OK." Rather than no response" (Yorgason et al., 2007, pp.227).

Communication partners mentioned only the stigma of hearing loss (n=6 complaints). In particular, this was made in reference to ageing or a sign of "getting old" (see also Self: Identity).

Communication partners also reported being in denial (n=3 complaints), or unwilling to accept their partner's hearing difficulties were due to hearing loss "…as a spouse you actually perpetuate. I suppose you deny it yourself as a well as a spouse. You say "Oh well, maybe it isn't as bad as that, maybe I'm just impatient…" (Scarinci et al., 2009b, pp.147).

2.4.6.9 Self: Identity

This domain refers to the way hearing loss has negatively changed an individual's perception of themselves, or, in the case of communication partners, their perception of themselves as a couple. The subdomain "self-image" is common to both perspectives. The subdomain feelings of inadequacy/self-esteem was highly reported (n=17 complaints); "…there's no connection, you can't hear. Well, it actually becomes part of your self-esteem as well" (Jonsson and Hedelin, 2012, pp.318), with persons with hearing loss complaining of feeling bothersome to others, 'I don't find it too much of a problem but other people do', particularly during conversation whilst having to ask people to repeat themselves. Another frequently reported complaint was feelings in relation to negative self-image (n=6 complaints); "You feel incomplete... mutilated" (Jonsson and Hedelin, 2012, pp.318). For communication partners, four complaints regarding image related to striving to maintain the social image of themselves and the person with hearing loss as a couple.

2.4.6.10 Self: Effort and fatigue

This domain refers to the additional resources required to listen and participate in conversation. The subdomain, "feelings of fatigue" appears in DoHL-P and DoHL-CP frameworks, (patient: n=13 complaints; partners: n=12 complaints) across perspectives. People with hearing loss frequently reported exerting greater effort in order to listen and follow a conversation (n=8 complaints), and

consequently reported feelings of fatigue (n=6 complaints). For example, "I fell asleep when I was at the meeting and after they said to me I know how you fell asleep, because you couldn't concentrate the whole period" (Granberg et al. 2014b, pp.783). For communication partners, complaints related to effort involved in communication comprised the highest reported subdomain, particularly due to frequent misunderstandings and communication breakdowns. Collected data that could not be assigned to a subdomain within the framework were coded as miscellaneous, these are listed in Appendix 8.1.2. There were 40 specific examples which could not be coded.

2.4.7. Quality assessment of included studies

2.4.7.1 Qualitative studies

Structured appraisal methodological quality is key to assessing the reliability and to test accuracy studies included in a systematic review (Whiting et al., 2003). The purpose of quality assessment is to establish how reliable the study findings are and whether the study is relevant (Centre for Reviews and Dissemination, 2009). Quality assessment typically considers risk of bias, quality of reporting, statistical issues and choice of outcome measures. Several assessment tools have been developed to assess the quality of the quantitative studies. For systematic reviews, quality assessment has typically been used to establish a quality threshold below which studies are excluded, or to distinguish between studies in terms of comprehensiveness of reporting (Centre for Reviews and Dissemination, 2009).

The application of quality criteria to qualitative research is widely debated (Dixon-Woods et al., 2004). This is due to the lack of distinction between the quality and process of a study, and those concerned with transparency of reporting (Dixon-Woods et al., 2004). Several quality assessments for qualitative research have been developed. However, there is a lack of

consensus as to those that should be routinely adopted. This is also due to the argument that different qualitative methods need to be appraised in different ways (Centre for Reviews and Dissemination, 2009), and appraising the most important qualities of qualitative studies can be challenging (Dixon-Woods, 2004).

The Critical Appraisal Skills Programme (CASP) (CASP, 2016) is a 10-item quality appraisal tool developed explicitly for use in systematic reviews (Centre for Reviews and Dissemination, 2009) (Table 2.10). The items of the CASP tools are:

1. Was there a clear statement of the aims of the research? This question considers whether the authors of the study have listed out the purpose of the research and its relevance.
2. Is a qualitative methodology appropriate? This considers whether qualitative methods were appropriate to address the research question.
3. Was the research design appropriate to address the aims of the research? This question assesses whether the author of the study has justified the study design.
4. Was the recruitment strategy appropriate to the aims of the research? This item explores whether the author has outlined how the study participants were selected and why the participant group was appropriate to address the research question.
5. Was the recruitment strategy appropriate to the aims of the research? This question assesses whether the author has outlined exactly how the data was collected, if the author has justified the methods chosen, and if the author has discussed data saturation.
6. Has the relationship between researcher and participants been adequately considered? This question assess whether the author has

assessed their own role in data collection/analysis, and considered any potential for bias.

7. Have ethical issues been taken into consideration? This questions confirms whether the authors have outlined ethical approval for the study and/or made reference to consent where appropriate.
8. Was the data analysis sufficiently rigorous? This question assesses whether the author has described the analysis process in detail and if sufficient data has been presented to support the findings.
9. Is there a clear statement of findings? This question assess whether there is an adequate discussion of the findings.
10. How valuable is the research? This question assesses whether the author talks about the wider study implications of the study such as within research or clinical practice.

Each question scored in either “yes”, “can’t tell”, or “no” category. The guidance information provided with each question was used to help prompt assessment of each paper. Each of 34 qualitative studies included in the present review were rated using the 10-item CASP checklist (Table 2.10). Two researchers (VV and DAH) independently conducted the appraisal. Where there was disagreement in appraisal for a particular study, this was resolved through discussion.

Table 2.10 Quality appraisal of qualitative studies using CASP checklist (table continued on next page…)

	Study Aims clearly stated	Appropriate methods	Justification of methods	Recruitment strategy given	Data collection described	Researcher bias discussed	Study ethics description	Description of data analysis	Description of results	Value of research
Magilvy (1985)	Yes	Yes	No	Yes	Yes	No	Can't tell	No	Yes	Yes
Thiede (1986)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Hetu et al. (1988)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hetu et al. (1990) (Study 1))	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hetu et al. (1990) (Study 2)	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Can't tell	Yes
Bade (1991)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Hallberg and Barrenas (1994)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hetu et al. (1994)	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cowie et al. (1995)	Yes	Yes	No	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
Stephens et al. (1995)	Yes	Yes	Can't tell	No	Yes	Can't tell	Yes	Yes	Yes	Yes
Tesch-Romer (1997)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hallberg (1999)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gething (2000)	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes
Laroche et al. (2000)	Yes	Yes	No	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes
Brooks et al. (2001)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Morgan-Jones (2001)	Yes	Yes	No	Can't tell	Can't tell	No	No	Yes	Yes	Yes
Hass-Slavin et al. (2005)	Yes	Yes	Can't tell	Yes	Yes	Yes	No	No	Yes	Yes
Ross and Lyon (2007)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Punch et al. (2007)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Yorgason et al. (2007)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hallam et al. (2008)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Hidalgo et al. (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2.10 Quality appraisal of qualitative studies using CASP checklist cont…

	Study Aims clearly stated	Appropriate methods	Justification of methods	Recruitment strategy given	Data collection described	Researcher bias discussed	Study ethics description	Description of data analysis	Description of results	Value of research
Jennings and Shawb (2008)	Yes	Yes	No	Can't tell	Can't tell	No	No	Can't tell	Yes	Yes
Scarinci et al. (2009b)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Wallhagen (2010)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Kelly and Atcherson (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Claesen and Pryce (2012)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Jonsson and Hedelin (2012)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Manchaiah et al. (2013b)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ekberg et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Granberg et al. (2014c)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Preminger and Laplante-Levesque (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Wanstrom et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Heffernan et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Studies that used interviews as the research method varied in the way the results of the interview or focus group were reported. Some authors stated complaints in the form of direct quotes from the interview. Other authors specified the domains of hearing loss supplemented with quotes from the interview (Punch et al. 2007; Wanstrom et al. 2014), or the domain only. Where studies scored lower on the CASP checklist was in relation to justifying the methods used in the study; only 24 out of the 34 qualitative studies. Another item that did not score as well was a description of risk of bias of the researcher conducting the qualitative research, with only 20 studies reporting this.

2.4.7.2 Quantitative studies

The remaining 44 studies reporting quantitative data were subjected to a second quality appraisal as defined in the protocol (Vas et al., 2016) (Table 2.11). Studies were assessed for (i) reporting a wide variety of ages (mean and SD), (ii) inclusion of men and women in study, (iii) justification of sample size, (iv) reporting ethical considerations, (v) rigour of data analysis and (vi) no eligibility criteria that would exclude particular hearing loss subgroups. Each criterion was scored 0 (“no”), 1 (“can’t tell”) or 2 (“yes”) to give a composite score out of 12. A score of zero indicated the study did not report the item being assessed, a score of one indicates that a judgment could not be made as to whether the item was taken addressed based on what the authors have included. A score of two indicates the study reported and addressed the item in question well. The mean quality score was 5.02 (SD=1.85). The most poorly reported aspect was the justification of sample size, which was not reported in any of the quantitative studies. Additionally, a statement of ethical considerations was also poorly reported.

Table 2.11 Quality assessment of quantitative studies (table continued on next page)

	Reporting of participants age	Reporting of participants gender	Reporting of sample size	Reporting of ethics	Reporting of data analysis	Reporting of inclusion and exclusion criteria	Total
Newman and Weinstein (1986)	2	2	0	0	0	0	4
Garstecki (1987)	2	2	0	0	0	0	4
Hetu et al. (1987)	2	2	0	0	2	2	8
Vesterager et al. (1988)	1	2	0	0	0	1	4
Martin et al. (1989)	1	2	0	0	0	0	3
Mulrow et al. (1990)	1	2	0	2	2	1	8
Stephens et al. (1990)	0	2	0	0	0	0	2
Knutson and Lansing (1990)	2	2	0	1	0	1	6
Mulrow et al., (1990b)	0	2	0	0	1	1	3
Vesterager and Salomon (1990)	2	2	0	1	0	2	7
Plath (1991)	1	2	0	0	0	1	4
Slawinski et al. (1993)	1	2	0	0	1	0	4
Lormore and Stephens (1994)	0	2	0	0	0	0	2
Hallberg and Barrenas (1994)	2	2	0	0	2	2	8
Gilbertson et al. (1996)	2	2	0	2	2	2	10
Hallam and Brooks (1996) (Study 1)	2	2	0	0	1	0	5
Hallam and Brooks (1996) (Study 2)	2	2	0	0	0	0	4
Hallam and Brooks (1996) (Study 3)	2	0	0	0	0	0	2
Caissie and Gibson (1997)	2	2	0	0	1	0	5
Newman et al. (1997)	1	1	0	0	1	1	4
Gatehouse (1999)	0	2	0	0	1	0	3
Strawbridge et al. (2000)	1	2	0	0	2	0	5
Kochkin and Rogin (2000)	1	2	0	0	2	0	5
Albera et al. (2001)	1	2	0	0	0	2	5
Morgan-Jones (2001)	2	1	0	1	2	2	8
Tsuruoka et al. (2001)	2	2	0	0	2	2	8

Table 2.11 Quality assessment of quantitative studies cont…

	Reporting of participants age	Reporting of participants gender	Reporting of sample size	Reporting of ethics	Reporting of data analysis	Reporting of inclusion and exclusion criteria	Total
Espmark et al. (2002)	1	2	0	0	2	0	5
Miyakita et al. (2002)	2	1	0	0	2	0	4
Robinson and Hames (2004)	1	2	0	0	0	0	3
Stark and Hickson (2004)	2	2	0	1	0	2	7
Anderson and Noble (2005)	2	2	0	0	1	0	5
Vuorialho et al. (2006b)	2	2	0	2	2	2	10
Saunders and Forsline (2006)	2	1	0	0	0	0	3
Leposavić et al. (2006)	1	2	0	0	2	0	5
Cox et al. (2007)	2	2	0	0	0	2	6
Helvik et al. (2007)	2	2	0	1	2	0	7
Hallberg et al. (2008)	2	2	0	0	2	0	6
Scarinci et al. (2009a)	2	2	0	2	2	2	10
McNeil et al. (2011)	0	1	0	2	2	2	7
Scarinci et al. (2012)	2	2	0	2	2	1	9
Preminger and Meeks (2012) (Study 1)	2	2	0	2	2	0	8
Preminger and Meeks (2012) (Study 2)	2	2	0	2	2	0	8
Zekveld et al. (2013)	2	2	0	2	2	2	10
Govender et al. (2014)	1	1	0	1	2	2	7
Senkal et al. (2014)	2	2	0	2	0	2	8
Schulz et al. (2016)	2	2	2	0	2	2	10
Schulz et al. (2017)	2	2	2	2	2	2	12

Sixteen studies referred to a theoretical framework either to support their scientific approach to their main study objectives (n=6 studies) or to describe their findings (n=10 studies). Other studies stated particular theoretical frameworks or theories, but did not use them to inform the study methodology or analysis.

2.4.8. Influence of hearing loss severity on reported complaints

The first of the secondary objectives investigated the pattern of reported complaints in relation to severity of hearing loss, where hearing status was adequately specified. Only 28 studies reported the hearing status of participants, and even in these studies there was considerable variation in the way hearing loss was reported (e.g. mean pure-tone audiometric hearing thresholds, sensorineural or conductive, or self-reported judgement). The breakdown of complaints relating to hearing loss severity (where provided in the included studies) is presented in Table 2.12. Where possible, the complaints were categorised according to hearing loss severity into three categories using UK audiometric descriptors (BSA, 2011a) based on the average of the pure tone hearing threshold levels at 250, 500, 1000, 2000 and 4000 Hz: (i) mild hearing loss (20-40 dB HL), moderate hearing loss (41-70 dB HL), and severe to profound hearing loss (>=71 dB HL). Using this classification, a subset of 19 studies could be synthesised (7 mild; 8 moderate; 1 mild-moderate; 2 severe-to-profound). Extracted domains and complaints for mild and moderate hearing losses were split according to these categories. There was insufficient data for the severe-to-profound category to make meaningful interpretations. In total, there were 70 individual complaints reported from studies that stated hearing loss severity. Of those, 18 complaints were reported from studies using participants with mild hearing loss, 23 complaints from studies with moderate hearing loss and four that included participants with mild-moderate hearing loss.

Complaints relating to communication and speech comprehension were the most commonly reported across the included studies that reported hearing loss, as well as emotional subdomains (Table 2.1). The data extracted in the present review showed considerable overlap across hearing loss severity and the domains extracted. The social impact of hearing loss, particularly social withdrawal was also represented across both hearing loss severities. The classification of hearing loss severity however, was based on pure-tone averages only.

2.4.9. Comparing the data-driven DoHL-P with the Brief ICF Core Set

The DoHL-P (Table 2.13) was compared to the Brief ICF Core Set for hearing loss. The domains in DoHL-P derived from the review were conceptually mapped to the 27 domains of the Brief ICF Core Set (see section 2.1) using the descriptive labels of each domain and the ICF definitions to assist in interpretation where differences were simply due to terminology (e.g. ‘occupational impacts’ versus ‘remunerative employment’).

Table 2.12 Breakdown of hearing loss complaints according to hearing loss severity from the 28-studies that reported hearing loss status of participants

Mild Hearing Loss	Mild-moderate hearing loss	Moderate hearing loss
Negative social consequences of HI in everyday life	Casual beliefs	Social situations
Unable to hear non-verbal sounds in everyday life	Controllability/curability	Emotional consequences
Participation restriction	Emotional representations of hearing loss	"I understand that I am too cautious about my hearing. I am about everything"
Cannot hear when people ae speaking from a distance	Cognitive representations of hearing loss	"I don't have a good understanding of what hearing aids can and cannot do"
Communication problems		"I am not always aware of what I can hear"
Communication partner domains only		"I have more respect for the hearing aids and wear them more regularly now"
Stigma		"I feel as though hearing aids help me more than I originally thought they did"
Changes in speech since their hearing loss		"I need to think about what to expect from hearing aids"
Emotional problems		Frustration
Subjects felt handicapped because of their hearing loss		Detection difficulties
Hearing loss limits their lives		Feelings of inadequacy
Perceive hearing loss to be less handicapping than what spouse perceives		Problems with conversation
TV/Radio too loud		Feeling left out in group conversation
"The positive feedback you gave me about my hearing being better with my hearing aids than I thought was very helpful		Little enjoyment of free time
"I am willing to depend more on my hearing aids now"		Feeling lonely or remote
"You telling me about my hearing loss has helped me explain it to my wife and daughters"		Not feeling close to others
		Feeling left out in a group
		Noise at work

Table 2.13 Domains ad subdomains in DoHL-P framework only. (Table continued next page…)

AUDITORY	SOCIAL	SELF
Hearing	**Interventions**	**Emotions**
Hearing warning sounds Hearing telephone ring Hearing the doorbell Hearing television and radio sounds Hearing distant sounds Hearing environmental sounds Hearing speech sounds Sound localisation	Expectations of rehabilitation Technical problems with hearing aid	Embarrassment Rejection Worry Frustration Anger Upset
Listening	**Social life**	**Effort and fatigue**
Listening to speech on the telephone Listening to speech in noisy environments Listening to birdsong Listening to music Pleasure of listening to music Listening to quiet speech (whispering) Listening to speech (at work) Listening to speech (speech in general) Listening to speech in a group of talkers Listening to speech in a travelling vehicle Listening to speech in public places Listening to speech in quiet environments Listening to speech (unfamiliar speakers) Raising the volume of the television/radio	Social withdrawal Altered social interactions	Listening effort Feelings of fatigue

The first column displays the domains and subdomains in the supra-domain “Auditory”, the second column displays those in “Social”, and the third column displays domains and subdomains in “Self”

Table 2.13 Domains and subdomains in DoHL-P framework only cont…

Communicating	**Isolation**	**Identity**
Asking people to repeat Communicating at work Communicating, general conversation Communicating, speech in quiet Conversing on the telephone Reduced communication Conversing in a group of talkers Conversing in noisy environments Conversing one to one Having to speak on behalf of partner with hearing loss Reduced spontaneous conversation	Sense of isolation	Feelings of inadequacy/self-esteem Self-image
Speaking	**Occupational**	**Stigma**
Speaking with a loud voice	Fear for loss of employment Reduced employment prospects Opportunities at work	Stigma of hearing aids Pretending to understand speech Denial Stigma of hearing loss
	Relationships	
	Relationship with family members Relationship with spouse/family member	

Where possible, the domains from the frameworks were conceptually mapped onto the domains within the Brief ICF Core Set categories (Table 2.14). Eight of the domains clearly mapped onto those of the Brief ICF Core Set for hearing loss, while six further domains appeared to be unique to the framework. These were “isolation”, “social life”, “effort and fatigue”, “stigma” and “identity”. With respect to “identity”, the Brief ICF Core Set does contain the domain ‘societal attitudes’ that is defined as “…beliefs held by a social group about other individuals…” but this represents a different theoretical concept than the one identified in the review which was concerned specifically with the way hearing loss negatively changed the person’s perception of themselves. “Social life” was the domain with the highest reported data items across the literature included in the present review. Therefore, if it appears that some of the patient-reported implications are *not* represented within the Brief ICF Core Set for hearing loss. Furthermore, while the ICF framework was designed to be widely disseminated across the field of audiology (Granberg et al., 2014a), it focuses exclusively on the person with the health condition and excludes aspects relating to the communication partner. If the ICF framework solely was used to guide clinical practice (such as by framing the patient assessment appointment) then it would risk diminishing the value of implementing family-centred care principles in audiological practice.

Table 2.14 Summary of how domains have mapped findings onto the DoHL-P framework defined by the Brief ICF Core Set for hearing loss.

Unique to DoHL-P	Both	Unique to ICF Brief Core Set for Hearing Loss
Isolation **Social Life** **Effort and Fatigue** **Identity** **Stigma**	**Hearing** (Hearing functions b230, sound e460, Sensations associated with hearing aid/vestibular b240) **Emotions** (Emotional functions b152) **Communicating** (Communicating with receiving spoken messages d310) **Relationships** (Immediate family e310, family relationships d760, Individual attitudes of immediate family members e410)) **Occupational** (Remunerative employment d850) **Speaking** (Conversation d350) **Listening** (Listening d115) **Interventions** (Using communication devices and techniques d360)	Temperament and personality functions (b126) Functions (attention, memory, seeing) (b140, b144, b210) Structure of (brain, external ear, middle ear, inner) (s110, s240, s250, s260) Handling stress and other psychological (d240) School education (d820) Community life (d910) Products and technology (e125) Societal attitudes (e460) Health services, systems, and policies (e580) Health professionals (e355)

Some of the ICF domains are not within the scope of the review question.

All ICF Core Set data that was coded as “component not covered” (Granberg et al. 2014b) was obtained from the original authors (Granberg; personal communication) and mapped onto the domains and subdomains in DoHL-P and DoHL-CP frameworks using descriptions of each category (Table 2.15). Due to the generalisability of the category names, the meaning of some of the categories was ambiguous and could not be mapped onto the frameworks such as “mutations” and “waking up” and therefore was placed in the “miscellaneous” category. In other cases some categories were interpreted as being applicable to more than one domain such as “participation” and “behaviour of others”.

All of the “components-not covered” that were mapped onto DoHL-CP domains fell into the subdomain “Role of communication partner” (Table 2.15). This may provide a reason as to why these could not be coded within the ICF since the ICF only captures problems experienced by the hearing-impaired person. The absence of these categories from the ICF potentially excludes information regarding the broader impact of hearing difficulties and relationships changes due to hearing loss that are considered important to people with hearing loss. Issues concerning stigma and identity (“Self") are not routinely considered by questionnaires such as the HHIE (Ventry and Weinstein, 1982), nor existing frameworks such as the ICF Core Set for hearing loss (Danermark et al., 2013). Yet, excluding those personal aspects of hearing loss regarded to be important by patients and their communication partners is not in line with patient-centred communication principles and may have negative consequences for audiological assessment and management decisions (Ekberg et al., 2014, Grenness et al., 2014b).

Table 2.15 ICF Core Set data that was coded as 'component not covered'

Component not covered categories	DoHL-P	DoHL-CP
s-nc mutations	-	-
d-nc waking up (waking up in the morning)	-	-
e-nc outdoor (outdoor in general as a context)	Hearing	-
e-nc behaviour of others	Social life, Relationships, Occupational	-
d-nc participation (engaging in general activities)	Social life	Role of CP
e.nc other people skills and knowledge of HL	Occupational	Role of CP
d-nc activities (general activities)	-	Role of CP
e-nc home environment	-	Role of CP
e-nc visual cues	-	Role of CP

2.4.10. Additional perspectives

The domains described in 2.4.3 represent hearing loss complaints from patients and communication partners in their own lives. There were further complaints extracted from patients with hearing loss referring to the implications of hearing loss on their communication partner (Table 2.16). Conversely, there were also complaints describing the implications of hearing loss on their hearing-impaired partner (Table 2.17).

These complaints could be mapped onto all three supra-domains of the frameworks. The most highly reported complaint expressed by communication partners about their partner with hearing loss was in relation to 'social withdrawal' (n=6 complaints), 'hearing warning signals' (n=5 complaints), 'hearing non-speech sounds' (n=5 complaints), 'hearing the telephone ring' (n=5 complaints) and 'stigma of hearing loss' (n=5 complaints). All of these complaints could be mapped onto the frameworks.

Table 2.16 Difficulties that a person with hearing loss can experience expressed by their communication partner.

Supra-domain	Domain	Subdomain
AUDITORY	Hearing	Hearing warning signals
	Hearing	Hearing non-speech sounds
	Hearing	Hearing telephone ring
	Hearing	Hearing television and radio sounds
	Listening	Listening to distant sounds
	Listening	Raising the volume of the TV/radio
	Communicating	Non-specific communication
	Communicating	Conversation in noise
	Communicating	Avoidance
	Communicating	Having to repeat
	Speaking	Speaking with a loud voice
SOCIAL	Social life	Social withdrawal
	Stigma	Stigma of hearing loss
	Relationships	Misunderstandings
	Isolation	Rejection
	Occupational	Restrictions at work
	Emotions	Denial
	Miscellaneous	N/A

Table 2.17 Difficulties that a communication partner can experience expressed by their partner (with hearing loss)

Supra-domain	Domain	Subdomain
AUDITORY	Listening	Television/radio complaints
SOCIAL	Relationships	CP not understanding hearing loss
	Relationships	Different perspectives on hearing loss (friends, family)
	Relationships	Family complaints about hearing loss (general)
	Relationships	Effect on intimate relationship
SELF	Role of CP	CP additional responsibilities
	Emotions	Adjustment for spouse
	Miscellaneous	N/A

2.5. DISCUSSION

The primary objective of this comprehensive review was to collate and analyse the available evidence from published studies that have reported what adults with hearing loss and their communication partners themselves report as problematic in everyday life. After extensive searching 78 eligible articles

(comprising 82 studies) were identified. Information presented across these studies broadly encapsulated auditory and non-auditory effects of hearing loss. These effects were extracted in the form of individual complaints or domains predefined by the publication author that were re-conceptualised as two hierarchical frameworks (DoHL-P and DoHL-CP) each comprising the same three supra-domains (Auditory, Social and Self), 14 domains and 79 subdomains representing the impact of hearing loss.

There was considerable overlap in some of the domains reported across both perspectives. Many of the subdomains within “Communicating” were experienced by both individuals with hearing loss and communication partners. For example, individuals with hearing loss reported difficulties participating in conversation in several different situations, which in turn had impacted on the communication partner. Another subdomain in DoHL-P was difficulty hearing the telephone ring and listening to speech on the telephone. This was represented conversely in DoHL-CP within “Role of communication partner” domain as “Having to answer the telephone” and “Having to say that phone is ringing”. This domain overall comprises the accommodations or additional roles communication partners have had to undertake as a result of their partner’s hearing loss. It represents the ways in which hearing loss has multifaceted effects on those close to a person with hearing loss, rather than purely at an individual level of someone experiencing hearing difficulties. Across domains that were common to both frameworks, there was some variability within the subdomains. For example, the subdomains within “Relationships” of DoHL-P differ from that of DoHL-CP. For people with hearing loss, this was acknowledged in terms of the effects of hearing loss on relationships with communication partners and family members in general. Within the domain “Social life”, communication partners reported that as a result of the negative

experiences encountered by people with hearing loss, they experienced a reduced enjoyment of social activities and attending social events alone. This was also represented in the “Sense of isolation” subdomains where communication partners reported feeling isolated as couple at social events and a reduction in attending events as a couple. This ties in with the person with hearing loss domains with the subdomain of social withdrawal.

Furthermore, there were considerably more subdomains reported in the “Emotions” domain by communication partners. Communication partners reported the burden and stress of having to adjust to their partner’s hearing loss as well as the emotional consequences hearing loss imposed on the relationship with their hearing-impaired partner. Communication partners reported feelings of guilt and upset in relation to the way they reacted to hearing loss and their lack of understanding of the person with hearing loss’ difficulties. Furthermore, communication partners reported far more subdomains within the “Effort and fatigue” domain. “Effort” in this context was particularly associated with having to accommodate and additional responsibilities and strategies undertaken to adapt to hearing loss. It is noteworthy that fatigue in relation to communication is present in both perspectives rather than the person experiencing hearing loss alone.

The “Communicating” domain within the supra-domain “Auditory” contained the greatest overlap between patients and communication partners. This was particularly true for subdomains relating to conversation in different situations such as in noise or amongst a group of talkers. There was also some overlap in the subdomains within “Emotions” such as the frustration, anger and the upset of coping and living with hearing loss across patients and communication partners. In addition, “self-image” was a subdomain present in both frameworks. For communication partners, this was in relation to the image of themselves as

a couple in society following hearing loss, as well as the image of the individual with hearing loss alone. Feelings of fatigue, in relation to listening and participating in conversation were also reported by individuals with hearing loss and communication partners which again the shared problems hearing loss has on communication which involves interaction with other people.

Unsurprisingly, most of the subdomains in the “Auditory” supra-domain were unique to people with hearing loss, particularly those associated with listening and hearing sounds. In addition, the occupational impact of hearing loss on those experiencing hearing difficulties is only present in DoHL-P. These subdomains did not appear in DoHL-CP.

2.5.1. Comparison with other studies

Hearing loss is a chronic condition that has the potential to affect family members of someone diagnosed with hearing loss. Yet, this work represents the first endeavour to create empirically derived frameworks of hearing loss complaints from the perspective of individuals with hearing loss *and* communication partners. Evidence from video-recorded audiology appointments indicates that family members have a strong interest in being involved and sharing their experiences of the patient’s hearing loss, but that they are typically discounted by the audiologist (Ekberg et al., 2014). Interestingly some behaviours observed in the conversation analysis showed how family members sometimes self-selected to speak in the appointment by responding to audiologist questions directed at the patient. This behavioural observation fits well with one of the subdomains, “having to act as an interpreter”, whereby communication partners described their role in speaking on behalf of the hearing-impaired individual.

Kamil and Lin (2015) reported some negative experiences of communication partners including decreased social function and emotional functions, increased burden of communication which concurs with the subdomains within ‘Social Life’, ‘Emotions’, and ‘Role of communication partner’ of DoHL-CP. The authors explored studies that have investigated the impact of hearing loss on communication partners only, without taking into consideration the impact on those with hearing loss.

Examining a corpus of 63 video-recorded first-time appointments between an audiologist and a person with hearing loss, Grenness et al. (2014b) observed many closed-questions about medical and lifestyle issues, but there was very little emotionally focused conversation. Moreover, from the same dataset, Ekberg et al. (2014) observed that patient-expressed concerns often conveyed their negative emotions, but that such concerns were not always adequately addressed by the audiologist. The field of health psychology provides a number of alternative frameworks for understanding a long-term health condition and its personal impact. Heffernan et al. (2016) recently described the application of Leventhal’s self-regulatory model (Leventhal et al., 1997). This model proposes that the ways in which a person construes their own health condition affects the way that they cope with it and ultimately their health outcomes. Important mediating components are thoughts and beliefs, and the emotional reactions to the condition. Interviews with 25 people with hearing loss explored these components of the self-regulatory model observing that “Most individuals with hearing loss reported negative emotional representations of hearing loss.” (Heffernan et al. 2016, pp. 6). Expressed emotions included frustration, irritation, embarrassment and loneliness, which are captured as subdomains in the DoHL-P and DoHL-CP.

The domain groupings derived from the present review are congruent with the self-regulatory framework and the subdomains identified from the data-driven analysis could easily fit into this theoretically motivated framework. For example, aspects of “disengaged coping” mechanisms are captured here as “social withdrawal”, “pretending to understand speech”, and “effort of having to act as an interpreter”. Further work, beyond the scope of the present synthesis, is needed to decide this. Information regarding the onset of hearing loss and duration of hearing aid use are both important pieces of information for examining the lived experiences of hearing loss as a function of the time that an individual has to adapt to their hearing loss. Neither of these parameters were consistently reported.

2.5.2. Strengths and limitations of the study

This is the first comprehensive review of the published qualitative evidence on the problems of hearing loss from the perspective of people with hearing loss and their communication partners. The paired domain grouping frameworks identify what experiences of living with hearing loss are shared and what are unique. In particular, those shared experiences give insights into the two different perspectives. For example, people with hearing loss are concerned by raising the volume of the television, and communication partners are concerned about having to listen to the television louder than they would normally prefer. However, it was identified that data pertaining to communication partners *exclusively* concerned spouses or partners, and so there is nothing in the present literature about impacts on other potential communication partners such as siblings, children (including adult children), friends, relatives, colleagues, and carers (Manchaiah et al., 2012).

The three additional studies identified in the updated manual search were subjected to the same data collection. The extracted complaints of hearing loss

were considered with the frameworks to decipher if any new information or complaints were reported in these studies. However, these studies did not identify any new domains/subdomains that were not already in the frameworks.

An additional important finding of the quality assessments was the heterogeneity in reporting hearing loss and justification of analysis, which concurs with the systematic review findings reported in Kamil and Lin (2015). However, this did not pose a limitation for the review. The primary aim of the review was to collect and synthesise hearing loss-related complaints irrespective of the severity of hearing loss or the method of data analysis. Studies that did not report this did not meet the eligibility criteria and thus were not included in the review. Whilst the Kamil and Lin (2015) review aimed to characterise the impact of hearing loss on a communication partners, the authors were unable to draw specific conclusions regarding the functional impact of hearing impairment on communication partners. The current review therefore represents the first study to have surveyed the current literature where both quantitative and qualitative study findings of the impact of hearing loss have been synthesised to create a unified framework, wholly driven by the data.

The included studies demonstrated considerable variation in the study population characteristics and in the degree and aetiology of hearing loss among participants. Many studies did not fully describe the hearing status of the people with hearing loss and rarely if ever disclosed the hearing status of the communication partners. There may be cases where the communication partner may have an undiagnosed hearing loss themselves, and some of their own hearing difficulties might unknowingly contribute to the experiences described here. These limitations make it difficult to investigate how hearing status might influence the type of experiences and difficulties associated with hearing loss, but they also make it difficult to draw generalisable conclusions.

In the survey, 17 different closed-set questionnaires were used to obtain hearing-related complaints across the included studies. The HHIE was the most frequently among included publications that used questionnaires to obtain individual complaints cited and was identified ten times across the 78 included articles (Magilvy, 1985, Newman and Weinstein, 1986, Garstecki, 1987, Mulrow et al., 1990, Newman et al., 1997, Dalton et al., 2003, Stark and Hickson, 2004, Saunders and Forsline, 2006, Vuorialho et al., 2006b, Cox et al., 2007). It taps into domains relating to hearing and listening ability in various different situations as well the emotional consequences of hearing loss. Some of the most frequently reported domains, such as social withdrawal (n=42 complaints), conversing in a group of talkers (n=12 complaints), feelings of frustration (n=11 complaints), listening on the telephone (n=10 complaints) and listening to the television (n=6 complaints) are items in the HHIE. Moreover, some of the questionnaires used (such as the GHABP, the HDHS and the APHAB) include items concerning speech understanding and this provides a possible reason as to why the “Auditory” supra-domain contains the highest number of domains (n=4) and subdomains (n=34). In contrast, very few closed-set questionnaire items concern issues relating to “Identity” and so this may account for the relatively fewer instances of subdomains in DoHL-P.

2.5.3. Questionnaires for diagnostic assessment

The questionnaires extracted in the review tapped into the subdomains depicted in the framework to varying degrees. For example, the items extracted from the HHIE could be consolidated into various subdomains across all three supra-domains of the framework. On the other hand, the questionnaire, Your Hearing (Slawinski et al., 1993) extracted items could only be mapped onto subdomains of the hearing supra-domain only.

None of the questionnaires used in the studies included in the review tapped into the subdomains “Communicating at work”, “Pretending to understand speech”, “Stigma of hearing loss” and “Stigma of hearing aids”, which mean that these subdomains emerged from studies that employed qualitative methods only. The frameworks created from the data collated in the present review has been purely driven by the data collected from the 78 included articles. Whilst the framework aims to be inclusive of hearing loss related complaints, any complaints that were not reported in the included studies are therefore not represented in the frameworks given the data-driven synthesis.

Many clinical measures do not adequately capture the psychosocial consequences of hearing loss from both perspectives, and they are not typically aimed at communication partners. Many questionnaire tools have been developed for use in diagnosis and rehabilitation programmes for patients with hearing loss (Ventry and Weinstein, 1982, Demorest and Erdman, 1987, Owens and Raggio, 1988, Van den Brink et al., 1996, Kaplan et al., 1997, Gatehouse and Noble, 2004, Cox et al., 2005). Questionnaire instruments developed for (communication) partners are also emerging (Robinson and Hames, 2004, Govender et al., 2014). The DoHL-P and DoHL-CP frameworks provides a structured representation of the implications of hearing loss on those affected individuals and their communication partner. It can be used to guide the development of such questionnaires, particularly for measures that are directed at individuals with hearing loss and their communication partner. The frameworks translates and summarises the vast qualitative research evidence of complaints of hearing loss into an evidence-based hierarchy.

2.5.4. Future directions

The present review has captured the auditory and non-auditory effects of hearing loss, many of which (such as “communication” and “relationships”) have

been reported by people with hearing loss *as well a*s their communication partners. Typically these perspectives have been considered separately and, have not been synthesised into a single framework for each perspective. The results derived from the current review has incorporated both of these perspectives into a structured representation. The overlap across the two perspectives depict the different manifestations of the same domain. That is, how a particular difficulty of someone with hearing loss can have a secondary impact on their communication partner. Audiological assessments in clinic emphasise the hearing status of an individual but the results of the current review demonstrate the multidimensional effects of hearing loss and their widespread impact across the family unit.

Considering the challenges encountered by communication partners as a result of hearing loss may contribute a more complete clinical profile of a patient undergoing audiological assessment. There were also domains identified from DoHL-P that mapped with domains within DoHL-CP. For example, communication partners commented on constantly having to repeat themselves or having to tolerate the increased volume of the television, identified as a frequent reported problem. The 'Role of communication partner' subdomain within DoHL-CP represents the role of the communication partner in providing support to the individual with hearing loss in order to overcome the everyday challenges imposed by hearing loss, such as by answering the telephone or the use of communication strategies. Considering the perspectives of communication partners during clinical appointments to inform clinical assessment of an individual experience hearing difficulties and involving communication partners in rehabilitation may optimise rehabilitation outcomes as well as ease the patient's journey through rehabilitation.

Future research could investigate coping strategies adopted by communication strategies in cases where spouses and family members have made accommodations in order to adjust to hearing loss. In particular, the results from this review highlight the negative impact hearing loss can have on the people around a hearing-impaired individual, such as on relationships with communication partners and family members, or those who play an integral role in the life of an individual diagnosed with hearing loss.

2.6. CONCLUSION

This review provides the first comprehensive compilation of quantitative and qualitative research studies investigating the impact of hearing loss on the impact of the individual and the communication partner. Currently auditory rehabilitation primarily serves to address the auditory degradation of hearing loss. However, the consequences of hearing loss are multifaceted and can extend to various aspects of life as well as on people close to those with hearing loss. These comprehensive frameworks aims to capture the important implications of hearing loss. Domains and subdomains mutual to both perspectives encompassed concepts related to “Auditory” (listening, communicating, speaking), “Social” (relationships, isolation, social life, occupational, interventions), and “Self” (effort and fatigue, emotions, identity and stigma. These domains therefore could highlight aspects of hearing loss that are not currently addressed in currently aural rehabilitation plans. The frameworks also highlight the need to consider the far-reaching effects of hearing loss that may extend beyond the patient, particularly the effects on family members and their involvement the patient’s experience living with hearing loss. This is particularly important during the early stages of auditory assessment and diagnosis in order to form complete a clinical profile of patients

with hearing loss and facilitate personalising rehabilitation plans to consider the patient in the wider context of their circumstances.

CHAPTER 3. FACE-VALIDITY OF THE DOMAINS OF HEARING LOSS FRAMEWORKS: HEARING AID USER, COMMUNICATION PARTNER AND HEARING HEALTH PROFESSIONAL PERSPECTIVES

3.1. INTRODUCTION

In Chapter 2, frameworks representing domains of hearing loss from the perspective of individuals with hearing loss and the perspective of communication partners were derived from a meta-ethnography of the research evidence of hearing loss complaints (DoHL-P and DoHL-CP) (version 1.0).

The domains and subdomains of the frameworks were derived from the data using inductive (data-driven) methods. Whilst the derivation of these domains consisted of a rigorous synthesis of a large amount of data, the domains and subdomains only represent hearing loss complaints that were reported in the studies analysed. There were a number of advantages of taking this approach, the primary one being that the frameworks are representative of patient- and communication partner-reported complaints, with minimised researcher bias or influence. This does mean however, that additional complaints of hearing loss that were not reported in the included studies thus do not appear in the frameworks.

Face validity in qualitative research is defined as “how accurately the account represents participants realities of the social phenomena and is credible to them” (Schwandt, 1997). This concept of validity is routinely assessed in quantitative research (Smith, 2015), and has been deemed applicable to qualitative research, with validity referring to precision in which findings accurately reflect the data. The importance of determining validity in qualitative

research has been acknowledged by several researchers (Creswell and Miller, 2000, Rajendran, 2001, Morse et al., 2002, Flick, 2004, Noble and Smith, 2015). Yardley (2000) provides some consideration of different ways in which validity can be promoted with the framework of various qualitative methods. The author suggests that due to the challenges facing qualitative researchers in remaining "neutral" when conducting qualitative methods and analysis, the design of the study should incorporate consideration of the general and specific effects of the researcher's actions and characteristics (such as gender, health professional or sufferer of the condition of interest). As depicted in section 2.4.7.1, there were very few included studies subjected to the CASP criterion that explicitly addressed investigator bias and how to minimise it.

In order to guarantee sensitivity to the potential differing perspectives of those involved in qualitative research, and the wider community to whom the study is relevant, some qualitative researchers use explicit procedures for incorporating the opinions of those studied, or of other professionals in the field who may have a contrasting approach to the topic (Yardley, 2000, Campbell et al., 2011). This process of "testing" validity of previous findings allows for qualitative findings to be checked to see how accurately participant's realities have been presented in the final account.

The process of data analysis in qualitative research is not a single step, but requires several iterations. The inductive methods undertaken to form the frameworks in Chapter 2 were conducted by a team of three researchers from different backgrounds who worked together over several weeks to create the domain grouping frameworks. The development of the supra-domains, domains and subdomains as a team was a step taken to minimise any single observer bias. Rajendran (2001) suggests that there is potential that the observers may not fully grasp the perspective of the participant. In order to consider the

'external' view of the observer and the 'internal' view of the participant, the validity of the findings should be assessed independently (Hammersley and Atkinson, 2007).

Various typologies of validity have been constructed by qualitative researchers such as triangulation, researcher reflexivity and member checking (Creswell and Miller, 2000). Triangulation is a validity procedure where researchers look for convergence among different sources to form themes in a study (Creswell and Miller, 2000, Flick, 2004). Research reflexivity gives qualitative researchers the opportunity to self-disclose their assumptions and potential biases that may shape their study findings. For face validity, participants are usually presented with individual items and asked to evaluate the degree to which items are representative of the definition of the construct (Hardesty and Bearden, 2004). For example, Manning et al. (1995) required at least 50% of their participants to rate an item as representative in order for it to be retained.

Member checking is another quality control process that involves sharing the findings of a study and commenting on them (Lincoln and Guba, 1985, Creswell and Miller, 2000). It involves showing key stakeholders the study findings in order for them to evaluate the credibility of the findings. Member checking is also known as respondent validation, external validity, informant feedback and fittingness (Morse et al., 2002). Member checking typically comprises a focus group to review the findings (Creswell and Miller, 2000).

To assess face validity of the two frameworks, three key stakeholder groups reviewed version 1.0 of DoHL-P and DoHL-CP using a member checking approach. This approach was most appropriate to addressing the primary objective of this study because the frameworks derived from Chapter 2 formed the material for participants to evaluate based on their unique and diverse

experiences of hearing loss. Triangulation was not deemed to be appropriate at this point because its purpose is for themes to emerge from the data. In this case, the 'themes' (i.e. domains) were the focal point of interest of this study. The stakeholder groups included hearing aid users, communication partners and hearing health professionals. Hearing health professionals were defined as those working in the clinical and research fields of hearing loss (Granberg et al., 2014d). This chapter reports a series of focus groups that assessed the validity of DoHL-P and DoHL-CP, including personal experiences of the domains and subdomains of participants with hearing loss and their communication partners.

3.1.1. Aims and Objectives

The primary objective was:

1. To explore comments made by hearing aid users and communication partners on the domains in the frameworks, with respect to their own personal experience and understanding of the construct.

Secondary objectives were:

2. To explore whether hearing aid users and communication partners identified additional domains for the frameworks.
3. To explore whether hearing aid users, communication partners and hearing health professionals recommended modifications to terminology of the frameworks.

3.2. METHODS

3.2.1. Design

This was a single-centre, prospective cross-sectional study design. All focus groups were conducted with participants enrolled from a single stakeholder group, using a semi-structured interview approach. Hearing aid users and

hearing health professionals reviewed DoHL-P (version 1.0). Communication partners reviewed DoHL-CP (version 1.0).

3.2.2. Ethical approval

This study was approved by The Faculty of Medicine and Health Sciences Research Ethics Committee, University of Nottingham on 18th January 2016. The Ethics reference number is A18012016.

3.2.3. Sample size and recruitment methods

The recruitment target for each focus group was four to seven participants. It was estimated that the study would require between one to three focus groups, for each stakeholder group. The number of focus groups held for each stakeholder group depended on whether the research objectives could be answered. The sampling strategy used to recruit each stakeholder group was convenience sampling (Marshall, 1996).

3.2.3.1 Hearing aid users and communication partners

All couples (hearing aid user and communication partner) were awarded an honorary payment of £25 for their participation and travel expenses up to £15, and were offered refreshments during the focus group sessions. Participants were recruited via the National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre's (BRC) participant database (Hearing section). This database comprises participants with hearing loss and those with normal hearing who have expressed an interest in being contacted about research conducted by researchers at the NIHR Nottingham BRC. Therefore, this resource was highly appropriate for the purpose of recruiting suitable participants for the focus group. The database was searched for potential participants who were known hearing aid users and they were invited via email. The email contained information about the study and information about what

participation in the study would entail. Participants who expressed an interest in taking part were screened for eligibility over the telephone/email. To participate, hearing aid users must have worn hearing aids for a minimum of two years and have a communication partner (i.e. someone they communicate with on a regular basis such as a spouse or partner).

3.2.3.1.1 Hearing healthcare professionals

Hearing healthcare professionals were recruited via email within the author's professional network within Nottingham University Hospitals NHS Trust. Hearing health professions who were clinicians volunteered available clinical time to take part in the study and therefore reimbursement was not offered. They were offered refreshments during the focus group session.

The hearing healthcare professional's focus group comprised one hearing therapist, two adult aural rehabilitation audiologists and one researcher with otology and hearing expertise. The recruitment target for the hearing health professional's focus group was between 3-4 participants.

3.2.4. Eligibility criteria

3.2.4.1 Hearing aid users and communication partners

The inclusion criteria for the adults with hearing loss was that they must have been experienced hearing aid users (≥2 years) and have a partner or spouse (who is their nominated communication partner). The criteria for the partner/spouse was that they must have self-reported normal hearing. Therefore, partners/spouses must not have been past or current hearing aid users. All participants were required to be ≥18 years and have a good verbal understanding of English. Participants were excluded if they could not communicate in English and had bothersome tinnitus.

3.2.4.2 Hearing health professionals

Participants of the hearing health professional's focus group must have had clinical expertise in adult auditory rehabilitation.

3.2.5. Materials

The focus group schedules was designed by the lead facilitator (VV) and refined with input from the three supporting facilitators involved in the focus group. The materials that were developed for the focus group included cards printed with the name of each domain and subdomains. The participants were also issued with a domains of hearing loss survey (Chapter 4) which required them to rank the domains in order of importance to them.

For the hearing health professional's focus group, participants were additionally given the data items used to code each of the domains and subdomains. The rationale for this was for the hearing health professionals to give their perspective as to whether they thought the data was adequately coded and with the appropriate terminology.

3.2.5.1 Domains of Hearing Loss Framework

The frameworks reviewed in the current study are those presented at the end of Chapter 2, version 1.0 (DoHL-P and DoHL-CP). The hearing aid users reviewed domains in DoHL-P, based on their experience of living with hearing loss. The communication partners reviewed the domains in DoHL-CP, based on their experience of living with someone who has hearing loss. The hearing health professionals reviewed DoHL-P only, based on their clinical experience of diagnosing and treating patients with hearing loss. The hearing health professionals did not review DoHL-CP because the concept of 'third party' disability as described in Chapter 1 is a relatively new concept and not one

routinely considered in UK audiological clinical practice (Manchaiah et al., 2012).

3.2.5.2 Facilitators

3.2.5.2.1 Hearing aid user and communication partner focus groups

The focus groups for hearing aid users and for their communication partners were each facilitated by four researchers. Each sub-group was led by two facilitators (hearing aid users: VV and AH, communication partners: DAH and AH2). The experience of the facilitators comprised a broad set of expertise spanning (research and clinical) otology and qualitative research, and patient and public involvement in research. One of the facilitators was an experienced qualitative researcher in hearing loss (AH2), with experience of conducting qualitative research methods, including interviews and focus groups. Another facilitator was a Public, Patient Involvement (PPI) manager (AH) with experience of engaging members of the public (with hearing loss and normal hearing) in research. The two other facilitators (VV and DAH) were researchers in hearing loss with experience of qualitative research methods. The facilitators (AH, DAH, AH2) were briefed on their role prior to the focus group. VV gave the AH and AH2 an outline of the domains of hearing loss frameworks, how they were developed and the purpose of the focus groups. They were also briefed on the preliminary itinerary for the focus group, and this was refined with their input. One of the facilitators had conducted previous work that involved two of the hearing aid users as participants. Otherwise, none of the hearing aid users or communication partners were known to the facilitators.

3.2.5.2.2 Hearing healthcare professionals focus group

The hearing health professional focus group was led by one lead facilitator. The lead was VV whom had gained experience of facilitating the focus group through the experience co-facilitating the hearing aid user focus group. VV is a

qualified audiologist with clinical experience in adult aural rehabilitation. Of the three healthcare professionals participating in the focus group, one of the hearing health professionals was known to the facilitator. To minimise bias, the other aural rehabilitation audiologists was unknown to the facilitator. The professionals were instructed to review the framework based on their clinical expertise and experiences of working in aural rehabilitation.

3.2.6. Procedure

3.2.6.1 Focus groups – Hearing aid users and Communication Partners

Two focus groups were held in parallel at the Medical Research Council (MRC) Institute of Hearing Research (IHR), University of Nottingham. The focus group session lasted approximately 2 hours. The focus discussion group was audio-recorded and subsequently transcribed verbatim. Examples of excerpts taken from unedited transcripts from each focus group is given in Appendix 8.2.

First, participants were briefed on the agenda of the focus group and informed consent was obtained from all participants prior to commencing. The participants were then divided into two sub-groups: hearing aid users and communication partners. Each group continued in a separate room. The hearing aid users reviewed the DoHL-P and communication partners reviewed DoHL-CP in separate focus groups. The facilitators introduced the first domain and its corresponding subdomains from the framework. The lead facilitators for each subgroup (VV and AH) were responsible for introducing each domain and facilitating the discussion among participants. The supporting facilitator for each subgroup (AH and DAH) were responsible for monitoring the time, but were also involved in general facilitating of the discussions. The facilitators introduced the “Auditory” domains and subdomains first, followed by the domains and subdomains of “Social” and “Self”. In order to answer the first objective of the study, participants were asked to share their experiences of each subdomain.

Where at least one participant was able to relate to a subdomain, this subdomain was considered appropriate. In the focus group, the facilitator introduced each subdomain and then allowed time for participants to discuss the domain. This helped to minimise any potential bias in coding, given the participants were instructed to talk about a specific subdomain. Any subsequent discussion could then be coded to that subdomain. All the domains contained within “Auditory”, “Social” and “Self” were discussed across the two focus groups. Once the discussion of the domain concluded, the lead facilitator introduced the next domain in the framework.

3.2.6.2 Focus group – Hearing healthcare professionals

The hearing healthcare professional’s focus group was held at the NIHR Nottingham BRC (hearing section). The focus group lasted approximately 2.5 hours. The focus group was also audio-recorded and subsequently transcribed verbatim. The participants were briefed on the aims of the focus group and given a copy of DoHL-P (version 1.0) to review one week prior to the focus group. In a similar manner to the hearing aid user and communication partner focus groups, the lead facilitator (VV) introduced a single domain and from the framework and asked the clinicians to share their clinical expertise of the subdomains. The lead facilitator introduced the next domain once discussion of the previous domain was completed in a similar format until all of the domains of hearing loss had been discussed.

3.3. PLAN OF ANALYSES

The focus groups were transcribed in Microsoft word, by a leading UK transcription service (UK Transcription). Each speaker was coded separately so that it was clear to the researcher performing the analysis (VV) what data was attributed to which person. It also ensured that the same comment wasn’t considered twice if it came from the same person.

Thematic analysis is a widely adopted form of qualitative analysis (Taylor et al., 2015) and was deemed the most appropriate method for analysis of the focus groups for a number of reasons. First, thematic analysis allows for themes or patterns within the dataset to be identified in one of two primary methods: an inductive approach or a deductive approach (Braun and Clarke, 2006). In this case, the themes, or 'domains' to be analysed were predefined by the domains grouping frameworks (Chapter 2) and so the process of coding the focus group dataset examined the degree to which the comments agreed or disagreed with the pre-existing coding frame (the domains). A deductive (or theoretical) thematic analysis allows for the analysis to driven by the researcher's analytic interest in the area (Braun and Clarke, 2006). Other qualitative analysis approaches were considered, such as grounded-theory (Urquhart, 2012) and meta-ethnography (Noblit and Hare, 1988), but these approaches are typically inductive which is not appropriate for analysing the current dataset. Thus, the qualitative data analysis selected was a deductive thematic analysis defined in accordance with the process outlined in Braun and Clarke (2006). This article offered step-by-step guidance on the analysis and reporting of the data.

3.3.1.1 Thematic Analysis

The hearing healthcare professional focus group data transcription was initially analysed separately from the hearing aid user and communication partner focus groups since hearing healthcare professionals reviewed the framework based on their clinical experiences of patients with hearing loss but the hearing aid users and their partners, reviewed the frameworks based on their lived experience of hearing loss. Steps 1 and 2 of the analysis were conducted by the primary researcher and lead facilitator of the focus groups (VV). Step 3 was conducted by SS, a research assistant with experience in coding transcripts for

qualitative hearing loss research. This provided an independent viewpoint to minimise bias.

Step 1: Familiarisation with the dataset

The transcripts were read thoroughly and each relevant data excerpt was paraphrased if it corresponded to one of the subdomains in the framework.

Step 2: Generating initial codes & searching for themes

A code in this context refers to "the most basic segment of the raw data that can be accessed in a meaningful way regarding the phenomenon (Boyattzis, 1998: pp63). Specifically, this stage involved organising the data into meaningful groups. Since the facilitator introduced each domain for discussion, all the relevant data pertaining to the domain in question were all contained together in the same section of the transcript. Any additional complaints of hearing loss that did not appear in the framework were also coded. For all three focus groups, the data was then further reviewed ad recoded to correspond to: (1) evidence for domains within framework, (2) additional subdomains identified, and (3) recommendations to modify terminology of domains or subdomains in the frameworks.

Aspects of the dataset considered pertinent to the research question were coded as well as excerpts that were not explicitly related to the research questions, to ensure relevant information was not overlooked. For example, data relating to coping strategies to hearing loss were also coded.

Step 3: Reviewing themes & independent peer assessment

Peer assessment was undertaken to strengthen the reliability of the coding process. It was conducted at two stages during the analysis. First, a coding comparison was conducted to reinforce the rigour of the analysis and to ensure

that the interpretation of the data was not bias to one researcher. A researcher (SS) independently 'second' coded a sample of 10% of the transcripts. The purpose of second coding was to ensure that the initial codes derived from the primary researcher conducting the analysis were appropriate and aligned with another researcher's interpretation. SS was independent of involvement and conduct of the focus groups. The second coding was then compared to the first coding for consistency. It was important to ensure the pre-defined themes were representative of the dataset. There were no noteworthy differences in the coding. This was judged by a discussion with the second coder to ensure consistency.

The second stage of independent peer assessment comprised of an in-depth discussion between first coder and supporting facilitator involved in the hearing aid user focus group. This took place after analysis of the data. During this meeting the coders discussed the themes derived from the focus groups and whether or not these themes were representative of the transcripts. If at any point the discussion was veering off point or potentially overlapping with another subdomain, the coders examined the terminology as well as the underlying meaning of the discussion. In addition, the coders referred back to the definitions of the subdomains.

Step 4: Defining and naming themes

The overarching themes in this study were defined prior to the focus group (Table 2.7, Table 2.8, Table 2.9) and so this step was not relevant here.

Step 5: Producing the report

The final phase of thematic analysis is to report the results by providing sufficient evidence for the themes. This is explained in the Results section.

3.4. RESULTS

3.4.1. Participants

In total, 13 participants consented to take part in the focus group. There were five hearing aid users, five nominated communication partners, and three hearing health professionals (see section 3.2.3.1).

Hearing aid users and communication partners were retired couples that lived together. Four out of the five couples were married. In the hearing aid user group, there were two men and three women, with a mean age of 64 years old. In the communication partner group, there were three men and two women, with a mean age of 69 years old. All participants in the hearing aid group had been diagnosed with hearing loss during retirement, apart from one participant who was diagnosed with hearing loss in young adulthood. The mean usage of hearing aids was 8.6 years.

Recruitment discontinued once saturation in the data had been achieved. Data saturation was achieved following one focus group per stakeholder group. Data saturation was defined as the point where there was agreement in the content and structure of the domains of hearing loss frameworks. To ensure data saturation was achieved, the domains were ranked by members of the same population of interest in a survey study Chapter 4. Furthermore, participants who completed this survey were given the opportunity to suggest additional complaints of hearing loss. This ensured that evidence was provided for all subdomains in the frameworks.

None of the participants from any of the focus groups suggested that any of the domains or subdomains should be removed from the frameworks. For the purpose of this study, at least one person from the focus groups must have endorsed the domain (by means of sharing their experience of it) in order for

that to qualify as evidence for the domain, additional to what is reported in the literature.

The results are presented in terms of the subdomains contained within each domain of hearing loss framework from each perspective: hearing aid users, communication partners and hearing healthcare professionals. Evidence pertaining to the domains from the focus group are presented in turn. Where quotes are given, an identifier for the participant is provided to prevent providing the evidence for the same domain from the same participant multiple times. Similarly, if all participants made comments pertaining to one subdomain, this was noted.

3.4.2. Assessing face validity of those subdomains that appear in the DoHL-P *and* DoHL-CP

Overall, there was positive confirmation for all subdomains in both frameworks. Between the hearing aid users and communication partners, they were able to relate to the majority of subdomains that fall in both frameworks. None of the participants were able to comment on the subdomain 'Reduced spontaneous conversation". The subdomain that none of the participants from DoHL-CP could comment on was "Threat to relationship".

The first section of these results will cover the domains that appear in both frameworks (Table 3.1).

3.4.2.1 Listening: Raising the volume of the television/radio

All of the hearing aid users were able to relate to this subdomain. Hearing aid users complained of continually having to raise the volume of the TV*; "I constantly adjust the volume on mine" (Female 3).* Another mentioned having a similar experience but explained her spouse would complain that she had set the volume to high; *"You know, I, I am struggling to the volume up. My husband*

walking through will say, "Blasting out"" (Female 1). Others commented on the variation of intelligibility between television programmes which subsequently influences volume preference; *"and varies one programme to another" (Male 1)* and "We've got the volume turned right up". Due to constantly having to raise the TV volume, one hearing aid user mentioned that they have invested in assistive listening devices to prevent constantly having to fiddle with the TV volume control ; *"I have got special, erm, pho- er, things I put in my ears……it works wonderful" (Female 1).* Another hearing aid user felt that the background noise of some television programmes made the dialogue less intelligible; *"Cause I'm sort of saying, "Is it just me?" because, you know, the background noise is, is kind of drowning the dialogue" (Female 2).* Another hearing aid user reported a similar experience, and this causes him to decrease the volume due to the poor acoustics; *"It's dreadful, it's dreadful, we turn the TV down" (Male 2).*

Three out of five communication partners agreed with the relevance of this subdomain to their circumstances. Two communication partners mentioned that they often have to tell their partner that the volume is very loud; *"I say to him "turn that down"" (Female C2)* and requests for the volume to be lowered. The remaining communication partner who shared his experienced of this subdomain commented that his wife has the TV volume louder than he would sometimes prefer.

3.4.2.2 Communicating: Conversing in a group of talkers

All of the hearing aid users had personal experience of this subdomain. Most of the difficulties were in relation to having conversation with a group of friends in a social setting; *"When there's a group of us in a restaurant, I'm usually lost, I can't always keep up with the conversation so dip in and out of it" (Female 3).* One communication partner discussed the difficulties their partner had in group

conversations; *"I think with, like, the group conversations, you know, like we find that… I know I struggle talking to her, with a larger group generally. I think that was an important one" (Male C1).*

3.4.2.3 Communicating: Conversing in noisy environments

Four out of five communication partners commented on the challenge of conversing with their hearing impaired partner in places where there is background noise. This was particularly true in social settings where there were lots of people talking; *"A conversation in a noisy environment is definitely difficult" (Female C1)*, or where there is music, *"Of course in pubs they've got these hidden speakers everywhere as well" (Male C1)*.

3.4.2.4 Communicating: Conversing one to one

Two hearing aid users mentioned occasional difficulty having a one-to-one conversation occasionally, but this is dependent on the level of background noise in the room*; "Background noise makes a lot of difference, I've noticed" (Female 1)*.

All of the communication partners stated that having a conversation one to one with their hearing impaired partner had become more difficult since having hearing loss. Three communication partners also said conversational difficulties arose depending on the level of background noise; *"conversation in background noise is difficult" (Male 1).*

3.4.2.5 Communicating: Having to speak on behalf of partner with hearing loss

Two of the hearing aid users reported that because listening and engaging in conversation was so difficult, they often found themselves mishearing and responding inappropriately; (Name's) husband died in January, she was just telling you about that." And I'm smiling and grinning away" (Female 3). Due to

recurrent instances like this, hearing aid users reported letting their communication partner engage in the conversation and respond on behalf of them; “I sit back and let (Name) do the talking now” (Female 2).

All of the communication partners mentioned that having to speak on their partner’s behalf within their own experience; “I sometimes have to make phone calls on (Name) behalf” (Female C2). Another communication partner mentioned that it was almost habit for him to respond when someone asked his wife a question; “This is a bit like, "Does he take sugar" syndrome, isn't it? You know, I try quite hard not to answer on behalf of (name)” (Male C3). Two other communication partners agreed with this perspective.

3.4.2.6 Communicating: Reduced communication

Three hearing aid users shared their experience that since having hearing loss, they found that they did not talk and engage in conversation as much as before. Two hearing aid users attributed this to extent of difficulty in conversation, *“Just don’t make the effort to engage in conversation as much” (Male 1)*; and “*Yes. I don’t make the effort so much, you know” (Male 1)* and *“…because it’s a lot more effort you tend not to” (Female 1).* In response to the question as to whether she found that she was engaging less in conversation since having hearing loss, another hearing aid user responded with *“Yes, yes, definitely” (Female 3).*

3.4.2.7 Speech production: Speech production

In relation to the speech production subdomain, the complaint from one hearing aid user here related to his difficulty in being aware of the volume of his own voice when he was speaking; *“I’m not sure whether I’m sp-speaking loudly enough” (Male 2)*. This suggests some difficulty of voice monitoring. This was also reiterated by two other hearing aid users; “*I’m not sure exactly how loud I*

should speak at times" (Male 1) and "*I always think I'm speaking quite loudly" (Female 2).*

3.4.2.8 Relationships: Relationship with spouse/family member

Three hearing aid users made comments that related to this subdomain, Two communication partners mentioned that hearing loss had affect their relationships, but portrayed this positively; *"…you say something silly and it was nothing to do with" (Male C1).*

3.4.2.9 Emotions: Frustration

Two of the hearing aid users shared their that the listening and communication difficulties attributed to hearing loss gave rise to feelings of frustration; *"… it is quite frustrating" (Female 3).*

All of the communication partners were able to relate to this subdomain. Issues relating to frustration were all in the context of communicating difficulties with their hearing impaired partner; *"It can be frustrating if you can't get through to your partner what you're trying to say. Sometimes (Name) doesn't pick up even when I've said something two or three times" (Female C2)* and *"I find it a bit frustrating at times" (Female C1).* Another communication partner attributed his frustration to the impact of his wife's hearing loss in social situations, "*I think I've experienced the frustration at times, erm, in the social context where I think it's, erm, we might have gone to concerts or the theatre more often, whereas (name) would say, "Well, I'm not sure if I'll be able to hear that, because it's playing with very local strong accents from the actors and so" (Male C3).*

3.4.2.10 Emotions: Upset

Two hearing aid users expressed the closeness of this subdomain to them. For one hearing aid user, this emotional construct was mentioned when describing

another subdomain; "…it's very sad so I don't get so much pleasure listening to music" (Male 1).

Three of the communication partners could relate to this subdomain as a result of the difficulties they observe their partner to have because of their hearing loss; "I've had a lot of upset coinciding with (name)'s deafness" (Female C1). Another communication partner indicted that the impact of hearing loss on her husband's enjoyment of social activities was particularly upsetting for her; "Sorry it really upsets me. Sorry. He, erm, his social life is very much wrapped up within it, because of course they often go to the pub afterwards and he can't hear very well" (Female C3).

3.4.2.11 Effort and fatigue: Feelings of fatigue

One hearing aid user reported that hearing loss made the process of listening tiring for him; *"…also listening is suddenly more tiring" (Male 1).* This was also expressed by another hearing aid user; "*My brain is going to explode" because it just, this cacophony of noise" (Female 1).* The impact of hearing loss on fatigue was also reported by communication partners. For one communication partner, this was in relation to constantly having to repeat; *"Repetition is sometimes very tiring" (Female C2).*

3.4.2.12 Identity: Self-image

One hearing aid user felt that they perceived hearing loss to be a hidden disability; "*And, erm, (Laughter) when they found out I was deaf, erm, they, they were delighted because I was their token disabled person. (Laughter) It's a disability that people don't see." (Female 3).* Another hearing aid user mentioned that hearing loss had become part of his identity and he wanted people to know that he had hearing loss to ease communication; *"I'd like a little badge that said, "I am partially deaf" (Male 1).* Communication partners mostly

made reference to their image in terms of the new roles they have had to adopt since their partner's hearing loss.

3.4.2.13 Stigma: Stigma of hearing aids

Three out of five hearing aid users admitted being conscious about the appearance of their hearing aid(s); *"Well, like I say I'm still conscious about keeping my hair, 'cause my hearing aid's quite large, you know, so I sort of cover my ears" (Female 3) .*

Two communication partners made reference to the stigma; "*There's no cure for that apart from large hearing aids that you stick on your, your ears" (Male C1).* Another communication partner made the comment that he felt hearing aids are still stigmatised within society; *"I think there's a bit of a contradiction in our society because it's, well I think it's still quite cool to have, erm, erm, an iPod and dangle it out of your ears, but if it's a hearing aid" (Male C3).*

Table 3.1. Table of domains that appear in both frameworks

Domain	Subdomain	✓/x
LISTENING	Raising the volume of the television/radio	✓
COMMUNICATING	Conversing in a group of talkers	✓
	Conversing in noisy environments	✓
	Conversing one to one	✓
	Having to speak on behalf of partner with hearing loss	✓
	Reduced spontaneous conversation	X
Speech production	Speech production	✓
RELATIONSHIPS	Relationship with spouse/family members	✓
EMOTIONS	Frustration	✓
	Anger	x
	Upset	✓
EFFORT AND FATIGUE	Feelings of fatigue	✓
IDENTITY	Self-image	✓
STIGMA	Denial	x
	Stigma of hearing loss	✓

The tick confirms that participants are able to relate to that particular subdomain The cross indicates that the participants did not share experiences of that particular subdomain.

3.4.3. Assessing face validity of those subdomains in DoHL-P only

The hearing aid users were able to comment and provide personal experience of all but one of the domains and subdomains within DoHL-P. The subdomain participants could not comment on was “Rejection”.

This section will cover the domains that appear in DoHL-P only (Table 3.2).

3.4.3.1 Hearing: Hearing telephone ring

Two hearing aid users could think of several scenarios where they had difficulty hearing the telephone ring. For one participant, this this was only a problem if there was background noise; “*I can usually hear the phone unless there’s television or something” (Male 2).* Another participant made reference to a phone amplifier to help him hear the telephone ring; “*I mean I’ve got a volume thing on the phone” (Male 1).*

3.4.3.2 Hearing: Hearing the doorbell

Two hearing aid users made reference to difficulty hearing the doorbell; “*I have trouble detecting that the door bell has been rung” (Male 1).* Another participant admitted to having the same problem which she had alleviated by the time of the focus group since she uses a device to indicate when the doorbell had been rung; *“I have a special adapter, with a flashing light” (Female 3).*

3.4.3.3 Hearing: Hearing television and radio sounds

All hearing aid users made reference having constant difficulty in hearing the television dialogue; *“Certainly TV sounds for me” (Female 1),* and two hearing aid users commented on their difficulty hearing speech sounds over the background noise/music of the programme; *“There always seems to me to be much louder music than there is speech” (Female 3).* Another hearing aid user also made reference to his inability to hear the radio *“Oh, I can’t hear the radio” (Male 2).*

3.4.3.4 Hearing: Hearing distant sounds

Two hearing aid users made reference to their struggle hearing sounds from a distance; *"The number of times I've jumped out of my skin because I haven't heard somebody come into the room or walk up behind me" (Female 1).* For another participant, his ability to hear unwanted distant sounds through his hearing aids, such as background noise was an issue; "*…can't block out all the extraneous noise of the room" (Male 2).*

3.4.3.5 Hearing: Hearing environmental sounds

Comments generally related to the lack of ability to hear and distinguish environmental sounds, such as the weather; *"And my husband says, "The storm last night…" "What storm?" And I've slept through, erm, that earth tremor that was quite violent a while ago, everybody was saying the house" (Female 1).*

3.4.3.6 Hearing: Hearing speech sounds

Two hearing aid users commented on the relevance of this subdomain, e.g. *"I've lost the ability to hear low frequency sounds" (name).* For another hearing aid user, the inability to hear speech sounds was in relation to the level of background music on some TV programmes; *"There always seems to me to be much louder music than there is speech" (Male 2).*

3.4.3.7 Listening: Listening to speech on the telephone

All five hearing aid users expressed difficulty listening to people on the telephone; *"But, erm, telephone, erm, if somebody's speaking softly on the phone I'm completely lost" (Female 2).* In particular, two hearing aid users mentioned their tactics for optimising listening on the phone; *"You could always put it on speaker phone as well, I sometimes do that 'cause it's louder. 'Cause sometimes I have the inprint of the phone receiver on my face 'cause I'm holding it so…" (Female 3)* and *"I mean I've got a volume thing on the phone" (Male 3).*

3.4.3.8 Communicating: Asking people to repeat

Two of the hearing aid users regularly asked people to; *"And then you say, "Could you repeat it?" and then you might be able to hear 50% of it" (Female 2),* whereas another user felt as though he couldn't keep asking people to repeat themselves; *"Trying to say the right thing, you know, you can't just keep asking people to repeat." (Female 3).*

3.4.3.9 Listening: Listening to quiet speech (whispering)

Two hearing aid users reported difficulty understanding people who speak with a quiet voice; *"speaking either very softly or, you know, with their head down" (Female 3).* Another user felt this was even more of a problem when the person she was trying to converse with someone who did not know she had a hearing loss; *"But it's probably not because other friends have said to me, "You speak so softly" so I can't join in because they don't hear me, you know, I'm, they're kind of just" (Female 1).*

3.4.3.10 Listening: Listening to speech in noise

All hearing aid users were able to relate to this subdomain; particularly in reference to social settings; *"Can't listen to friends so much with the general noise background and that" (Male 1).* This was reported as a problem when also watching a TV programme with background noise or music that competed with the speech; "*The background noise is, is kind of drowning the dialogue" (Female 2).*

3.4.3.11 Listening: Listening to speech in a group of talkers

All of the hearing aid users had relevant experience of this subdomain. Again, it was issue a particular problem in social settings; *"I have been in the same situation as you where you're sitting round a table, in a pub or something" (Male 1).* Another hearing aid user mentioned that he deliberately avoided places that

were noisy in order to listen and participate in conversation; "*And almost exclusively when we go in the pub we want to go into a pub with no background noise, with no live music, with none of that. We want to go where we can have a talk" (Male 3)* and "*If we're in a group together sometimes I can't hear what's being said" (Male 1*). Another hearing aid user mentioned particular difficulty when the speakers came from all directions in a group conversation; *"…you're getting voices coming all over the place" (Male 2).*

3.4.3.12 Listening: Listening to speech in public places

All the hearing aid users were able to relate to this subdomain. This was particularly pertinent to listening to speech in public places such as restaurants and pubs; *"the worst situation is a pub for me" (Female 3)* and "*I have been in the same situation as you where you're sitting round a table, in a pub or something…. you can't join in because you can't actually hear" (Female 2).* Two of the hearing aid users attributed their listening difficulty in public places to the 'loop system' not working; *"So I wanted an off switch because, you know, the loop settings anyway don't work pretty much anywhere you go" (Female 3)* and "*I tried it once at ___(0:22:00) cinema and I got next door's bingo" (Female 2).*

3.4.3.13 Listening: Listening effort

One hearing aid user expressed this was as the result of additional effort in processing sound; *"My brain is going to explode because it just, this cacophony of noise, there's only three people…" (Female 1).* Another hearing aid user explained that having to listen in general had become fatiguing; *"…and also listening is suddenly more tiring" (Male 1).* Other participants reported trying to listen and trying to use visual cues to assist; *"Well I haven't, they've had a conversation with me and I've just stood there trying to follow their facial expressions and smile" (Female 2).*

3.4.3.14 Communicating: Communicating at work

Experiences in the workplace were somewhat limited because three of the five hearing aid users in the focus group were diagnosed with a hearing loss after retirement.

One of the hearing aid users shared his experience of communicating in different types of workplaces; *"If you walk into an office environment the speech is always much lower, so it's difficult to listen to and then respond to" (Male 3)* and "*If you work in a noisy environment, in a factory or something, you tend to talk much louder to each other" (Male 3).* Another who was diagnosed with hearing loss in adulthood mentioned her experience of working in different jobs whilst having hearing loss; *"It's certainly a difference in volume of talking between different people's job environments" (Female 3).*

3.4.3.15 Communicating: General conversation

One of the hearing aid users commented that she struggled talking to people who didn't know she was deaf, as well as people who didn't know how to communicate with people with hearing loss; *"…trained staff, who have had no training in communicating with deaf people" (Female 2).* Another reported struggling to have a conversation with someone when she was talking from another room; *"I think the biggest for, as far as I'm concerned is I can't have a conversation with someone if they are trying to tell me something from another room, its impossible" (Female 3).* One participant mentioned the extent and significance of their communication difficulties; *"…and I'm having to come to terms that I might never get really clos- close friends again because of the problems of communication" (Female 2).*

3.4.3.16 Communicating: Speech in quiet

Two hearing aid users reported struggling to listen in quiet environments, depending on whom the speaker was and whether he/she spoke with a quiet voice "*Talking to someone one to one in a quiet room is fine but if they speak with a quiet voice or turn away from me then I lose important bits of the conversation" (Female 3)*. Another reported that when she was working in a quiet office plan, other people would talk quietly to her which made which made engaging in a conversation difficult; *"they are in a work situation because it's an open plan office I think they talk very quietly and I couldn't hear what they said" (Female 1).*

3.4.3.17 Communicating: Conversing on the telephone

This subdomain resonated with all hearing aid users. Many of the quotes also tap into the "Listening to speech on the telephone". One participant mentioned a tactic she used to help her converse on the telephone; *"Cause sometimes I have the imprint of the phone receiver on my face 'cause I'm holding it so-like trying to hear what people are saying"(Female 3).* This hearing aid user also reported that trying to have a conversation on the telephone at work was incredibly difficult; *"I can't work like this, I need to be able to hear the telephone and speak on the end of the phone" (Female 3).*

3.4.3.18 Listening: Pleasure of listening to music

Two hearing aid users reported that in addition their trouble listening to music, their enjoyment of listening to music had reduced since having hearing loss "…it's very sad so I don't get so much pleasure listening to music" *(Male 1) and "I just don't enjoy it like to used it" (Male 2).*

3.4.3.19 Listening: Listening to music

Two of the hearing aid users said; *"You don't know whether you're listening to music 'cause you can't hear it all anyway" (Male 2)* and *"So, you know, to be able to hear music and bird song and my grandchildren" (Female 3).*

3.4.3.20 Interventions: Expectations of rehabilitation

Two participants reported having greater expectations for the treatment for hearing loss than they achieved; *"I don't think my expectations have been met" (Male 1)* and *"Hearing aids are only an aid" (Female 1).* The remaining hearing aid users admitted that wearing their hearing aids were vital to everyday life "I could not live without mine" *(Female 1 & Male 3)* and *"I just, you know, could not possibly function without them" (Female 3).*

3.4.3.21 Interventions: Technical problems with hearing aid

Two hearing aid users reported having technical problems with their hearing aids. One inferred that his hearing aid did not provide sufficient amplification; *"I have my hearing aid's set on full, I mean I, I can't, this is the highest they can go" (Female 2).* Another commented on acoustic feedback from her hearing aid; *"…there's a whistling noise in this one" (Female 3).*

3.4.3.22 Social life: Social withdrawal

Three hearing aid users reported withdrawing from certain situations because of their inability to hear speech and participate in conversation; *"you don't bother going to some places" (Male 1),* and *"I get social withdrawal" (Male 2)*. Participants commented on the significance of social withdrawal in terms of avoiding social interaction because of the difficulty in listening and conversing with friends under acoustically challenging situations, "*And it's too much effort and I know I'm not going to enjoy it very much so I don't want to go" (Female 3)*

or when there were multiple speakers; *"Can't talk to friends so much with the general noise background and that any social gathering basically" (Male 1).*

3.4.3.23 Social life: Altered social interactions

Examples of this subdomain in particular were in relation to the difficulty of listening and talking to other people at a social function; *"Even with the best will in the world and with the hearing aids I can't hear what's being said, so you tend to just sit there" (Female 3)*. Three of the hearing aid users reported their social interactions had changed since having hearing loss because those situations were more challenging for holding conversations; "*I mean I know that people burst out laughing when I've re- responded to something because I've heard something completely different to what they" (Female 3)* and *"I know I'm not going to enjoy it very much so I don't want to go" (Male 1).* Another hearing aid user reported a change specifically when meeting friends at a public place; *"Especially when there's no carpets down and you can hear all the footsteps" (Female 1).* Another hearing aid user reported finding social interactions more difficult with people who were less known to her; "*It's a lot more difficult, especially you might not know them quite so intimately" (Male 1).*

3.4.3.24 Isolation: Sense of isolation

Two hearing aid users reported feelings of isolation, again particularly in social settings; *"I can't hear what's being said, so you tend to just sit there" (Female 3)* and *"I do, isolated in groups occasionally feeling left out. Even though I've known my friends for 30/40 years" (Male 1).*

3.4.3.25 Occupational: Restrictions at work

One hearing aid user recalled a time in one particular workplace when she felt her hearing loss held her back; *"I had to say to them in the end, "Look, I can't hear what the person on the phone is saying because, the photocopier…I can't*

work like this, I need to be able to hear the telephone and speak on the end of the phone" (Female 3).

3.4.3.26 Relationships: Relationship with family members

Two hearing aid users felt that their hearing loss affected their relationship with grandchildren; *"And young children, you, you cannot, I couldn't form a relationship with them" (Female 1)* and; *"And I've just thought of something, erm, I hadn't, my own family but my niece's children, when they were young I just could not understand what the children were saying…that affected the relationship because I couldn't bond with them" (Female 2).*

3.4.3.27 Emotions: Embarrassment

This subdomain was described by two hearing aid users in relation to responding inappropriately when they have misheard what someone has said; e.g.*"…. Because I was so embarrassed after" and "I was so mortified, you know, you can keep it up to a point" (Female 3).*

3.4.3.28 Emotions: Worry

Four hearing aid described specific experiences of worry. Two explicitly expressed a worry about their hearing loss getting progressively worse; "*I do, I worry about deterioration and it getting worse" (Male 1)* and *"I do, yeah, I do" (Male 2).*

3.4.3.29 Effort and fatigue: Listening effort

Two hearing aid users mentioned that because listening was so much harder since having hearing loss, they did not make as much effort engaging in conversation; *"I don't make the effort so much, you know" (Male 1)* and "*It's too much effort" (Female 1).*

3.4.3.30 Self-image: Feelings of inadequacy/self-esteem

Feelings of inadequacy and self-esteem resonated with two hearing aid users. One participant likened her hearing loss to a sign of aging; *"I feel an older person now, somehow" (Male 1).* Due to some upsetting experiences in talking to people at a friend's house, one respondent said she did not visit anymore; "*I just don't feel comfortable going there" (Female 3).*

3.4.3.31 Stigma: Pretending to understand speech

Two hearing aid users admitted to pretending to understand speech from time to time; *"Well I do pretend to understand sometimes when I can't be bothered" (Female 1)* and *"Yeah, you just hope and think it, you don't think it's that important so you go along with it" (Female 2).*

Table 3.2 Domains from DoHL-P

Domain	Subdomain	✓/X
HEARING	Hearing warning sounds	✓
	Hearing telephone ring	✓
	Hearing the doorbell	✓
	Hearing television and radio sounds	✓
	Hearing distant sounds	✓
	Hearing environmental sounds	✓
	Hearing speech sounds	✓
LISTENING	Listening to speech on the telephone	✓
	Listening to speech in noisy environments	✓
	Listening to birdsong	✓
	Listening to music	✓
	Pleasure of listening to music	✓
	Listening to quiet speech (whispering)	✓
	Listening to speech (at work)	✓
	Listening to speech (speech in general)	✓
	Listening to speech in a group of talkers	✓
	Listening to speech in a travelling vehicle	✓
	Listening to speech in public places	✓
	Listening to speech in quiet environments	
COMMUNICATING	Asking people to repeat	✓
	Communicating at work	✓
	Communicating, general conversation	✓
	Communicating, speech in quiet	✓
	Conversing on the telephone	✓
	Reduced communication	X

Domain	Subdomain	✓/X
SPEECH PRODUCTION	Speech production	✓
INTERVENTIONS	Expectations of rehabilitation	✓
	Technical problems with hearing aid	✓
SOCIAL LIFE	Social withdrawal	✓
	Altered social interactions	✓
ISOLATION	Sense of isolation	✓
OCCUPATIONAL	Fear for loss of employment	✓
	Reduced employment prospects	✓
	Opportunities at work	✓
RELATIONSHIPS	Relationship with family	✓
EMOTIONS	Embarrassment	✓
	Rejection	X
	Worry	✓
EFFORT AND FATIGUE	Listening effort	✓
IDENTITY	Feeling of inadequacy/self-esteem	✓
STIGMA	Stigma of hearing aids	✓
	Pretending to understanding speech	

The tick indicates that participants could share experiences of each subdomain. The cross indicates they did not share experiences of that particular subdomain

3.4.4. Assessing face validity of those subdomains in DoHL-CP only

The subdomains that only appear in DoHL-CP will now be presented in turn (Table 3.3). Overall, communication partners were able to relate to the subdomains in DoHL-CP. The subdomains communication partners could not comment on were “Threat to relationship”, “Having to say that the phone is ringing” and “Goes out alone”.

3.4.4.1 Communicating: Having to repeat

Communication partners gave examples only in reference themselves having to repeat something to their spouse/partner, but also having to repeat what other people had asked, *“What did they say? What was that?” (Male C1).* One participant mentioned that when his wife set the television volume, she still looked at him to repeat what had been said on the TV; *“I notice even when it's the volume she's chosen, erm, she's constantly asking me, "What did they say?” (Male 2).* Another acknowledged that since his wife had a hearing loss he had developed new conversational tactics; *“I've actually developed a new skill, the ability to sort of listen and repeat quickly while still listening” (Male 3).* Another communication partner mentioned that he felt partner had now got used to asking him to repeat things, rather than trying to figure out what he had just said; “*I do think that (name) probably, erm, asks me to repeat when she's saying it as an automatic, "Pardon, what did you say" rather than just stopping and thinking what I've just said” (Male C2).*

3.4.4.2 Speech production: Speech production

Communication partners were also able to share their experiences with this subdomain. One participant felt that he now speaks more loudly when talking to his wife but is sometimes too loud for those with normal hearing; “*My daughter always tells me to talk more quietly and I think that's because I've automatically got used to speaking more loudly” (Male C2).* Two others felt

there had been changes in their own speech since their spouse's hearing loss, in terms of level and clarity of articulation; *"Well I think I just make more attempt to pronounce everything" (Female C1)* and *"Erm, in as clear and distinct and perhaps sharp a way as I can" (Female C2).* Another communication partner also said that he spoke at a slower pace when his partner was struggling to understand; *"Certainly if (name) hasn't heard the first time, I will try and make more effort to slow down and speak more clearly" (Male C3).*

3.4.4.3 Social life: Goes out alone

Whilst three of the hearing aid users claimed their partners went to certain social events on their own, none of the participants in the communication partner subgroup said this. Communication partners did not explicitly disagree with the relevance of this subdomain, but did not give any examples of their experience with it. The participants in this group commented on other aspects difficulty in social situations.

3.4.4.4 Social life: Reduced enjoyment of social activities

Four communication partners said that their partner's listening and communicating difficulties had affected their overall enjoyment of social events. This was particularly true for social events with friends, and to unknown acquaintances ; *"but I think it puts him off going to some social occasions where he can't prepare for it, because he doesn't know who he's going to sit next to, so I always have to be on guard" (Female C1).*

3.4.4.5 Isolation: Don't go out much as a couple

Three communication partners admitted that they had skipped social events in the past; *"On one or two occasions I would have like to go and generally we do go, but I know there have been a couple of occasions where we haven't been" (Female C1)*. Another also agreed that his wife's hearing loss had negatively

affected him and his wife of going out to social events as a couple; *"Not greatly, but it has, yes. Yes" (Male C3)*. Another felt because of his and his wife's bad experiences of going out and struggling with conversation, it put them off attending future social events as a couple; *"(Name) would think would be stressful because she'd be-. Er, lets take an extreme, we go to a party and she can't hear anything and you feel, "Gosh I wish I'd never come"" (Male C3)*.

3.4.4.6 Isolation: Isolated as a couple at social events

Only one participant said that he and his wife felt isolated as a couple at social events due to the constant struggle his wife had in engaging in conversation at parties with background noise; *"I just felt bad for her, and I felt bad to talk to other people because she couldn't really participate, so we were just sort of there but not really there" (Male C2).* The discussion around isolation predominantly focussed on the communication partner's observation of their partner feeling isolated.

3.4.4.7 Relationships: Effects on intimate relationship

Two communication partners described relevant experiences. One participant had met his wife after she had been diagnosed with hearing loss and so their relationship had developed from the outset to take it into account; *"Because our whole relationship was built knowing that that was there" (Male 1).* For another, she mentioned that she had had to think about accommodating to his hearing loss*; "I sometimes think (name) can place himself better for us to communicate and then I think, "Well that's unreasonable, why aren't I thinking that I should place myself". I mean I think there is that thing about balancing it out, isn't there really? It's not just down to him" (Female 2).*

3.4.4.8 Relationships: Misunderstandings

All of the communication partners were able to relate to this subdomain. One mentioned that misunderstandings often occurred when his wife spoke rather too quietly because she had difficulty monitoring her voice, and so he occasionally misheard what she said; *"Misunderstandings interestingly are usually the wrong way round, in the sense that (name) will speak quite softly. I mean she's got no way of understanding how loud she's speaking or now, erm and she'll often speak quite in a low voice up in the, er, above the garage, in the room above the garage and I'm in the kitchen or in the utility room somewhere and she's very annoyed with me because I can't hear it and I'll say, "Well there are several walls and doors between us, I'm not going to be able to hear it", you know and that recurs on a weekly basis" (Male C1).* Conversely, the remaining communication partners shared that misunderstandings typically occurred because their partner did not hear them. Importantly, these experiences were not always negative; *"Sometimes I'm not sure whether he is having a bit of fun so that I mean, that's a small thing but sometimes there is an amount of humour there if you're close to somebody that you can actually have a bit of something positive out of it" (Female C1).*

3.4.4.9 Relationships: Relationship conflicts

While all communication partners reported instances of misunderstandings, this very rarely, if at all led to arguments; "*You tend to laugh it off" (Male C2).* Another highlighted the importance that the misunderstanding was acknowledged in order to prevent any risk of future arguments; *"We have one difficulty, in as much as I was waiting for (name) at one area and he was waiting for me at another because he'd misheard what I'd said and I find, erm, what I really need from him is an acknowledgement that he's heard me correctly" (Female C2).* Another shared a similar experience. He said he typically made joke out of the

situation to prevent it from escalating; *"…like (name)' says, is quite amusing we find but and I'll say, "What"? (Laughter) "Why you said so and so, didn't you"? I said, "No, I didn't say anything of the sort", but we usually have a laugh about it, that, it's just one of those things isn't it?" (Male C2).*

3.4.4.10 Role of communication partner: Having to answer the telephone

Another subdomain that all communication partners were able to relate to was 'having to answer the telephone'. For one participant, this also involved reported having to speak on to someone on behalf of her husband and take messages on his behalf on the phone; "*Well, I have been called because my husband hasn't been able to understand what's on the other end of the phone so he sometimes calls me to come and take over, erm and he, yes he likes me to answer the phone really" (Female C2).* Another communication partner mentioned that she had to tell her husband when the telephone was ringing; *"Well (name) rarely hears his phone ringing so I have to tell him" (Female C2).* She also mentioned that her husband found speaking and listening on the phone too difficult and so did not want to receive calls; "*I'm quite interested that he doesn't leave it in the room where he is. He usually leaves it somewhere else, it's erm. He either doesn't want it; well it's hard to work out the motivation. Does he not want the calls or does he not want to have it there in front of him frustrating him" (Female C2).*

3.4.4.11 Role of communication partner: Accommodating to the hearing loss

All of the communication partners made reference to several day-to-day instances where they had to accommodate to their partner's hearing loss. For one communication partner, this was in relation to making small adjustments in the way she spoke to her *"I just make more attempt to pronounce everything" (Female C1).* Another mentioned that she always tries to place herself in the best way to facilitate hearing; "*I've got something that I'm really sure I need*

[Name] to know, well I often actually hold him by the arms and have that face to face" (Female C2). Others also mentioned strategies to accommodate to their partner's hearing loss, such as changing their speech rates and volume; *"Well that's me, me speaking loudly to (name)" (Female C2)*.

3.4.4.12 Role of communication partner: Having to act as an interpreter

Two communication partners described scenarios where they have had to act as an interpreter, mainly in social or group conversations; *"And if that's happening and she's unaware of it, I'd, I'd quickly say to her what's going on and I explain to the person as well, if she doesn't, that you know, "She's got hearing aids in both ears so she didn't quite catch what you were saying" (Male C1).* Instances like this was of a regular occurrence for another communication partner that he's gotten used to*; "I've actually developed a new skill, the ability to sort of listen and repeat quickly while still listening" (Male C2).*

3.4.4.13 Role of communication partner: Burden of adjustment

One communication partner mentioned that they had grown to accept their partner's hearing difficulties; *"Unless you went out separately, but if you're going to go there, I mean you, you would ha- or ___(0:06:52), you would have to accept the problems that the, er, partner has got" (Male C1).*

3.4.4.14 Emotions: Emotional consequence on relationship

Whilst there was a considerable amount of discussion on the consequences of hearing loss on the participant's relationships, only one communication partner mentioned the emotional impact on her relationship with her husband; *"Out enjoyment of going to social events together has changed a lot, I see how it affects (name) and that really upsets me too" (Female 2).*

3.4.4.15 Emotions: Guilt

One of the communication partners was keen to share her experience of this because it was something she had thought about regularly; *"When this happened to him, we kind of linked it up with this being on the motorbike for hours and hours and so I certainly feel, you know, sometimes I think if we hadn't done that, maybe this, you know, however reasonable or unreasonable that is, erm, I do think, you know, it didn't help him certainly" (Female C1).* Another mentioned that whenever he got annoyed about his wife mishearing speech, he tried to remind himself that it was not her fault; *"It's more like inwardly if you like and then, I think well, "You know, it's silly really". She can't help it, it's just one of those things that could happen to anyone I think" (Male C2).*

3.4.4.16 Emotions: Stress

Two communication partners gave examples to the stress subdomain; e.g. *"I've had a lot of stress and upset coinciding with (name's) deafness" (Female C1).*

3.4.4.17 Effort and fatigue: Effort and fatigue of having to accommodate

All participants shared experiences of the increased effort needed to modify the way they talked to their hearing-impaired partner, in order to make it easier for them to listen; *"I will try and make more effort to slow down" (Male C2)* and *"The effort of concentrating to listen" (Female C2).*

3.4.4.18 Effort and fatigue: Effort involved in communication

Two communication partners commented on the additional effort required for communicating with their partners. One stated that she had to ensure she had her partner's full attention before talking to him; *"I have to make sure he's sort of paying attention to me before I speak to him" (Female C2).*

3.4.4.19 Effort and fatigue: Effort of having to act as an interpreter

One communication partner commented on the effort of having to interpret*; "To project your voice if it's a particularly bad situation or a bad, bad day for the, for the hearing I think it's frustrating and if perhaps other things are going on in your life and you're quite tired" (Female C1).*

3.4.4.20 Effort and fatigue: Effort of having to repeat

Two communication partners discussed the effort of having to repeat and the implications of having to do so; *"I think repetition is sometimes very tiring" (Female C1)* and *"It takes a lot of effort" (Male 1).*

3.4.4.21 Role of communication partner: Speech production by partner

Two communication partners made reference to changes in their own speaking voice. One man said even his wife had noticed these changes; *"She says, "You don't have to shout" (Male C2).*

Table 3.3 Table of domains that appear in communication partner version of framework only (DoHL-CP)

Domain	Subdomain	✓/x
LISTENING	Raising the volume of the television/radio	✓
COMMUNICATING	Having to repeat	✓
SOCIAL LIFE	Goes out alone	X
	Reduced enjoyment of social activities	✓
ISOLATION	Don't go out much as a couple	✓
	Isolated as a couple at social events	✓
RELATIONSHIPS	Effects on intimate relationship	✓
	Misunderstandings	✓
	Relationship conflicts	✓
	Threat to relationship	X
ROLE OF CP	Having to answer the telephone	✓
	Having to say that phone is ringing	X
	Accommodating to the hearing loss	✓
	Having to act as an interpreter	✓
	Speech production by partner	✓
EMOTIONS	Burden of adjustment	✓
	Having to raise the TV/radio volume	✓
	Emotional consequences on relationship	✓
	Guilt	✓
	Stress	✓
EFFORT AND FATIGUE	Effort and fatigue of having to accommodate	✓
	Effort involved in communication	
	Effort of having to act as an interpreter	✓
	Effort of having to repeat	✓
		✓

The tick indicates that participants were able to share experiences of that particular domain. The cross indicates that they could not share experiences of the subdomain

3.4.5. Additional (sub)domains suggested by hearing aid users, communication partners and hearing health professionals

A few additional subdomains were proposed for the hearing aid user framework. Only where there was sufficient extracted data to warrant the creation of a suggested subdomain, then that subdomain was introduced into the framework. Additions to DoHL-P based on the suggestions from participants in the hearing aid user group are discussed in turn. The participants in the communication partner subgroup did not suggest any additional subdomains to DoHL-CP.

3.4.5.1 DoHL-P - Sound localisation

Some of the hearing aid users felt that having difficulty distinguishing between where sounds are coming from was not reported in the framework; *"But for me it's just surround sound"* and *"Detecting noise or sound from behind" (Female 1).* The data used to code for the subdomains in 'Hearing' (Chapter 2) and the miscellaneous category were also revisited to see if there was potential justification for creation for this subdomain from the extracted data too. Difficulty determining the direction of sound was reported in one data item containing multiple constructs the subdomain was subsequently named 'Sound localisation' (Table 3.4). This subdomain refers to difficulties in determining the direction of a speech (or non-speech) sound.

Table 3.4 Summary table of subdomains added to DoHL-P

Domain	Additional subdomain
Hearing	Sound localisation
Listening	Listening to speech (unfamiliar voices)

3.4.5.2 DoHL-P - Listening to speech (unfamiliar speakers)

The complaints relating to difficulty understanding strong or foreign accents was perceived to be rather ambiguous in that the difficulty in understanding certain accents could be attributed to many things, rather than solely due to hearing

loss. Therefore, it was not possible to create a subdomain relating to accents only. However, the subdomain 'Listening to speech (unfamiliar voices)' was initially included in the framework but taken out due to the potential ambiguity of this subdomain and questioned whether difficulty understanding unfamiliar speakers was a necessary distinction. However, due to the reoccurrence of this subdomain in the hearing aid user focus group, it has been put back into the 'Listening' domain of DoHL-P. Thus, the 'listening to speech (unfamiliar voices)' subdomain represents difficulties in understanding speech of a speaker who is unfamiliar or has an unfamiliar voice to the hearing aid user.

One hearing aid user also gave the perspective that they have held back in meeting new people because they have difficulty following new voices. However, this complaint is now somewhat represented in the listening domain, by the subdomain "Listening to speech (unfamiliar people)" subdomain but explicitly related to understanding the speech of unfamiliar speakers. The inability to network is represented by the subdomain "Social withdrawal".

The communication partner subgroup did not have any suggestions for additional subdomains to DoHL-CP.

3.4.6. Recommendations to modify terminology of (sub)domains within DoHL-P and DoHL-CP frameworks

This section focuses on suggestions made by participants to modify the structure and terminology of the frameworks. Communication partners did not have any suggestions to modify the terminology of any of the subdomains in DoHL-CP (version 1.0). Hearing aid users and hearing health professionals contributed some suggestions for modification to DoHL-P. Suggested modifications to the framework will be discussed first, following those comments made by participants about the structure.

One out of five hearing aid users suggested as to whether one of the existing listening subdomains could be modified to account for listening to unfamiliar voices; "*It's a lot more difficult, especially you might not know them quite so intimately as you do when you're speaking one to one with your partner, could the definition of one of these subdomains incorporate that?" (Female 1).*

Overall the hearing healthcare professionals agreed with the framework based on their clinical experience, but they did suggest some modifications to the terminology. One of the hearing health professional's didn't feel there was a clear distinction between "Hearing" and "Listening" and felt that whilst they are defined differently, the distinction between these two domains would be made clearer if 'Hearing' was modified to 'Detection'; *"which is actually detecting sounds isn't it, that's what we're really after. So maybe, we need to change all of hearing to detect" (Audiologist 1).*

Another audiologist agreed and also questioned the need to separate the domains 'Listening' and 'Communicating'; *"I don't think I would separate two and three, unless you've got some justification for…" (Audiologist 2).* The hearing therapist felt "Listening" and "Communicating" were too similar; *"Listen, the term listening implies, erm, taking on a sound, and processing it, and doing something with it, some kind of active engagement, which is why there's, there's kind of that confusion between listening and communication terms" (Hearing therapist).* However, it was deemed necessary to specify 'Hearing', 'Listening' and 'Communicating' as separate domains given the data analysed to form them were distinct. Furthermore, 'Communicating' in the context of the DoHL-P framework implies a two-way process. It requires to an individual hearing a sound, listening to it and then responding to it in some way, such as conversation. The term listening only refers to listening to a (speech) sound with intention and attention but is not a two-way process. Thus, examples of

subdomains within ‘Communicating’, such as ‘Asking people to repeat’ and ‘Conversing on the telephone’ require the individual to partake in the conversation as oppose to simply listen to it. It was also clear from the extracted data from the included studies of the review (Chapter 2), that a distinction had to be made between the data. Since the domains are data-driven, the term ‘hearing’ was selected due to the occurrence and context of this term in the data used to code for this domain. Therefore, is was the rationale for why the domain name ‘Hearing’ was not modified.

Another hearing health professional felt that one of the listening subdomain should be modified to include difficulties distinguishing sounds; *“You hear a noise you’ve never heard in your life, and you think, “What, what’s that strange, what’s that noise?” So you can detect a noise, but you can’t recognise it, if you’re got hearing impairment, you’re going to get that much more so, so are you able to detect, discriminate what it is, or work out whether it’s speech or noise, or important, or unimportant, or a warning sign” (Hearing therapist).*

Another felt that ‘Speech production’ could be more clearly defined; *“…when I’d saw it written down, what I presumed you were meaning by that, were more attached to people’s fears about deaf speech, erm, and one’s ability to produce those sounds, rather than, er, volume level” (Audiologist 1).* The hearing aid user group’s comments around the ‘Speech production’ subdomain suggested some confusion regarding its meaning. This confusion was also shared among two hearing health professionals, thus the extracted data used to form this domain was revised and the subdomain was then changed to ‘Speaking with a loud voice’ (Table 3.5).

The audiologists and hearing therapist agreed that hearing loss can have on impact at work- but suggested some terminology changes to subdomains in the

'Occupational' domain; "*I'm not sure about restrictions at work, from the point of view of how it's termed" (Audiologist 2)* and "…*but looking at that, restrictions at work, if somebody says to me, "I'm, I'm worried about being restricted at work", when they say that, my first thought would be, they're talking about their opportunities, their prospects, and not necessarily what's…" (Audiologist 2).* This audiologist thought that the subdomains 'Restrictions at work' and 'Reduced job prospects' were negatively worded subdomains compared to the rest of domains in DoHL-P which are more neutrally phrased. The other two audiologists agreed with this point and the data used to form this subdomain was revisited and the subdomains were modified to 'Opportunities at work' and 'Ability to perform duties at work' (Table 3.5).The latter revised subdomain also resonates with the account given by one of the hearing aid users who struggled to hear on the phone at her former workplace.

With respect to 'Pleasure of listening to music,' two participants felt this comprised an emotional construct and therefore should appear in the 'Emotions' domain; *"Can you understand speech?" The, the, there's a different level in there, isn't there? There's a, in the pleasure of listening to music bit, there's a, erm, there's an emotional thing in there, as there is in asking people to repeat, because then you stop asking when you have to, you, you don't get the communication" (Hearing therapist).* However, due to the dominating listening construct within the data used to code for this subdomain, it was kept within the 'Listening' domain.

Table 3.5 Summary table showing domains where terminology of existing (sub) domains were modified

Domain	Original subdomain	Revised subdomain
Speaking (originally speech production)	Speech Production	Speaking with a loud voice
Occupational	Restrictions at work	Opportunities at work
Occupational	Reduced employment prospects	Abilities to perform duties at work

The final version of the frameworks (following implementation of the modifications to the person with hearing loss domains) is presented in Table 3.6, Table 3.7 and Table 3.8. These tables depict version 2.0 of DoHL-P and DoHL-CP.

Table 3.6 Modified domains of hearing loss frameworks (version 2.0) following modifications from focus groups for 'Auditory' supra-domain

Domain	DoHL-P		Both	DoHL-CP
Hearing				
	• Hearing warning sounds • Hearing telephone ring • Hearing the doorbell • Hearing television and radio sounds	• Hearing distant sounds • Hearing environmental sounds • Hearing speech sounds • Sound Localisation		
Listening				
	• Listening to speech on the telephone • Listening to speech in noisy environments • Listening to birdsong • Listening to music • Pleasure of listening to music • Listening to quiet speech (whispering)	• Listening to speech (at work) • Listening to speech (speech in general) • Listening to speech in a group of talkers • Listening to speech in a travelling vehicle • Listening to speech in public places • Listening to speech in quiet environments	• Raising the volume of the television/radio	
Communicating				
	• Asking people to repeat • Communicating at work • Communicating, general conversation	• Communicating, speech in quiet • Conversing on the telephone • Reduced communication	• Conversing in a group of talkers • Conversing in noisy environments • Conversing one to one • Having to speak on behalf of partner with hearing loss • Reduced spontaneous conversation	• Having to repeat
Speaking				
			• Speaking with a loud voice	

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

Table 3.7 Modified domains of hearing loss frameworks (version 2.0) following focus group for "Social" supra-domain

Domain	DoHL-P	Both	DoHL-CP
Interventions			
	• Expectations of rehabilitation • Technical problems with hearing aid		
Social Life			
	• Social withdrawal • Altered social interactions		• Goes out alone • Reduced enjoyment of social activities
Isolation			
	• Sense of isolation		• Don't go out much as a couple • Isolated as a couple at social events
Occupational			
	• Abilities to perform duties at work • Opportunities at work		
Relationships			
	• Relationship with family members	• Relationship with spouse/partner	• Effects on intimate relationship • Misunderstandings • Relationship conflicts • Threat to relationship

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

Table 3.8 Modified domains of hearing loss frameworks (version 2.0) following focus group for "Self" supra-domain

Domain	DoHL-P	Both	DoHL-CP
Role of CP			
			• Having to answer the telephone • Having to say that phone is ringing • Accommodating to the hearing loss • Having to act as an interpreter • Speech production by partner
Emotions			
	• Embarrassment • Rejection • Worry	• Frustration • Anger • Upset	• Burden of adjustment • Having to raise the TV/radio volume • Emotional consequences on relationship • Guilt • Stress
Effort and Fatigue			
	• Listening effort	• Feelings of fatigue	• Effort and fatigue of having to accommodate • Effort involved in communication • Effort of having to act as an interpreter • Effort of having to repeat
Identity			
	• Feelings of inadequacy/self-esteem	• Self-image	
Stigma			
	• Stigma of hearing aids • Pretending to understand speech	• Denial • Stigma of hearing loss	

Column 2 displays the subdomains that appear in Domains of Hearing Loss-Persons with hearing loss (DoHL-P) only. Column 3 shows the subdomains that appear in both frameworks. Column 4 displays the subdomains that appear in Domains of Hearing Loss-Communication partners (DoHL-CP) only

3.4.7. Comments by communication partners about hearing-impaired person's difficulties

There were some instances within the hearing aid user and communication partner focus groups when participants made comments about their partner's difficulty, as opposed to their own. These comments were not appropriate to demonstrate evidence for the subdomains in 3.4.2 but some examples will be discussed here. The comments reflect the observed changes and difficulties the person with hearing loss experiences made by their communication partner.

One communication partner felt that her husband initially experienced "denial" of their hearing loss and suggested this may have been due to the prospect of having to wear a hearing aid; "*It may be because he's rather, perhaps, newer to the total problem and in the beginning I think he avoided, well first of all he didn't want to make him the hearing aid because he wanted a solution that wasn't a hearing aid" (Female C1).* However, her husband in the hearing aid user group did not admit to this. This does not suggest a lack of agreement within this couple or that the partner actively denied, but rather this was something her husband did not mention.

Not all of the communication partners participating in the research focus group experienced 'embarrassment'. Two communication partners however, commented on the potential of embarrassment when their wives did not hear correctly what someone else has said; *"I think the potential for embarrassment is there all the time, because quite often (name) will mishear what someone says"* and then responded inappropriately; "*And answer the question she thought, or answer the point she thought they were making" (Male C1).*

Another communication partner shared that her husband felt nervous when in the company of big groups of people; *"because he doesn't know who he's going to sit next to or he, he doesn't find it easy" (Female C2).* This was a similar

observation made by another communication partner about her husband; *"I think he's, he's fine if he's in a group of his immediate friends who know quite a lot about him and have known him for a long time, but I think it puts him off going to some social occasions where he can't prepare for it" (Female C1).* In both cases, the communication partners felt that their spouses' apprehensions about social activities were worsened when there is a potential of meeting new people whom are unaware of their partner's hearing difficulties.

As found in the hearing aid user group, communication partners talked about their observation of their partner having difficulty understanding foreign accents; *"if I'm going to be in an environment with, erm, a lot of people with a strong accent she will make sure she manages her own expectations as well as the situation…because she finds it very hard" (Male C3).* However for one communication partner, this reported difficulty was in related to her husband's difficulty in understanding unfamiliar speakers with foreign accents; *"…well particularly about meeting people that he hasn't met before and he always says there's only so many times you can say, "Pardon, well you know I'm a bit __(0:48:51)", so he obviously worries about that" (Female C1).*

One communication partner observed communication strategies utilised by his wife such as making people aware of her hearing loss; *"I think (name) almost, erm, feels it important to let people be aware that she has a problem."* Another mentioned that his partner has let people know when she has struggled to follow what has been said; *"I mean (name) always tells people if she's having any difficulty understanding"* and *"She says, "I wear hearing aids in both ears, could you speak up please"."*

3.5. DISCUSSION

The aim of the study was for three key stakeholder groups of the domains of hearing loss frameworks to review the (sub)domains. Any modifications made to the frameworks were based on member checking and triangulation across stakeholder groups. For the hearing aid users and communication partners, these participants provided evidence for the subdomains by sharing their experiences of each one, for each framework. These participants also suggested additional (sub) domains to be added to the frameworks. In addition, all participants (including hearing health professionals) were given the opportunity to suggest modifications to the terminology of sub(domains) in the frameworks.

The findings from the focus groups held with people with hearing loss and their partners support the notion that the DoHL-P and DoHL-CP are representative of the experience of living with hearing loss. The outcomes for each of these objectives will be discussed in turn.

3.5.1. Evidence for domains and subdomains in framework

Both groups shared their experiences and confirmed face validity for most subdomains in both frameworks. However, some subdomains were not supported through the experiences of the focus group participants (Table 3.9).

Table 3.9 List of subdomains participants could not relate to

Supra-domain	Domain	Subdomain
Auditory	Communicating	Reduced spontaneous conversation (Both frameworks)
Social	Relationships	Threat to relationship (CP)
Self	Role of partner	Having to say that the phone is ringing (CP)
Self	Emotions	Rejection (PHI)
Self	Emotions	Denial (Both frameworks)
Self	Emotions	Anger (Both frameworks)
Auditory	Hearing	Hearing warning sounds (PHI)

For the subdomains in Table 3.9, none of the participants explicitly disagreed with the subdomains. The participants did not comment on the subdomain because they felt that it wasn't relevant to them or their experiences, but could be for other people with hearing loss and their communication partner. Based on these reasons alone and given these subdomains have been reported as issues for people with hearing loss in the literature, it was inappropriate to remove the subdomains from the frameworks.

What was apparent from the data was that all hearing aid users shared their experiences of having listening to speech in various environments. Difficulty listening to speech and conversing in noisy environments has been reported in various studies (Magilvy, 1985, Garstecki, 1987, Stephens et al., 1990, Bade, 1991, Hetu et al., 1993, Slawinski et al., 1993, Laroche et al., 2000, Tsuruoka et al., 2001, Miyakita et al., 2002, Hass-Slavin et al., 2005, Hidalgo et al., 2008, Kelly and Atcherson, 2011, Jonsson and Hedelin, 2012).

Participants mentioned that the greatest listening difficulty is typically in situations where there is various types of background noise, and usually during social activities such as meeting friends for dinner. The secondary implication of increased listening difficulties expressed by hearing aid users, was enjoyment of social activities. Complaints relating to difficulties in social situations because of hearing loss is the most frequently reported domain in the literature.

Partners also concurred with the implications these listening difficulties has on their enjoyment of the social activity, a domain also frequently reported in the partner literature (Hetu et al., 1993, Hallberg, 1999, Kochkin and Rogin, 2000, Govender et al., 2014). Three partners noticed in particular that the frequency of going out together as a couple had decreased since hearing loss which was

another social subdomain frequently reported in the literature (Scarinci et al., 2008, Scarinci et al., 2009c).

The active involvement of communication partners in social situations on behalf of their hearing aid user partner was reported among all partners in the group. In social situations, communication partners reported having to speak on behalf of their partner and convey parts of the conversation with friends their partner. This concurs with a lot of communication partner-reported complaints in the literature (Morgan-Jones, 1998, Stephens et al., 1995, Ross and Lyon, 2007, Yorgason et al., 2007, Preminger and Meeks, 2012, Manchaiah et al., 2013b) as they reported often having to act as a translator and keep their informed with the conversations. The communication partners overall were able to recall the additional roles and responsibilities they have had to undertake due to their partner's hearing loss.

The World Health Organisation (WHO) has branded the impact of hearing loss on the partner or spouse as "Third Party Disability" (Hickson and Scarinci, 2007, Scarinci et al., 2009c). For example, whilst the spouse may not have a hearing loss, this concept proposes that they still may experience difficulties or problems as a result of their partner's hearing loss. This is highlighted in the communication partner list of domains, particularly the domain 'Role of Communication Partner'. In this case hearing loss creates an environmental factor which forms the spouse's third-party disability and is exemplified by the complaints given by participants in Table 4.15. These increased demands may exert pressure on the communication partner which may negatively affect their relationship with the hearing impaired individual (Preminger and Meeks, 2010). This may also provide rationale as to why the domain 'Relationships' is ranked joint second place by communication partner respondents.

The IDA Institute has developed a “Goal-sharing for Partners Strategy” (GPS) for audiologists to involve communication partners in aural rehabilitation. This tool is based on the Client Oriented Scale of Improvement (COSI) (Dillon et al., 1997) and the method of Goal Attainment Scaling (Preminger and Lind, 2012). It provides patients and their communication the opportunity to share their perspectives as to how hearing loss has affected them. Manchaiah et al. (2012) states that this tool also gives the patient and their communication partner the chance to understand the extent at which hearing loss affects them, predominantly in terms of communication. For example, this process may make each partner aware of their role in communication, how hearing loss affects those roles and what steps can be taken to improve their roles in communication to achieve better communication in difference listening environments.

What the results also emphasise is acknowledgment from people with loss and communication partners of the broad implications of hearing loss. Whilst it may be impossible to capture every single scenario of hearing loss complaints, the frameworks provide a starting point for identifying important domains, and then delving further to capture and address specific hearing loss-related complaints. The frameworks also confirm statements made by researchers in the past regarding uncertainty around the use of psycho-acoustic measures alone to measure hearing loss disability or these measures as outcomes of hearing aid benefit.

There has been some evidence to suggest that audiologists are often faced with the challenge of having to listen to accounts from patients with hearing loss as well as their significant other (Hetu et al., 1993, Lunner, 2013). These potentially conflicting accounts potentially highlight the disparity between the patient’s view of their hearing loss and the associated difficulties, and the communication partner’s perspective of the patient’s hearing loss and difficulties. There is also

a potential risk, that patients are unequipped to make decisions about their rehabilitation.

3.5.2. Strengths and Limitations

A major strength in developing the domains of hearing loss frameworks is that the inductive methods undertaken in Chapter 2 were reviewed by deductive methods in the current chapter to be as inclusive as possible, as well as taking a multidimensional approach to refine version 1.0 of the DoHL-P and DoHL-CP frameworks. Five sources of information were used to develop the frameworks: extracted qualitative research data from patients and communication partners, focus group data from patients and communication partners, and focus group data from hearing health professionals.

Another strength of this focus-group approach to review the data-driven frameworks was its emphasis on examining whether the domain frameworks captured the lived experience of hearing loss, using methods that explicitly sought to reduce responder and investigator biases. The focus groups examined the domains of hearing loss frameworks using open-ended questions to minimise bias of the participant's responses. That is, discussion was driven purely by each subdomain of the framework, but participants were also given the opportunity to share their additional opinions of the frameworks. The facilitators did not share their opinions or research experiences of any of the subdomains.

Furthermore, the facilitators did not give examples of the data that was used to code each subdomain that might influence the type of experiences the participants share. This ensured that the examples given by participants was purely driven and interpreted by the subdomains and their definitions. The hearing aid users and the communication partners were separated into distinct

stakeholder groups. This also enabled the participants to share their experiences of hearing loss without their partner which gives rise to various advantages. Participants may feel less inhibited and may potentially speak more freely For example, whilst hearing aid users acknowledged the key role of their partner in living with hearing loss, they may not be aware of the 'burden' or other consequences of this role on their communication partner that were discussed.

Furthermore, the complaints used to form the frameworks were extracted from studies that included study participants aged 18 years old and over. All of the participants who took part in the (hearing aid user and communication partner) focus group were >40 years old. The participants were also recruited from a database of people who have consented to take part in hearing and tinnitus research, many of whom are experienced hearing aid users and are of a similar demographic.

One potential limitation of the study was that the focus groups contained fairly small group sizes which may have risked missing certain data that would have otherwise emerged. However, achieving data saturation also does not depend on the number of participants involved in the study, but rather on the richness of the data (Dibley, 2011, Burmeister and Aitken, 2012, Fusch and Ness, 2015). Bernard (2012) states that in order to achieve data saturation the questions should be structured to facilitate gaining multiple responses to the same questions, which was what was achieved in the current study. The analysis used in Chapter 2, meta-ethnography, is well known for its data saturation because of the multitude of data collection methods that are synthesised. Whilst the current study used a relatively small number of participants, the data used to form the frameworks initially were formed from all the relevant literature pertaining from the research which spanned more than 30 years. The

frameworks were therefore developed from a vast amount of data (>1000 extracted ‘complaints’ of hearing loss).

Within qualitative research particularly, there is not a universal method to reach data saturation. However, qualitative researchers do agree on some general principles such as when there is no new data, no new themes and ability to replicate the study (Guest et al., 2006, O’reilly and Parker, 2013). For the communication partners and audiologists, neither of these groups suggested any new or additional domains/subdomains to the frameworks in the focus groups. The hearing healthcare professionals did have some suggestions to modify terminology, and this was considered. However, due to the data-driven requirements of meta-ethnography, it was important that the terminology of the domains reflected the data from which it was formed. Furthermore, the study presented in Chapter 4 presents another approach to reviewing the frameworks to ensure validity. The focus group data from the current study was triangulated with the findings from Chapter 4 (see section 4.5.4).

3.6. CONCLUSION

Overall, the hearing aid users and communication partners involved the focus group felt that the DoHL-P and DoHL-CP frameworks are representative of the broad spectrum of complaints associated with hearing loss. Participants were able to relate to all of the domains of both frameworks, and the majority of subdomains, thus demonstrating validity of the frameworks. The primary outcome of the focus group was the introduction of two new subdomains into DoHL-P: “Sound localisation” and “Listening to speech (unfamiliar talkers)”.

CHAPTER 4. SURVEY STUDY INVESTIGATING THE MOST IMPORTANT DOMAINS OF HEARING LOSS: PERSON WITH HEARING LOSS AND COMMUNICATION PARTNER PERSPECTIVES

4.1. INTRODUCTION

Hearing loss is known to affect various aspects of an individual's life (Ng and Loke, 2015). The broad range of these everyday impacts were synthesised into supra-domains, domains, and subdomains to form two hierarchical frameworks (Chapter 2), DoHL-P and DoHL-CP and subject to "checking" with different stakeholders (Chapter 3); one for people with hearing loss and one for their communication partners. Following these focus groups, DoHL-P required some modification, but DoHL-CP did not.

The subdomains within each domain are closely related in that all the subdomains within a domain tap into the same area or aspect of life that is considered problematic for someone with hearing loss. A domain therefore captures a common aspect of complaint, but a subdomain is specific to a particular situation.

The constructs represented in the each framework were not based on the frequency of reporting in the literature, rather the construct contained within the extracted data. All the domains and subdomains in the framework are therefore equally weighted. What remains unknown, is whether that equivalence in weighting is a conceptual reality. Do people with hearing loss and their communication partners actually consider certain domains to play a more significant role in the daily lives? And to what extent are those impacts common to most people? This objective is the same as the secondary objective in

Chapter 3. Here, the populations of interest assess the face validity of the domains. This ensured the credibility of the content of the frameworks. The present survey identified which of the person with hearing loss- and communication partner-reported domains reported in Chapter 3 are considered most important to people with hearing loss and their communication partner.

The secondary objective was to explore whether respondents felt there were any aspects of life affected by hearing loss that were not represented in the frameworks ("member checking"). There were several advantages to doing this again. The survey provided another opportunity to sample a larger sample of the population of interest to test the frameworks, whom might have different perspectives to those who participated in the focus groups (Chapter 3). The survey therefore enabled the opportunity to triangulate (Creswell and Miller, 2000) the findings from an anonymous questionnaire survey with the findings to the same question asked in the face-to-face focus group. Hence, the survey also allows additional opportunity for the frameworks to undergo another qualitative credibility assessment (Knudsen et al., 2012). These steps increase the confidence of the hierarchical frameworks. Furthermore, the survey design maintains the advantages of interacting with target population (hearing aid users and communication partners) while removing factors that could potentially influence their response (influence of other participant's perspectives).

Triangulation is typically used as a validation strategy for qualitative research. Yeasmin and Rahman (2012) defines triangulation as *"a process of verification that increases validity by incorporating several viewpoints and methods".* There are different forms of triangulation used for different purposes. Data triangulation is the method by which data is taken from different sources to form one profile of data, investigator triangulation is an approach where multiple researchers take part in gathering and interpreting the data, theoretical

triangulation is where the researcher analyses the data taking multiple theoretical positions. Finally, methodological triangulation is where more than one research method is employed to answer the same question. This was the approach taken to the current study and represents the most common definition of the term.

Triangulation has been used to converge qualitative and quantitative data but is typically used to synthesise qualitative data from different research techniques. Whilst triangulation can be used to combine data obtained from different perspectives (within-group triangulation), it can also converge data drawn from different sources (between-group triangulation) (Flick, 2008). In order to further validate the domains of hearing loss frameworks, the data from the focus groups (Chapter 3) were compared to survey-response data in the current study. Triangulation approaches are also useful for cross-checking and typically used to provide confirmation and completeness which brings together two or more types of research. In Chapter 3 one of the objectives was to converge the different perspectives between hearing aid users and their communication partner for domains that appear in both frameworks.

4.1.1. Aims and Objectives

The primary objective was:

1. To identify those domains relating to the most important patient- and partner-reported aspects of hearing loss.

Secondary objectives included:

2. To explore whether hearing aid users and communication partners identify additional domains for the frameworks and thus to perform “member checking” of the frameworks.

4.2. METHODS

4.2.1. Design

A questionnaire survey design was chosen for a number of reasons. Survey research are commonly used in health and applied special research studies. A 'survey' generally refers to a large sample population (the population of interest), followed by the collection of a relatively small amount of data from those respondents. The data can then be used to make some inferences about the wider population (Kelley et al., 2003). A survey design containing the domains to be ranked in order of importance allows the two stakeholder groups (hearing aid users and communication partners) to make their responses privately, avoiding social pressures or influence from their partner (Okoli and Pawlowski, 2004). The survey design also allows for respondents to express their own perspective of what is important to them, by considering each domain on the basis of personal experience alone, as oppose to making choices based on other people's experience or consensus of others around them (Okoli and Pawlowski, 2004). Hearing aid users ranked and reviewed DoHL-P (version 2.0) and communication partners reviewed DoHL-CP (version 2.0).

4.2.2. Ethical approval

The study received favourable opinion from the University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee on 16th October 2016. The Ethics reference number is F14102016.

4.2.3. Sample size and recruitment methods

4.2.3.1 Hearing aid users and communication partners

There is currently no consensus on sample size required for a survey. The aim was to elicit responses from 150-200 (range) hearing aid users and communication partners with various mail-out options. Thus far, the frameworks

had been subjected to review from three stakeholder groups. The purpose of the survey was to sample the frameworks on a larger number of people with hearing loss and communication partners.

The target range was based on an expected response rate of 20-30% (Kelley et al., 2003) using four dissemination methods to advertise the survey. The survey was distributed using four different networks of communication (Table 4.1). The participants in the communication partner focus group (Chapter 3) were recruited via their hearing aid user spouse/partner. None of the survey dissemination strategies employed contain direct access to communication partners. It was anticipated that respondents who were communication partners would be a more challenging group to reach, and therefore it was unrealistic to expect to receive a similar number of responses from participants who were communication partners compared to hearing aid users.

1. The primary route for distribution was to the participants of the NIHR Nottingham BRC's database. This database contains the names and contact details of participants who have expressed an interest in taking part in research, or have taken part in NIHR Nottingham BRC research. There are 1000 people on the database comprising adults with hearing loss, normal hearing and/or tinnitus. An email invitation containing information about the study and a direct link the survey was emailed out to 803 people on the database. Invitation emails were sent out during February 2017. The survey was not emailed out to all members of the database because the remaining 197 members were documented as having normal hearing and/or tinnitus only.
2. Social media channels (Facebook and Twitter websites) were also employed. The Facebook page has 195 followers and the Twitter page >900 followers. Some information about the survey and a direct link to

the survey was posted on the NIHR Nottingham BRC's (hearing section) Facebook and Twitter page. It is unknown how many of these followers have hearing loss or are communication partners since these pages are open to members of the public.

3. A guest blog was written for Action on Hearing Loss (AoHL). The blog was released on 1st December 2016. It contained a background of the survey, eligibility criteria and a direct link to the survey. This blog was posted on the website. A link to the blog was also included as an item on AoHL's monthly email bulletin that is sent to its mailing list. It is also unclear here how many of these participants are the population of interest since they also include a professional network of interest.
4. The final route for distribution of the survey was to participant members of the MRC IHR (Scottish Section) database. This database comprises of participants who have expressed an interest in taking part in research or have taken part in research at MRC IHR. Due to standard operating procedures of the MRC IHR participant database, not all participants were invited to take part in the survey. The number of participant contacted to take part in the survey was 248. These participants were sent a letter and Participant Information Sheet (PIS) containing information about the study and the criteria to take part. A consent form (developed by MRC IHR) and a paper version of the survey with a pre-paid addressed envelope was also enclosed for participants who agreed to take part. The survey sheet itself did not contain any identifiable information. Although the target population here was identified by name, the surveys were returned anonymously.

Respondents recruited from NIHR Nottingham BRC participant database, social media channels and AoHL were incentivised by a prize draw for online Amazon

vouchers. The prize draw question was not present on the paper version of the survey. This was because collection of personal details on research documents does not confirm to MRC IHR ethics terms.

The exact number of participants reached by the four methods are unknown, but given our knowledge of methods used in strategies 1, 2 and 4 it was certainly >1000. Given the exact number of participants approached for the NIHR Nottingham BRC and MRC IHR database are known, the estimate of the minimum number of participants reached is 1051.

Table 4.1 Summary of survey dissemination methods

Dissemination Strategy	Background	Number of Participants contacted	Date Participants contacted
NIHR Nottingham BRC participant database	Database of participants (hearing aid users and non-hearing aid users) who have expressed an interest in taking part in research.	803	February 2017
NIHR Nottingham BRC's Social Media account	Facebook, Twitter and website	Facebook/twitter website =unknown	January-March 2017
Action on Hearing Loss (AoHL)	AoHL are the largest UK charity supporting people with hearing loss and deafness problems.	Guest blog about survey made available on AoHL website = unknown	Guest blog for website went live on 1st December 2016. Survey news item emailed out on 7th December 2016.
MRC Institute for Hearing Research Participant Database (Scottish Section)	Database of participants who have participated in research at MRC IHR Glasgow. These participants were initially sources on the NHS ENT/Audiology Clinics in the Greater Glasgow Hospital area.	248	November-December 2016

The survey opened December 2016 and closed in March 2017 when the recruitment target (150-200 responses) had been met.

4.2.4. Eligibility criteria

4.2.4.1 Hearing aid users and communication partners

For participants to be eligible to take part in the survey they must have been either an individual who has been diagnosed with hearing loss and wears

hearing aid(s), or someone who is the partner or spouse of someone who had hearing loss. All participants must have been at least 18 years old and have a good understanding of English.

A screening question at the start of the survey asked the respondent to indicate which stakeholder group they belonged to: i) those diagnosed with a hearing loss (irrespective of whether they wore hearing aid(s) and ii) those who were the spouse/partner of someone who had been diagnosed with hearing loss.

4.2.5. Materials

4.2.5.1 Survey development

Two versions of the 3-item questionnaire survey were generated based on Kelley et al. (2003) systematic approach to survey design: (1) planning the content of a research tool; (2) questionnaire layout; (3) piloting and (4) covering letter. The authors also highlighted the importance of subjecting the survey to a robust process of development and testing, in order to ensure the credibility of the research findings.

1. *Content and layout of the survey*

According to Kelley's recommendations, the topic of interest should be carefully planned and relate clearly to the research question. Kelley et al. (2003) identified the usefulness of involving colleagues and members of the target population of interest to ensure the validity of the coverage of the questions included in the survey (content validity).

There were two versions of the survey, one tailored to people with hearing loss, and the other for communication partners. The main content of the survey was the question that asked participants to rank the domains in order of importance to them. The person with hearing loss version of the survey contained the domains of hearing loss from DoHL-P (version 2.0). The communication partner

version of the survey contained the domains of hearing loss from DoHL-CP (version 2.0).

The instruction to respondents who had hearing loss was to rank the categories (domains) in order of importance to their lives based on their experience of living with hearing loss. The instruction to communication partners was to rank the categories according to importance, based on their experience of living and communicating with someone who has hearing loss.

2. Questionnaire layout

Kelley et al. (2003) suggests that questionnaire surveys should be clearly presented and questions should be numbered and grouped by subject. There should be instructions given for each question and headings to make the survey easy to follow. In terms of the form of the questions (i.e. open or closed format) Kelley et al. (2003) recommends considering the analysis method of the questions during development.

The survey had an online and paper version. The paper version was available only to those recruited via the MRC IHR participant database and those who participated in the study reported in Chapter 5. The survey administered online was delivered using Survey Monkey (www.surveymonkey.com). The survey was split into four sections. The first section was grouped under 'Background information and consent'. This part of the survey contained information regarding the purpose of the survey and how long the survey would take to complete. This page also contained 4-consent items for the participant to agree to (by ticking each point) in order to be admitted to the rest of the survey. The next part of the survey was grouped under 'Demographic information'. Demographic information deciphered which stakeholder group the respondent belonged to, age, and gender. The response determined which version of the survey each respondent received. This page also asked questions exploring

the age and gender of respondents. Following this, the next section was the main part of the survey, called ‘Category ranking’. For participants who indicated they had hearing loss, they were directed to the domains from DoHL-P. Participants who indicated that they were a communication partner (partner/ or spouse of a hearing-impaired person), these participants were directed to the DoHL-CP.

Respondents were instructed to rank each category (domain) in order of importance to them (1 being most important; 13 being least important; 11 for communication partner domains). The respondents could rank any domain as ‘not applicable’ if they felt it was not relevant to them. The format of this question was the same for both versions of the survey, but the domains to be ranked were different in both surveys.

One version of the survey asked people with hearing loss to consider the 13 patient-reported domains, and the other version asked communication partners of people with hearing loss to consider the 11 communication partner-reported domains (Table 4.2). A rank number of 1 corresponded to the most important with the maximum value (indicating least importance) being 13 for DoHL-P and 11 for DoHL-CP.

After the ranking exercise, respondents were asked in an open-format question to specify whether any aspect of their everyday life was affected by hearing loss, that they felt had not been already captured by the list of categories presented in the ranking exercise. The purpose of this question was to try and map the respondent’s answers onto the full frameworks at subdomain level, as well as to triangulate the findings of this question with that of the findings from Chapter 3. The survey took between 5-10 minutes to complete. Figure 4.1 shows a screenshot of the domains ranking question from the survey.

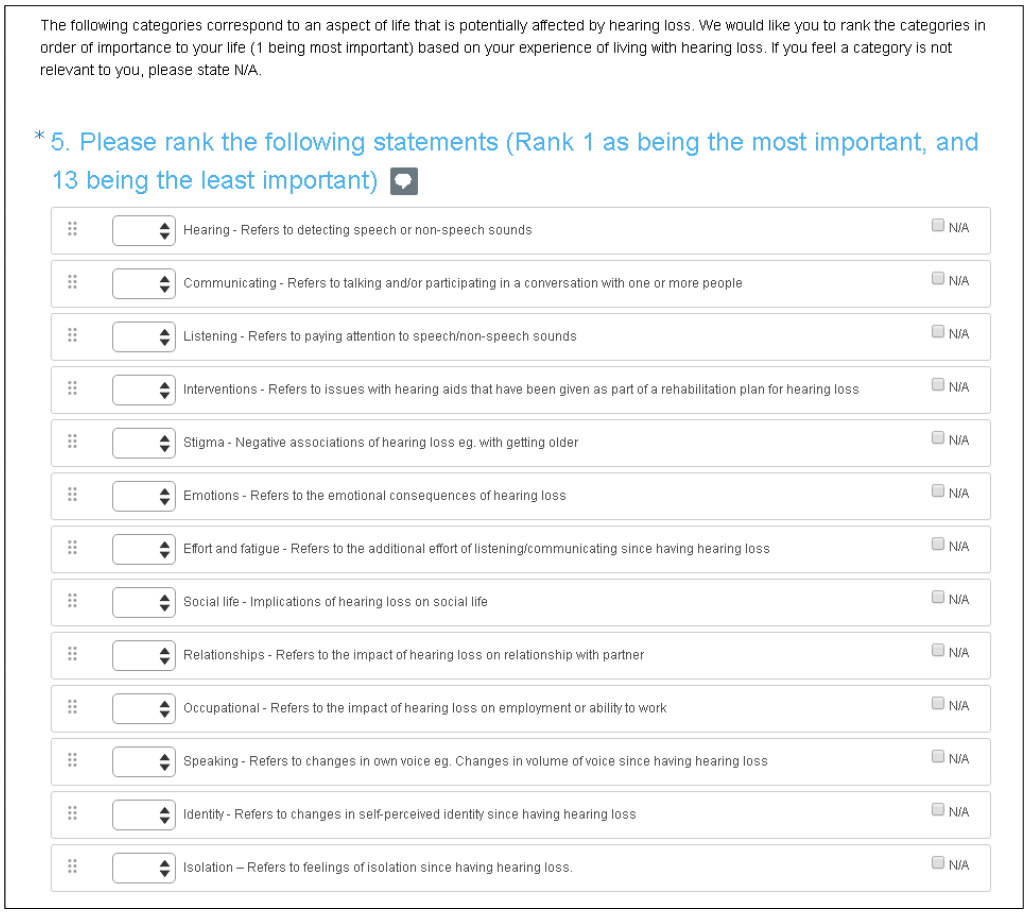


Figure 4.1 Screenshot of domains ranking question for DoHL-P

3. *Interview questions*

Kelley et al. (2003) suggests having a clear, well thought out set of questions and the questions can be either an open or closed format. All of the questions in the current survey were open format, apart from the final question that asked participants to share any additional domains they felt were missing form from the list of domains they were asked to rank.

4. *Piloting*

Kelley et al. (2003) also recommends testing the survey on a pilot sample of members of the target population. This process identifies whether respondents understand the question and instructions, and whether the participants respond to the questions correctly.

A draft version of the online survey was piloted on four members of a Patient, Public Involvement Steering Group of the NIHR Nottingham BRC (Hearing section) to comment on ease of use and navigation of the survey. The first version of the survey was the version piloted. This version of the survey asked respondents to consider to rank at subdomain level (59 subdomains for DoHL-P and 38 subdomains for DoHL-CP) *and* domain level. All participants who piloted the survey indicated that there were too many options *"quite testing for the responder to feel secure in their chosen judgements when ranking the domains, especially where the number of potential subdomains is high" (PPI 1)* and *"there seems to be a lot of categories" (PPI 2).* Indeed, one of the participants who withdrew from the pilot because he felt it was an impossible task given the number of subdomains. As a result, the final version of the online and paper version of the survey required ranking at domain-level only.

In the survey instructions, the term 'domain' was avoided as this was not considered a plain language term by members of a PPI panel who piloted the first version of the survey (See point 4). The concept of a domain also had to be explained to hearing aid users and their communication partners during the focus groups. To accommodate for this, the survey explained that the list of 'categories' correspond to an aspect of life that is potentially affected by hearing loss.

5. *Covering letter*

The final recommendation that Kelley et al. (2003) highlights is important is to provide sufficient information the organisation hosting the study, the contact details of the researcher conducting the study, and the aims of the study. For informed consent, these issues were covered in section 4.2.5.

Table 4.2 List of domains and their definitions for each version of framework

	Person with hearing loss	**Communication partner**
Hearing	Refers to detecting speech or non-speech sounds	N/A
Communicating	Refers to talking and/or participating in a conversation with one-to-one or in a group of people	Refers to talking and/or participating in a conversation one-to-one or in a group of people.
Listening	Refers to paying attention to speech/non-speech sounds	Refers to having to listen to the television at a loud volume
Interventions	Refers to issues with hearing aids that have been given as part of a rehabilitation plan for hearing loss	N/A
Stigma	Negative associations of hearing loss e.g. With getting older	Negative connotations of partner's hearing loss e.g. Association with getting older
Emotions	Refers to the emotional consequences of hearing loss	Refers to emotional consequences of hearing loss
Effort and fatigue	Refers to the additional effort of listening/communicating since having hearing loss	Refers to the additional effort of communicating with partner
Social life	Refers to impact of hearing loss on social and recreational activities	Implications of partner's hearing loss on social life
Relationships	Refers to the impact of hearing loss on relationship with partner	Refers to impact on relationship with partner due to hearing loss
Occupational	Refers to the impact of hearing loss on employment or ability to work	N/A
Speaking	Refers to changes in own voice e.g. Changes in volume of voice since having hearing loss	Refers to changes in own voice e.g. changes in volume of voice since having hearing loss
Identity	Refers to changes in self-perceived identity since having hearing loss	Changes in perceived image as a couple since partner's hearing loss
Isolation	Refers to feelings of isolation since having hearing loss	Refers to feelings of isolation due to partner's hearing loss
Role of communication partner	N/A	Refers to the additional role and responsibilities taken undertaken to accommodate partner's hearing loss

4.3. PLAN OF ANALYSES

4.3.1. Data collection and analysis

All data were collected into a single excel spreadsheet. The data were subjected to descriptive statistics performed in SPSS (version 22) to compute the highest and lowest ranked domains, and to examine the distribution of ranking for all those domains in between. Two different calculation strategies were used in order to assess whether the analysis method influenced the conclusions drawn from the data. It was also to ensure that the final results did not depend on the analysis method taken. The first method calculated all of the ranking scores from highest to lowest. The second method calculated only the data for the top ranking score for each domain.

In the first method, the number of people who ranked per level for each domains were calculated (e.g. the number of people who ranked 'communicating' as number one, number two etc.). The total for each rank for each domain was then given a score. For example, the number of people who ranked a domain as number one was given a score of 13, the number of people who ranked a domain as number two was given a score of 12 and so on. This was calculated for all 13 domains in DoHL-P and 11 domains in DoHL-CP (the highest points the communication partner domains could be allocated was 11). The highest score a domain could have obtained in DoHL-P was 2291. An example of the scoring method is given in Table 4.3.

Table 4.3 An example of the scoring system for the person with hearing loss domain, 'Communicating'

Rank	Points	n	Score
1	13	79	1027
2	12	49	588
3	11	27	297
4	10	15	150
5	9	4	36
6	8	7	56
7	7	4	28
8	6	4	24
9	5	3	15
10	4	3	12
11	3	2	6
12	2	3	6
13	1	2	2
N/A	0	5	0
		Total	2247

Column (1) rank, (2) allocation of points for each rank, (3) the number of people that ranked the domain at each level and (4) the overall score of each rank for the domain

The overall total for each domain was used to calculate the final rank order. The domain with the highest overall score was ranked number one, next highest number two and so on.

In the second method, the number of respondents who ranked each domain at number 1 was calculated. This allowed for the observation of the domains that respondents deemed the most important, and whether this correlated with the first analysis method.

4.3.1.1 Thematic analysis of open-format responses

The method for thematic analysis was based on Braun and Clarke (2006) (Chapter 3). To strengthen reliability, responses to open questions were analysed by a pair of researchers (VV and SS). By this point, VV had gained experience of coding qualitative data (particularly coding data to form the

domains ranked in the current study) through conducting the qualitative analyses (Chapter 2 and 3). SS also had experience of (second) coding qualitative data in otology and hearing research. The advantage of having two coders ensured the reliability of the subdomain mapping. SS was not involved in the development and modification of the domains reported in Chapter 2 and 3, or the development of the survey which meant that the interpretation of the subdomains and subsequent mapping of the free-field text answers was purely based on the terminology and definitions of the subdomains rather than prior knowledge. This counter balanced any potential bias that VV may have brought to the deductive analysis.

The stages of thematic analysis were conducted according to the methods described in section 3.3.1.1.

4.4. RESULTS

4.4.1. Participants

There were 255 people consented to take part in the survey (207 hearing-impaired individuals and 48 partner/spouse of people with hearing loss). The number of consented survey participants exceeded the initial target of 150-200. This can be explained because the survey met its target in advance of the closing date advertised on the AoHL blog. Therefore, a decision was made to keep the survey open until this date.

Of the 255 consented, the number of people who actually completed the survey was 200. The survey response rate was estimated via the known number of participants contacted from the databases and known number of enrolled from that recruitment method. The total number of participants contacted via these databases was 942, and the number of enrolments was 200 enrolled, giving a

response rate of 21.2% (200/942). Therefore the estimated response rate of 20-30% was met.

The mean age of consented people with hearing loss was 69.1 years (SD=11.6).The mean age of consented communication partners was 66.1 years (SD=12.2).

The number of people who completed the domains ranking task correctly on the paper version of the survey was 73.

4.4.1.1 People with hearing loss

This section will describe the rankings for each stakeholder group. The ranked domains with the points system for the DoHL-P are shown in Table 4.4.

Table 4.4 Ranked domains for DoHL-P

POINTS	13	12	11	10	9	8	7	6	5	4	3	2	1	
RANK	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**Total**
Communicating	1027 n=79	588 n=49	297 n=27	150 n=15	36 n=4	56 n=7	28 n=4	24 n=4	15 n=3	12 n=3	6 n=2	6 n=3	2 n=2	2247
Hearing	689 n=53	504 n=42	275 n=25	80 n=8	153 n=17	112 n=14	56 n=8	36 n=6	35 n=7	36 n=9	6 n=2	4 n=2	4 n=4	1990
Listening	169 n=13	444 n=37	539 n=49	200 n=20	162 n=18	96 n=12	112 n=16	84 n=14	30 n=6	8 n=2	24 n=8	4 n=2	0 n=0	1872
Social life	78 n=6	180 n=15	484 n=44	460 n=46	126 n=14	96 n=12	105 n=15	72 n=12	70 n=14	32 n=8	6 n=2	12 n=6	3 n=3	1724
Effort & fatigue	182 n=14	168 n=14	99 n=9	300 n=30	270 n=30	192 n=24	182 n=26	78 n=13	35 n=7	48 n=12	39 n=13	4 n=2	3 n=3	1600
Isolation	143 n=11	96 n=8	88 n=8	100 n=10	144 n=16	128 n=16	140 n=20	126 n=21	75 n=15	84 n=21	36 n=12	48 n=24	6 n=6	1214
Relationships	39 n=3	108 n=9	132 n=12	90 n=9	135 n=15	192 n=24	112 n=16	120 n=20	130 n=26	32 n=8	48 n=16	22 n=11	1 n=1	1161
Occupational	169 n=13	72 n=6	44 n=4	130 n=13	117 n=13	160 n=20	91 n=13	96 n=16	85 n=17	40 n=10	18 n=6	10 n=5	12 n=12	1044
Stigma	78 n=6	60 n=5	44 n=4	80 n=8	117 n=13	120 n=15	56 n=8	96 n=16	80 n=16	92 n=23	66 n=22	50 n=25	26 n=26	965
Interventions	13 n=1	72 n=6	77 n=7	150 n=15	117 n=13	136 n=17	98 n=14	60 n=10	90 n=18	72 n=18	36 n=12	28 n=14	16 n=16	965
Emotions	78 n=6	60 n=5	44 n=4	80 n=8	108 n=12	112 n=14	56 n=8	90 n=15	80 n=16	92 n=23	66 n=22	52 n=26	25 n=25	943
Identity	13 n=1	60 n=5	66 n=6	50 n=5	54 n=6	48 n=6	77 n=11	132 n=22	115 n=23	132 n=33	84 n=28	40 n=20	9 n=9	880
Speaking	0 n=0	12 n=1	11 n=1	50 n=5	135 n=15	96 n=12	91 n=13	84 n=14	105 n=21	92 n=23	93 n=31	36 n=18	16 n=16	821

Domains highlighted in green represent the top three ranked domains. The domains are listed in order of ranked importance with the highlighted (rank one) at the top and lowest (rank 13) at the bottom

According to the first calculation method explained in section 4.3.1, Table 4.4 gives the final ranked domains in order of importance for DoHL-P.

The domain that was ranked as most important (number one) by people with hearing loss and thus received the highest score (n=2247) was ‘Communicating’. The second most important domain was ‘Hearing’ (n= 1990) and the third was ‘Listening’ (n=1872). As shown in Table 4.4, the top three ranked domains were all those within the ‘Auditory’ supra-domain of the framework. These domains received the highest number of respondents who ranked these domains in their top three most important, and therefore these domains received the highest points-weighting, which is why they were ranked as the top three overall.

All of the domains apart from ‘Speaking’ were ranked as number one by some respondents. However, none of the respondents ranked ‘Speaking’ as number one. In fact, this domain received the least number of respondents who ranked this domain in their top three of most important, compared to all the other domains in the framework and therefore was allocated the least number of points. This is why the domain speaking was ranked 13 overall.

The domain that received the highest number of ‘not applicable’ responses was ‘Occupational’ (n=60). The reason that ‘Occupational’ received the highest number of respondents who scored it as ‘not applicable’ could be due to the demographic of the participants who completed the survey. The mean age of people with hearing loss who completed the survey was 69 years old and thus it is likely that most participants who completed the survey were retired. Given the demographic it is also likely that the noticeable onset of hearing loss was also during retirement. The domain that received least number of people who ranked it as ‘not applicable’ was ‘Communicating’ (n=5) the highest ranked

domain overall. The domains that received the least number of ‘not applicable’ were generally domains within the ‘Auditory’ supra-domain Table 4.5.

Table 4.5 The number of participants who ranked the each domain as ‘not applicable'

Domain	n
Occupational	60
Interventions	45
Speaking	37
= Relationships	37
Identity	32
Emotions	23
= Stigma	23
Isolation	19
Hearing	10
= Listening	10
= Effort and fatigue	10
= Social life	10
Communicating	5

For the second method of scoring, observation of the column for domains ranked at number one shows that ‘Communicating’ still has the highest number of respondents who ranked it at number one which conforms to the overall ranking of domains. The domains that received the highest number of votes for rank one were Communicating (n=79), Hearing (n=53) and Effort and fatigue (n=14) (Table 4.6).

Table 4.6 Table showing domains in order of those that received the highest number of 'rank ones' from respondents

Domain	n	Rank
Communicating	79	1
Hearing	53	2
Effort & fatigue	14	3
Listening	13	4
Occupational	=13	=4
Isolation	11	5
Social life	6	6
Emotions	=6	=6
Stigma	=6	=6
Relationships	3	7
Interventions	1	8
Identity	1	=8
Speaking	0	9

The top three ranked at one differ somewhat from the overall ranked scores, where 'Listening' came third instead of 'Effort and fatigue'. The reason 'Listening' was ranked third overall is because the distribution of scores for the three rankings was higher (1=169, 2=444, 3=539) compared to 'Effort and fatigue' (1=182, 2=168, 3=99). The domain 'Speaking' is still ranked lowest as it did not receive any respondents who ranked the domain as number one. From Table 4.4, it can be observed that the distribution of ranks that received the highest number of respondents is between rank four and ten.

The number of domains that were ranked highest at number two was 'Communicating' (n=588), 'Hearing' (n=504) and 'Listening' (n=444). This is consistent with the overall ranking of the domains.

In terms of the domains that received the highest number of people who ranked it at number 13 was 'Stigma' (n=26) and 'Emotions' (n=25). But overall these domains rank at number nine (stigma) and number 11 (emotions) due to the weighting of respondents who ranked these domains in their top three most

important. Four respondents stated in response to open-format question that they could not rank the domains as they felt they were all equally important.

4.4.1.2 Additional complaints mapped onto DoHL-P

In response to the open-format question asking whether the respondents felt there were any aspects of life they felt that were not captured in the (DoHL-P) framework, there were 41 responses (excluding responses from participants who said they could not rank the domains). Of these, 33 responses could be mapped onto the framework at subdomain level (Table 4.8, Table 4.9 and Table 4.10). Therefore, the purpose of this was to decipher what complaints could be mapped onto the framework at domain level and what complaints were new, 'additional' domains of the framework. This was important to the analysis of the responses to the open-format question because it filtered out complaints pertaining to the framework at the detailed subdomain level, and those domains that are not present in the framework at any level.

There were five complains relating to tinnitus could not be mapped onto the subdomains since tinnitus is not within the scope of the framework (Table 4.7).

Table 4.7 Tinnitus-related answers to Q6 that were not mapped onto framework

Participant response (tinnitus complaints)
"Interaction with tinnitus"
"Effects of daily strain of also managing tinnitus"
"Distress of tinnitus"
"Tinnitus associated with hearing loss"
"Tinnitus"

4.4.1.3 Reported complaints that could be mapped onto the framework at subdomain level

In response to the open-format question that asked participants whether they felt there was any aspects of life affect by their hearing loss that is not

represented in the list of domains, all of these responses could be mapped onto the framework at subdomain level. Some of these responses will be discussed here.

The majority of the open-format responses were those that could be mapped onto the 'Auditory' supra-domain of DoHL-P. Reponses were typically pertaining to the subdomains in 'Hearing' and 'Listening'.

There was also a response that was mapped on to the subdomain 'Sound localisation'; *"inability to locate directional sound".* This was a subdomain that emerged from the focus groups (Chapter 3). The fact that this complaint has been mentioned specifically by a respondent of the survey provides some level of further validation for this subdomain.

There were 23 responses that could be mapped onto the "Auditory supra-domain at subdomain level (Table 4.8).

4.4.1.4 Listening: Pleasure of listening to music

There were six responses that could be mapped onto this subdomain, the highest number of responses compared to those mapped onto other subdomains. One respondent indicated that they had a high-frequency hearing loss and made reference to the fact they could not appreciate the higher frequency musical sounds which affected their overall enjoyment of listening to music; *"My loss is at the highest frequencies so for example I cannot hear some music"* and *"Recognition/appreciated of well-known music-great loss."* These further insights into the relevance of this domain adds to the credibility of this subdomain.

4.4.1.5 Listening: Listening to speech in noise

There were four responses with data that could be mapped onto this subdomain, *"…noisy places because I have great difficulty in understanding what people are saying".* 'Listening to speech in noisy environments' was a subdomain that all hearing aid users could relate to in the focus group. Similarly to the comments made by those participants, the responses in the current survey pertaining this subdomain were in reference to social settings in particular. For example, *"I find it extremely difficult to isolate speech from background sounds when in an environment like a bar or when there is an ambient sound".* With this response, there is some overlap in construct with the subdomain 'Listening to speech in public places'.

4.4.1.6 Social withdrawal

This subdomain also received joint highest number of responses (n=6). The domain 'Social' was ranked fourth overall. All of the open-format responses pertaining to this domain were mapped on the 'Social withdrawal' subdomain. Respondents made reference to the effect of hearing loss on social participation; *"socialising in groups, this is really hard, e.g. when eating out. It's tempting just not to go"* and *"ability to participate fully in social events".* Other respondents made reference of having to withdraw from certain hobbies where a key component of the activity was listening which was thus impaired by hearing loss; *"I had to give up Thai boxing. I couldn't hear the instructor. Other classes are also affected"* and *"More difficult to lead an active social life e.g. theatre and concert visits, group activities, lectures etc."*

4.4.1.7 Occupational: Opportunities at work

Three respondents made reference to the impact of hearing loss on the workplace. One of the comments was in relating to difficulty performing day-to-day work duties because listening and communicating was a key component of

the role; *"…things got worse hearing on the telephone, I went to my employer to tell them, and they just couldn't take the information in".* Here the respondent also makes reference to a lack of accommodation and consideration from the employer which mean that this difficulty persisted; *"Nothing happened I have to say with regards to sorting out the telephone issue".* Another respondent also made reference to a lack of accommodation by employers; *"Because you don't have disability written on you, they just forget you and have to be within a distance to hear, they to face you or you need a different type of phone, it's just all forgotten"* as well as making use of opportunities at work; *"Taking courses at work has become difficult".* The mention of this subdomain helped to validate it presence in the framework, particularly since three out of five hearing aid users in the focus group were retired and their hearing loss diagnosis was post-retirement.

4.4.1.8 Identity: Feelings of adequacy/self-esteem

There were two responses pertaining to this subdomain. One respondent made reference to the impact hearing loss has had on their confidence; *"Hearing loss has affected my self-confidence quite a bit".* Another respondent indicated their experience of this subdomain explicit to social situations; *"Confidence – referring to meeting new people".*

All of the reported complaints shared by participants in response to open-format question that asked for additional complaints of hearing loss could be mapped onto the framework at subdomain level.

There were three complaints deemed to be miscellaneous. The criteria for miscellaneous data was the same as those depicted in Chapter 2. Data items that were non-specific or where the underlying construct of the data was not understood by the coders, these data were placed in the "miscellaneous"

category. The three data items coded as miscellaneous; *"Organisation- one more thing to remember when going out or away"* and *"sign language communication"* and *"Being out at night when you can't hear someone behind you".*

Table 4.8 Participant complaints mapped within 'Auditory' supra-domain of DoHL-P framework at subdomain level

Subdomain (Domain)	Participant complaint
Hearing environmental sounds (Hearing)	"Wind noise can severely affect listening" "Difficulty hearing sounds"
Sound localisation (Hearing)	"Impact on daily life, especially inability to locate directional sound"
Hearing warning sounds (Hearing)	"Sometimes wonder if I miss sirens on emergency vehicles" "Difficult to hear alarm"
Listening to speech in noisy environments (Listening)	"Background noise in loud areas" "I try avoiding noisy places because I have great difficulty in understanding what people are saying" "I find It extremely difficult to isolate speech from background sounds when in an environment like a bar or when there is an ambient sound"
Listening to music (Listening)	"Listening to music" "Inability to listen to music"
Listening to birdsong (Listening)	"Bird song"
Pleasure of listening to music (Listening)	"Listening to music" "The loss of pleasure of listening to music" "My loss is at the highest frequencies so for example I cannot hear some birdsong, music etc." "Recognition/appreciation of well-known music-great loss" "Enjoyment of music" "Enjoying fully, live music"
Listening to speech (Public places)	"Listening in restaurants/Cinema pubs and public places due to background noise"
Listening on the telephone (Listening)	"Inability to understand people on the telephone"
Communicating, general conversation (Communicating)	"Every time I visit GP or hospital I have to explain hearing loss which goes over everyone's head and is ignored, I usually am not looked at face to face, talked to the back of my head, or just mumbled at. This results in me being scared and on occasions unable to understand what the doctors are saying"
Conversing in a group of talkers (Communicating)	"Being able to hear and communicate in large groups, e.g. committees, meetings, conferences"
Speech production (Speaking)	"I'm told by others that I speak to loudly" "Tone of voice cannot always be heard/monitored-worried I cause offence unintentionally"

There were 13 complaints that could be mapped on to the “Social” supra-domain of the (DoHL-P) framework (Table 4.9).

Table 4.9 Participant complaints mapped onto subdomains within ‘Social’ supra-domain of framework

Subdomain (Domain)	Participant complaint
Social withdrawal (Social life)	“I had to give up Thai Boxing. I couldn't hear the instructor. Other classes are also affected” “Socialising in groups - this is really hard, e.g. when eating out - very isolating and distressing. It's tempting to just not go” “Ability to participate fully in social events” “Social interaction and inability to enjoy theatre anymore” “Restricted access to classes e.g. dancing, yoga, since I cannot hear the teacher” “More difficult to lead an active social life - e.g. theatre and concert visits, talks, lectures, group activities, etc.”
Sense of isolation (Isolation)	“I think it might be embedded in some category particularly Isolation the erosion of confidence has a huge effect on such things as planning (e.g. travel is stressful). Also worth noting that my answers would have been completely different was it not for the fact that I have a fantastic partner and family”
Fear for loss of employment (Occupational)	“How employers, and work colleagues treat you, and can't understand what deafness means”
Opportunities at work (Occupational)	“Because you don't have disability written on you, they just forget you have to be within a distance to hear, they need to face you or you need a different type of phone, it's just all forgotten” “… things got worse hearing on the telephone, I went to my employer to tell them, and they just couldn't take the information in, saying to me I had coped until now. I had also been in touch with the Job Centre special team for disability, so they could contact them. Nothing happened I have to say with regards sorting out the telephone issue” “Taking courses at work has become difficult”
Relationship with family members (Relationships)	“No longer feel that I can participate in family activities” “Family life, implications for wider family”

There were seven complaints that could be mapped onto the “Self” supra-domain within the (DoHL-P) framework (Table 4.10).

Table 4.10 Participant complaints mapped onto subdomains within ‘Self’ supra-domain of (DoHL-P) framework

Subdomain (Domain)	Participant complaint
Frustration (Emotions)	“Frustration” “Frustration”
Feelings of inadequacy/self-esteem (Identity)	“Confidence - referring to meeting new people - acceptance by others in a group because you are non-hearing” “Hearing loss has affected my self-confidence quite a bit”
Stigma of hearing aids (Stigma)	“Stigma associated with others negative reaction to the HAs” “Other people’s complete lack of understanding & finding deafness amusing”
Technical problems with hearing aid (Interventions)	“…but the loop system/amplification system at a public event wither isn't working or causes echoing e.g. making it more difficult to hear. Then yes this is a very important category”

Most of the additional complaints reported complaints fell within the ‘Auditory’ and ‘Social’ supra-domains of DoHL-P. For ‘Auditory’ the majority of these responses could be mapped onto subdomains within the ‘Listening’ and ‘Communicating’ domains. For ‘Social’, most of the responses could be mapped onto the subdomains within the domains ‘Social life’ and ‘Occupational’ domains.

There were some answers to this question that contained multiple underlying constructs, and thus could be assigned to more than one subdomain. For example, one participants reported; *“Frustration that I feel when visiting retail establishments due to the level of background music/conversation/coffee machines etc. - that and traffic noise”.* In this excerpt the respondent indicated an emotional construct (frustration) which is represented in the ‘Emotions’ domain of the framework, in addition to listening in background noise and in

public places which are represented by ‘Listening to speech in noisy environments’ and ‘Listening to speech in public places’ in the framework.

Another example includes: “Family know your hard of hearing but always accuse you of not listening to conversations they think you should listen to them and nothing else.” Again, multiple constructs are suggested that can be mapped onto various subdomains of the framework. The participant hints at possible misunderstandings with family members (relationship with family member’s subdomain) as a result of not being able to listen (listening to speech subdomain). The participant also makes a general reference to conversations.

The three remaining responses to the open-format question could be mapped onto the framework at domain level (Table 4.11). This was the original objective of this question. However, given the scope of nearly all answers, the mapping of the complaints was possible at subdomain level.

Table 4.11 Complaints mapped onto DoHL-P at domain level

Domain	Complaint
Hearing	“Not hearing at night with no hearing aids”
Hearing	“If take out hearing aids at night, feels unsafe and can’t hear spouse”
Hearing	“Not being able to wear hearing aids at night”

Therefore, there were no additional domains suggested by respondents that were unique to the domains already within DoHL-P.

4.4.2. Communication partners

The ranked domains for DoHL-CP is shown in Table 4.12. The same scoring method that was applied to the domains from DoHL-P was applied to DoHL-CP. A noteworthy difference however in the ranking system is that the person

with hearing loss domains had 207 respondents whereas the communication partner version only had 48.

Table 4.12 Ranked domains for the DoHL-CP

POINTS	11	10	9	8	7	6	5	4	3	2	1	
RANK	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**Total**
Communicating	308 n=28	50 n=5	63 n=7	48 n=6	14 n=2	12 n=2	0 n=0	8 n=2	0 n=0	0 n=0	0 n=0	503 (n=55)
Effort and fatigue	11 n=1	60 n=6	135 n=15	64 n=8	42 n=6	42 n=7	10 n=2	0 n=0	6 n=2	0 n=0	0 n=0	370 (n=55)
Social life	33 n=3	100 n=10	63 n=7	48 n=6	49 n=7	30 n=5	25 n=5	8 n=2	0 n=0	2 n=1	0 n=0	358 (n=55)
Speaking	22 n=2	70 n=7	27 n=3	40 n=5	105 n=15	42 n=7	5 n=1	16 n=4	15 n=5	4 n=2	0 n=0	346 (n=55)
Relationships	55 n=5	100 n=10	18 n=2	80 n=10	42 n=6	0 n=0	15 n=3	8 n=2	3 n=1	8 n=4	0 n=0	329 (n=55)
Role of partner	88 n=8	80 n=8	0 n=0	24 n=3	42 n=6	24 n=4	15 n=3	24 n=6	0 n=0	2 n=1	0 n=0	299 (n=55)
Emotions	0 n=0	20 n=2	81 n=9	40 n=5	35 n=5	54 n=9	35 n=7	16 n=4	0 n=0	10 n=5	0 n=0	291 (n=55)
Listening	33 n=3	0 n=0	54 n=6	32 n=4	0 n=0	60 n=10	40 n=8	12 n=3	3 n=1	8 n=4	0 n=0	242 (n=55)
Isolation	55 n=5	100 n=10	18 n=2	80 n=10	42 n=6	0 n=0	15 n=3	8 n=2	3 n=1	8 n=4	0 n=0	156 (n=55)
Stigma	33 n=3	0 n=0	9 n=1	0 n=0	14 n=2	6 n=1	25 n=5	28 n=7	24 N=8	4 n=2	3 n=3	146 (n=55)
Identity	0 n=0	0 n=0	0 n=0	0 n=0	0 n=0	0 n=0	10 n=2	20 n=5	3 n=1	6 n=3	15 n=15	54 (n=55)

Domains highlighted in green represent the top three ranked domains. The domains are listed in order of ranked importance with the highlighted (rank one) at the top and lowest (rank 11)

The domain that was ranked as most important (number one) by communication partners and thus received the highest score (n=503) was ‘Communicating’. The second most important domain was ‘Effort and fatigue’ (n= 370) and the third was ‘Social life’ (n=369). These domains received the highest number of respondents who ranked these domains in their top three most important, and therefore these domains received the highest points-weighting, which is why they are ranked as the top three overall.

All of the domains apart from ‘Identity’ have been ranked as number one by some respondents. However, none of the respondents ranked ‘Identity’ as number one. In fact this domain did not have any communication partners who ranked this domain in their top three. In fact, the highest rank this domain received was number seven.

The domain ‘Communicating’ was ranked as most important by both stakeholder groups. The number of people that ranked this domain as number one in each stakeholder group is also particularly striking. ‘Communicating’ in the communication partner version of the framework for example received a score of 308 points for the number of people that ranked this domain as number one. The domain with the second highest number of people who ranked at number one was ‘Role of communication partner’ (88 points) which is considerably less than ‘Communicating’. For DoHL-P, ‘Communicating’ received a score of 1027, with the domain “Hearing” behind, with a score of 689.

The ‘Role of communication partner’ domain did receive a considerable number of people ranking this domain as number one (n=88) or two (n=80). However, the total number of people who ranked the domains ‘Effort and fatigue’, ‘Social life’, ‘Speaking’ and ‘Relationships’ as their top three most important was higher than for ‘Role of communication partner’.

The domain ‘Effort and fatigue’ was ranked second most important by communication partners. Whilst this domain did not receive many people who ranked this domain as number one (score 11), it did received a larger number of people who ranked this domain as number two (score 60) and three (score 135).

The domain that was received the highest number of respondents indicate it as ‘not applicable’ was ‘Identity’ (n=29). The domain that received least number of people who ranked it as ‘not applicable’ was ‘Communicating’ (n=3) the highest ranked domain overall. The domains that received the least number of ‘not applicable’ were generally domains within the ‘’Self’ supra-domain Table 4.13.

Table 4.13 The number of participants who ranked the each domain as ‘not applicable' for the DoHL-CP

Domain	n
Identity	29
Isolation	24
Stigma	23
Listening	16
Role of Communication partner	16
Relationships	12
Social life	9
Emotions	9
Effort and fatigue	8
Speaking	5
Communicating	3

The top three ranked domains for the communication partner version of the framework each span a domain from the ‘Auditory’, ‘Social’ and ‘Self’. The top three ranked domains in DoHL-P on the other hand spanned the supra-domain ‘Auditory’ only.

Whereas the domain ‘Speaking’ was ranked the least important by people with hearing loss, the domain was ranked fourth most important by communication

partners. In DoHL-P on the other hand, this domain received the least number of respondents who ranked this domain in their top three of most important, compared to all the other domains in the framework and therefore was allocated the least number of points. This is why the domain speaking is ranked 13 overall.

In terms of the domains ranked in order of those ranked at number 1 (second scoring method) (Table 4.14), the highest ranked domain was “Communicating“(n=28). The second highest domains was “Role of Communication partner” (n=8) and “Relationships” (n=5) which were ranked jointly.

The domains ranked equally as least important were “Emotions”, “Listening” and “Identity” (n=0).

Table 4.14 Table showing domains in order of those that received the highest number of 'rank ones' from communication partner respondents

Domain	n	Rank
Communicating	28	1
Role of communication partner	8	2
Relationships	5	3
Isolation	=5	=3
Stigma	3	4
Social life	=3	=4
Speaking	2	5
Effort & fatigue	1	6
Emotions	0	-
Listening	0	-
Identity	0	-

4.4.2.1 Additional complaints mapped onto the communication partner version of the domains of hearing loss framework

There were 13 participants who responded to this question. Of these responses, 12 responses could be mapped onto DoHL-CP at subdomain level (Table 4.15). The one remaining response was the communication partner who

commented on hearing loss-related difficulties of their hearing-impaired partner; "*difficulty speaking to him in bed when he doesn't have his hearing aids on."* These types of responses were not within scope of the current study. There were no data coded as "miscellaneous".

Given the number of responses to the communication partner version of the survey than the number of responses to the person with hearing loss version of the survey, there were comparatively less responses to the open-ended questions. There were a total of 12 responses which spanned all three supra-domains of the framework. Some of these responses and the subdomain they map onto will be discussed here. A full list of the responses mapped onto the appropriate subdomain is given in Table 4.15.

4.4.2.2 Social life: Reduced enjoyment of social activities

This was a subdomain that four out of five communication partners in the focus group could relate to. Similar to the open responses of for DoHL-P, most survey respondents made reference to social difficulties; *"something that we no longer do is concert visits".* Here, the respondent indicates that the difficulty their partner has at concert has cause them both to withdraw socially.

4.4.2.3 Listening: Having to raise the volume of the television/radio

One respondent stated that the volume of the TV is too loud; *"Has the TV on very loud".* Another respondent made a generic comment to this subdomain; *"Listening to the TV/radio".* Most of the communication partners in the focus group were also able to relate and share their experiences of this subdomain.

4.4.2.4 Role of communication partner: Having to act as an interpreter

Two respondents made reference to this subdomain. Both responses inferred the respondent's role of having to communicate and speaker on behalf of their

hearing-impaired partner; *"Having to take the lead"* and *"Often get at cross purposes during conversation especially with strangers."*

Another respondent made reference to methods of accommodating to their partner's hearing loss; "*having to be aware of positioning when communicating"* which is represented in the "Role of communication partner" domain, 'Accommodating to partner's hearing loss.'

Table 4.15 Responses to open question that asked if there is an aspect of life affected by hearing loss that that are mapped onto the DoHL-CP framework at subdomain level

Subdomain (Domain)	Participant complaint
Having to act as interpreter (Role of CP)	"Have to take the lead" "Often get at cross purposes during conversation especially with strangers"
Having to answer the telephone (Role of CP)	"Having to answer phone calls/going to reception points"
Reduced enjoyment of social activities (Social life)	"Somethings that we no longer do such as visit concerts" "Doesn't go to live shows anymore with partner. Feels that partner is selective with his hearing"
Goes out alone (Social life)	"Going to cinema or theatre together"
Frustration (Emotions)	"Frustration"
Misunderstandings (Relationships)	"Mishearing causes arguments"
Having to raise the volume of the television/radio (Listening)	"Listening to TV/radio. Clarity of TV/radio" "Has the TV on very loud"
Having to repeat (Communicating)	"Constantly having to repeat"
Speaking with a loud voice (Speaking)	"Having to speak more clearly"

4.4.3. Complaints about partner

In response to the open-response question, some participants responded with complaints referring to their partner's difficulty with hearing loss, as oppose to the impact of hearing loss on themselves. These complaints were not within the scope of the objective of the study but will be described here. Similar to the

person with hearing loss version of the survey, there were some complaints from respondents that could not be mapped onto subdomains of the partner framework. In particular, some complaints were difficulties the respondents observe their hearing aid user partner having. For example, one respondent wrote *'[hearing loss] has affected enjoyment of music'* which could be mapped onto the hearing aid user framework subdomain, 'Pleasure of listening to music.'

Another observation made by a respondent; "… he plays instruments very loud" is related to the "listening to music" in DoHL-P. Another respondent made reference to difficulty with the telephone; '*Telephone conversations are impossible'.* This subdomain taps into multiple subdomains across both frameworks including 'Listening to speech on the telephone' and 'Having to answer the telephone.'

4.5. DISCUSSION

This survey study aimed to identify what people with hearing loss and communication partners consider as the most important domains of hearing loss. Results pertaining to the first scoring method will be taken as the primary analysis of interest because this method shows the distribution of ranked domains across each framework. Whilst the second method of scoring shows which domains having the highest number of respondents who ranked it at number 1, it infers that domains ranked least important are not considered important to hearing aid users at all, when in fact they could have been ranked in their top three, but just not first.

The findings showed that the issue of 'Communicating' was ranked as most important to people with hearing loss *and* communication partners, with approximately one third of respondents in each respondent stakeholder group

ranking this as the most important domain. Given the large amount of data pertaining to communication difficulties from studies synthesised in Chapter 2, this finding is not surprising. For communication partners, the domain 'Effort and fatigue' was ranked second highest, which highlights the perceived significance of their role in accommodating to their partner's hearing loss, particularly in relation to communication, and 'Relationships' ranked third. For people with hearing loss, the second highest ranked domain was 'Hearing' and third was 'Listening'.

The fact that the top three ranked domains all fall into the 'Auditory' supra-domain of DoHL-P was somewhat of an expected finding. "Auditory" contains the highest number of domains and subdomains (four domains and 35 subdomains). Furthermore, the highest number of complaints extracted from the included studies in Chapter 1 were auditory-related complaints. Since hearing aids often form the only intervention for patients with hearing loss, this finding emphasises that hearing aids alone are not adequate to address the degraded auditory capabilities for someone with hearing loss (Boothroyd, 2007).

For the person with hearing loss domains, both analysis methods gave rise to 'Communicating' ranked as the highest domain, and 'Hearing' as the second highest ranked domain. For the analysis method that only summed the responses of domains ranked number 1, the domains that came third overall was 'Effort and fatigue' (Table 4.16).

For the communication partner ranked domains, both analysis methods gave rise to 'Communicating' as being the highest ranked domain. There were differences in the second and third ranked domains (Table 4.17).

Table 4.16 DoHL-P ranked domains

Rank	First scoring method	Second scoring method
1	Communicating	Communicating
2	Hearing	Hearing
3	Listening	Effort and fatigue

Table 4.17 DoHL-CP ranked domains

Rank	First scoring method	Second scoring method
1	Communicating	Communicating
2	Effort and fatigue	Role of communication partner
3	Social life	Relationships

4.5.1. Third Party Disability

The domain ranked sixth most important to communication partners was the 'Role of Communication Partner'. The progressive onset of age-related hearing loss means that it can often be years, or even decades before help is sought (Meyer and Hickson, 2012, Meyer et al., 2014). As a result, the individual with hearing loss may not always be aware of all of the day to day implications that hearing loss has on their life. It is common for communication partners to play a role in encouraging the individual to seek help for their hearing loss as a result of the impact they perceive it to have on their relationship (Vestergaard Knudsen et al., 2010). Information from communication partners has also been suggested to be used as an indicator of any disparity between the level of measured hearing loss and the level of disability claimed by the stated needs of the patient (Cox, 2000). This could subsequently aid the design of an individualised rehabilitation plan (Heine et al., 2002, Caissie et al., 2005). One of the reasons "Role of communication partner" does not fall within the top three could be due to the progressive onset of their partner's hearing loss. During this time the communication partner might have taken on additional roles or communication tactics without realising. What could also be interpreted from

this list of ranked domains is that communication partner respondents did not actually view having to accommodate to their partner's hearing loss as an important complaint, but rather the effort of having to do so. These increased demands may exert pressure on the communication partner which may negatively affect their relationship with the hearing impaired individual (Preminger and Meeks, 2010). This may also provide rationale as to why the domain 'Relationships' is fourth most important by communication partner respondents.

Several studies have identified the negative effects of hearing loss on personal relationships (Hetu et al., 1993, Anderson and Noble, 2005, Donaldson et al., 2004, Govender et al., 2014). Hetu et al. (1993) explored the effects of age-related hearing loss couple interaction. Given the progressive onset of age-related hearing loss the authors acknowledge the process of getting to grips with hearing loss is atypical for couples. The accommodations a spouse or partner has to make for their hearing-impaired partner often occurs overtime before either partner is aware of the hearing loss. Hetu et al. (1993) classes those accommodations such as having to repeat or speaking with a louder voice as new social rules within the relationship. Since neither partner may be able to fully acknowledge the presence and burden hearing loss, this can result in feelings of hostility, defensiveness, and blame. The concept of 'attributions' are explanations that one partner makes for the other partner's behaviour (Crosbie-Burnett and Lewis, 2009). Hence, in the case of hearing loss, the message intended by the speaker might not align with the message intended and can lead to misunderstandings and conflict (subdomains captured in the domains of hearing loss framework). This concept has been suggested to be applicable to couples where one partner has hearing loss (Piercy and Piercy, 2002).

4.5.2. Comparison between hearing loss and communication partner rankings

The domain 'Communicating' was ranked most important by both stakeholder groups. From the perspective of people with hearing loss, complaints of effort and fatigue reported in the literature refer to the additional effort of listening, and the additional attentional resources required optimise listening, this domain was ranked fifth most important. 'Effort and fatigue' in DoHL-CP on the other hand was ranked second most important.

A lot of communication partner reported complaints relating to effort and fatigue are in relation to the additional roles they have adopted due to their partner's hearing loss and having to accommodate to the hearing loss (Scarinci et al., 2008). It is therefore perhaps unsurprising that effort and fatigue has been ranked highly by communication partners. An example of where effort and fatigue has been reported by communication partners in the context of the additional effort of having to repeat things to their partner *"It's an effort to repeat things over and over, talk more slowly, take care to be understood* (Hetu et al., 1994) and the additional effort in general of having to participate in a conversation (Hétu et al., 1993). In relation to hearing aid users, participation in conversation and even passive tasks such as listening are known to become effortful with hearing loss given the additional attentional resources needed in some situations. Thus, complaints pertaining to effort and fatigue in the literature often relat to auditory-related experiences such as listening or communicating (Vesterager et al., 1988, Hetu et al., 1993, Hetu et al., 1994, Hallam and Brooks, 1996). This also suggests that feelings of effort and fatigue occur often as a result of communicating and listening difficulties.

Some of the complaints given in the response to the open-ended question make reference to difficulty at specific social activities, such as the theatre, concerts

and the cinema. Such activities or social interactions generally are places where the acoustics are challenging and rely on optimal listening and communication skills. Since these are the primary factors affected by hearing loss, the overall enjoyment of the social activity is lessened. A lot of the complaints pertaining to communication from the hearing aid users and communication partners have been reported in relation to social events (Hidalgo et al., 2008, Jennings and Shawb, 2008, Scarinci et al., 2008, Manchaiah et al., 2013b, Ekberg et al., 2014, Heffernan et al., 2016). Both groups describe the communication as being a key issue, particularly at social events which could also provide rationale as to why these domains are ranked in this order. Similar to the domain "Effort and fatigue" this suggests that a lot of the social difficulties reported by people with hearing loss occur as a result of communication and listening difficulties. Furthermore, as identified in Chapter 2, the subdomain 'social withdrawal' received the highest number of complaints from people with hearing loss than any other subdomain in the framework, which again highlights the social implications of hearing loss as highly important to people with hearing loss and communication partners.

4.5.3. Comparison of ranked domains to the literature

Lormore and Stephens (1994) gave hearing loss patients an open-ended questionnaire which asked them to list the difficulties they have because of their hearing loss, in order of importance. The hearing-impaired (HI) patients' significant other (SO) was also given an open-ended questionnaire that asked them to list the difficulties their partner has due to hearing loss, in order of importance. Similarly to the number of domains in the DoHL frameworks, there were no significant differences in the number of problems listed by patients and their significant other. A total number of problems listed by patients and their significant other was 338 and 369, respectively. The patient responses were

grouped into major and minor categories. The major category represent where 20% or more of patients noted difficulty and the minor category. The most frequently occurring problems reported by both groups included ‘General conversation’ (HI- 49%, SO-46%), ‘Unspecified TV problems’ (HI-34%, SO-26%) and ‘TV needs to be loud’ (HI-17.4%, SO-32%). These categories are all aspects that fall within auditory-related domains of the DoHL-P that were ranked in the top three most important in the current study. A minor category reported by HI patients was ‘Speech in noise’ (11%) which compares to the ‘Listening’ domain ranked third by hearing aid users in the current study. In other aspects of where Lormore and Stephens (1994) findings compare to the current study findings include where the problem ‘Unaware of how loud they are speaking’ was not listed as a problem by any of the patients and the equivalent domain, ‘Speaking’ in DoHL-P was ranked least most important by hearing aid users. In DoHL-CP however, ‘Speaking’ was ranked third most important but only listed as a problem by 3% of SOs in the study conducted by Lormore and Stephens (1994).

In their study, Brooks et al. (2001) asked participants (hearing-impaired participants and their significant other) to rate the frequency of occurrence of hearing loss-related difficulties on a five-point scale as ‘Never’, ‘Occasionally’, ‘Sometimes’, ‘Often’ and ‘Always’. In addition to this, participants were asked questions about the emotional impact of the specific situation. The main themes that emerged from this study included person-to-person conversation, group conversations, and television viewing. The conversation domains fall within the ‘Communicating’ domains which was ranked most important by both perspectives. Brooks et al. (2001) also report that significant others report having to act as an intermediary for the hearing-impaired person which is captured in the DoHL-CP domain ‘Role of communication partner’, which was

ranked 9th by communication partners in the survey. The authors found that person-to-person conversation gave rise to the same level of self-assessed frustration and irritation to those experienced by hearing-impaired people. In their systematic review of studies that investigated the impact of hearing loss on communication partners, Kamil and Lin (2015) reported that the overall reported impact of hearing loss was restricted social life, increased burden of communication and relationship satisfaction. These themes compare to the overall domains ranking of DoHL–CP, where 'relationships' was ranked 5th by communication partner respondents.

In the MarkeTrak V series, hearing aid users were asked to describe in narrative form of their hearing aid experiences, particularly if they wore their hearing aids less than 1 hour a day (Kochkin, 2005). This received more than 1000 short letters from respondents; 348 were from hearing aid users who never wore their hearing aids. Following analysis of these letters, the authors identified 32 reasons why these respondents do not wear their hearing aids. The top 10 reasons included poor benefit received from hearing aids. The authors describe that respondents reported that hearing aids amplify sound, because they still could not understand speech. This reason compares the ranking findings in the current study, where in the first method of scoring communicating and listening is ranked 1st and 3rd, respectively. The second reason for non-usage of hearing aids stated by Kochkin and Rogin (2000) was issues concerning amplification of background noise. Again, this compares to those subdomains in 'Communicating' that depict various communication situations, including those where there is background noise or a group a people. Another reason derived from the MarkeTrak narratives is that respondents indicated that they don't need help with their hearing because they claim to be socially isolated. It is unclear whether this social isolation is due to hearing loss, but the domain

'Isolation' in the DoHL framework was ranked 6th by people with hearing loss. Further reasons for non-use demonstrated by the MarkeTrack survey results refer to technical issues of the hearing aids, the domain in the DoHL-P framework that capture these complaints is 'Interventions', ranked 10th by respondents.

Aside from the technical issues reported by the MarkeTrak respondents, a lot of the reasons for non-use of hearing aids align with the domains ranked in the current study. The mention of communicative, listening and poor benefit received from hearing aids compare to the argument presented in section 4.5.5 that states hearing aids alone cannot address all hearing loss-related difficulties. It also relates to how well audiologists manage the expectations of patients in regards to what hearing aids can and can't do. Given the improvements in technology from the shift of analogue to digital hearing aids, it was expected that uptake of hearing aids would increase. However, this has not been observed. The low incidence of hearing aid usage has been largely attributed to the stigma of hearing aids (McCormack and Fortnum, 2013), in the domains ranking survey however, "Stigma" was ranked 9th.

In addition to research into reasons for low-uptake of hearing aids, there has also been research into the non-use of hearing aid of hearing aid users. The general consensus among researchers as to why this may be the case is due to the negative experiences of hearing-impaired people with their hearing aids. The MarkeTrak data show that not only do 10.6% hearing aid users reported keeping their hearing aids 'in the drawer', but 62.3% of hearing aid users who wear their hearing aids are dissatisfied with their experience (Kochkin and Rogin, 2000).

Some domains reported in the qualitative literature that has investigated the impact of hearing loss on communication partners aligns with the domains ranked most important in the current survey. For example, in their interviews with the spouses of men with noise-induced hearing loss, a theme that emerged from the data was 'co-acting strategies' which is when the spouse co-acts in their husband's tactic of denying their hearing loss and fail to attribute the daily difficulties due to hearing loss. In the current study however, the domain 'stigma' which contains the subdomain 'denial' was ranked 10th. Another theme reported by Hallberg and Barrenas (1993) that emerged from the interviews was 'the impact of hearing loss on the intimate relationship' which is captured in the DoHL frameworks, and ranked 5th by communication partners.

4.5.4. Comparison of findings with focus group

The primary difference between the focus group study and this survey study, is that the focus group participants were only asked to share their experience of the domains, rather than to rank the domains in order of importance.

In the current survey study, all domains were ranked by respondents, indicating at the very least, the relevance of the domains ranked to the respondent's day-to-day lives. Whilst the purpose of the current study was for respondents to rank domains most important to them, it does not necessarily mean that domains ranked not as important should be ignored or discarded. The domain ranked least important in day-to-day life was 'Speaking' (0.0%) as none of the respondents ranked this domain as most important, and this domain received the highest number of respondents who ranked it as 'not applicable' (n=37). This was another interesting finding from the survey findings. In Chapter 1, there were 16 extracted complaints from the included studies pertaining to this domain. In Chapter 3, all of the hearing aid users in the focus group could relate 'Speaking'.

The two most highly discussed domains in the communication partner focus group was “Communicating” and “Role of communication partner”. All the participants within this focus group could relate to the all the subdomains contained within each of these domains. This compares with the survey study where the domain ‘Communicating’ was the highest ranked. A lot of the extracted complaints from the included studies relating to communicating and the discussions on this on the focus group were about communicating in different environments and/or in social settings. However, there were also a considerable number of complaints from hearing aid users relating to communicating with their spouse or communication partner specifically. This difficulty in communication reported by both perspectives also emphasises one of the gaps in current aural rehabilitation plans which involves counselling patients how to optimise listening with their hearing aids (Boothroyd, 2007, Abrams and Chisolm, 2013, Grenness et al., 2014a, Habanec and Kelly-Campbell, 2015). It could be that communication partners typically have higher expectations of hearing aids and communicate in a way that is not optimal for someone who wears hearing aids (Barker et al., 2017). It may also be that hearing aid users have higher expectations of their hearing aids or deem some communicative experiences, such as conversing on the telephone or watching television with their partner, more important than others.

Given the limitations of hearing aids, it is perhaps impossible to augment every listening and communicative experience for people with hearing loss. However, if there are particular situations that occur more frequently or are more important to a patient with hearing loss then these are potentially discussions to be had within a rehabilitation programme that incorporates counselling (Yorgason et al., 2010, Abrams and Chisolm, 2013, Manchaiah et al., 2013a). This is a component of rehabilitation that has been suggested by several researchers,

and one that aligns with the current impetus toward patient-centred care and identifying the individual needs of patients (Mead and Bower, 2000, Grenness et al., 2014a).

The results from this ranking survey also demonstrate that patients with hearing loss (and communication partners) are able to consider some aspects of their life that have been affected by hearing loss to be more important than others. Despite these findings however, which domains are most important may vary from individual to individual. If the emotional implications of hearing loss is considered most important to a patient diagnosed with hearing loss, then the provision of hearing aids alone are unlikely to address or capture this concern. This again highlights the need to consider the patient in a wider contact in order to extrapolate which domains are more important or applicable to the patient, as two patients with a similar audiogram may manifest very different problems (Boothroyd, 2007). Furthermore, given the progressive onset of hearing loss, there is potential that patients diagnosed with hearing loss are unaware of all the implications hearing loss has had on their lives. Including an additional perspective therefore, is likely to give a more complete clinical profile of the patient (Manchaiah et al., 2012, Manchaiah et al., 2015).

4.5.5. Implications for clinical practice

The findings strengthen the importance for research and clinical practice to ensure rehabilitation plans span the broader implications of hearing loss. There has been evidence to suggest that where patient have expressed concerns or psychosocial experiences after the recommendation for hearing aids, these concerns were not typically addressed during the appointment (Ekberg et al., 2014). Ekberg et al. (2014) found that audiologists tend to focus on providing technical support about hearing aids rather than responding to the emotional concerns shared by patients.

Over the last decade, there have been milestone advances in the design and signal-processing technology of hearing aids (Pichora-Fuller and Singh, 2006). Issues relating to the hearing aids themselves were not highly ranked in the domains list (Interventions= 0.5%). Despite these technological advancements, the research evidence for hearing aid benefit is mixed with users reporting significantly different levels of perceived benefit (Gatehouse, 1992, Gatehouse, 1993). Acclimatisation is however, typically measured using speech in noise tests which involves 'Listening' ability, a domain ranked third most important by hearing aid users. It cannot be assumed therefore that whilst amplification improves auditory function, that the carryover to other elements of rehabilitation, such as social participation and occupational life, will be either implicit or automatic (Boothroyd, 2007).

Therefore, there is a need for a holistic approach to adult aural rehabilitation that extends beyond sensory management (Boothroyd, 2007). Often clinicians are more inclined to focus rehabilitation on sensory management which may augment some of the deficits caused by hearing loss. However, as demonstrated by the domains ranked 5th (Effort and fatigue) and 6th (Isolation), are issues that extend beyond the auditory impairment itself are aspects also important to people with hearing loss. It is typical in clinical practice that when audiologists diagnose patients with hearing loss, they immediately move onto recommended hearing aids as the method of management (Boothroyd, 2007, Ekberg et al., 2014). On observation of audiological assessment appointments, Ekberg et al. (2014) found that once the audiologist told patients they have hearing loss, the patients did not have enough time to digest the news before the discussion moved forward to hearing aids.

Clinical behaviours relating to patient-centred care may be of particular importance when patients express emotional reactions to their hearing loss

(Ekberg et al., 2014). Pollak et al., 2007 states that empathy from health professionals may be considered as responses that directly address patient's emotions, validate their feelings, and further invite the patient to share more concerns and difficulties they may be having. A study conducted by Adams and colleagues (2012) found that discussions and responses that centred around the emotional aspects of the patients concerns, led to physician-patient alignment, and increased agreement about treatment plans.

As seen in Chapter 1, there is a considerable amount of evidence emerging on the communication partner's perspective on their difficulties and roles associated with their partner's hearing loss. However, there is very little research into the interaction between individuals and their communication partners, particularly during audiological appointments. Furthermore, whilst there is some research to explore the interaction between patients and audiologists during appointments, there has been no research that has explored the interaction between communication partners and audiologists.

Manchaiah and Stephens (2013b) promotes the use of open-ended questionnaires for use with communication partners as a way of trying to understand the experiences and concerns of communication partners. The authors also recommend the use of such questionnaires administered in a semi-structured interview to be useful in aural rehabilitation. Despite the role of communication partners in the life of a hearing-impaired individual, there is limited evidence to demonstrate their involvement in aural rehabilitation. There also currently has not been a structured approach suggested for involving communication partners in aural rehabilitation (Manchaiah et al., 2012).

A study found that those participants who went into rehabilitation with expectations for improvement in quality of life was a motivation factor to use

hearing aids, while those participants who perceived hearing aids as a stigma could either reduce or increase the barriers that to help-seeking hearing aids (Ekberg et al., 2014).

Given the pressures to overcome patient waiting lists, spending enough time with every patient and evaluating what concerns them about their hearing loss and discussing the options is not possible within the NHS. This could provide reason therefore that these other components of hearing loss are not routinely being considered could be due to limited time within appointments (Erdman, 2013). In the study conducted by Ekberg et al. the authors found that when patient's concerns are not addressed, the appointment can become longer because the patients are persistent in vocalising their concerns. Other researchers have also suggested a greater focus may need to be placed on patient-centred care, in particular psychosocial counselling (Rutman and Boisseau, 1995, Vuorialho et al., 2006a).

4.5.6. Strengths and limitations

To our knowledge, this study is the first to have asked individuals with hearing loss and communication partners to rank potential implications of hearing loss in order of importance to them. This study adds further verification of the domains within the hearing loss frameworks, as well as allows participants from the target population another opportunity to share experiences of living with hearing loss that may not be represented in the frameworks. The primary limitation of this study is the low-response rate of respondents for the communication partner version of the survey. The ranked domains for DoHL-P represents results from 210 respondents, whereas the ranked hearing aid user domains represents results from 48 respondents. The dissemination methods used are primarily mediums that contain or have subscriptions from people with

hearing loss only. This made targeting spouses and partners a much more challenging population to reach.

CHAPTER 5. THE PREFFERED LISTENING VOLUME OF HEARING AID USERS AND THEIR PARTNERS WHILST WATCHING TELEVISION

5.1. INTRODUCTION

This chapter reports the third study of the PhD research, which was a quantitative evaluation of preferred listening levels of hearing aid users and their partners whilst watching television.

The UK Time Use Survey 2000 describes leisure choices made by older people. People above 65 years old tend to spend more time doing sedate activities such as watching TV, reading and listening to music. The results of the survey showed that the amount of time spent watching TV per day increased as people got older (50-64, 150 minutes per day; 65-74, 190 minutes per day; 75 and over, 204 minutes per day) (Soule, 2005). This confirms watching television forms an integral part of older people's leisure time, particularly for those aged 65 and older.

Across the person with hearing loss and communication partner-reported domains (Chapter 2), there was considerable overlap across perspectives in term of the domains identified. For example, a domain present in both frameworks, "raising the volume of the television/radio" was frequently reported in the literature as being a problem due to hearing loss. From the person with hearing loss perspective, this was in relation to difficulties in hearing the television dialogue, thus having to raise the volume. From the communication partner perspective, this was in relation to the television being too loud due to their partner's hearing loss and constantly having to ask them to lower the volume.

A commonly reported complaint among people with hearing loss is an increased difficulty understanding speech in the presence of background noise (Stephens et al., 1990, Hetu et al., 1993, Hetu et al., 1995, Hass-Slavin et al., 2005, Jonsson and Hedelin, 2012, Ekberg et al., 2014). Given the high prevalence of hearing loss in the UK, this can be particularly challenging for broadcast audio content. National watchdog television organisations such Ofcom in the UK and the BBC often receive complaints from viewers with hearing loss, as well as from people with normal hearing, regarding the lack of intelligibility of certain television content (Shirley and Oldfield, 2015). Many of these complaints claim the difficulty to be attributed to background sounds, such as music that may mask the dialogue. Kochkin (2005) showed that approximately 25% of older hearing aid users do not report satisfaction with their hearing aids for television viewing. A later survey study conducted by the BBC in 2010 indicates that 60% of viewers had difficulty in understanding speech on television (VLV, 2011).

Several qualitative studies have identified difficulty viewing the television as being a reoccurring problem in studies that have investigated the impact of hearing loss on those with hearing loss and/or their communication partner (Stephens et al., 1990, Hétu et al., 1987, Hetu et al., 1995, Brooks et al., 2001, Tsuruoka et al., 2001, Hass-Slavin et al., 2005, Hallam et al., 2008, Hidalgo et al., 2008, Kelly and Atcherson, 2011, Scarinci et al., 2012). There are also numerous questionnaires that have been developed that tap into difficulties relating to the television due to hearing loss, such the Speech, Spatial and Qualities (SSQ) of Hearing questionnaire (Gatehouse and Noble, 2004) and the HHIE (Ventry and Weinstein, 1982).

Yet, there has been very little attempt to objectively measure the impact of hearing loss on television viewing. A study by Gordon-Salant and Callahan (2009) explored whether adults older adults with hearing loss show

improvements in understanding televised speech with the use of hearing aids and closed captioning compared to without these devices. the study conducted by Gordon-Salant and Callahan (2009) involved 12 hearing aid users. Participants watched three difference types of TV programmes including the news, drama and a gameshow that were edited into lists of speech segments, and provided an identification response. The authors found that participants shows a significant improvement in speech recognition scores in conditions with closed-captioning than those without closed captioning. Interestingly, the authors did not find a significant improvement in speech recognition of the television speech compared to the unaided condition, showing that participants still struggled with following the dialogue.

There has not been any research that has explored quantitative measures of preferred listening volume amongst individuals with hearing loss and their spouse/partners. This study therefore investigated the preferred listening volume for individuals with hearing loss and their spouse/partner. The study also assessed difficulty in self-reported difficulty listening and watching the television.

5.1.1. Aims and Objectives

5.1.1.1 Primary objective

1. To measure and relate the television volume set by participants across couples one of whom is a hearing aid user and the other is a spouse/partner.

5.1.1.2 Secondary Objectives

2. To measure and compare the television volume of participants across couples where one partner has set the television volume.

3. To identify self-reported television viewing habits for participants with hearing loss and their spouse/partners.

5.1.2. Design

A single centre, prospective case-control design. Participants were required to attend the research site for a single visit.

5.1.3. Ethical approval

The study received favourable opinion from the University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee on 16th October 2016. Ethics reference number: F14102016.

5.1.4. Setting

All testing was conducted at the Nottingham BRC (hearing section).

5.1.5. Sample size estimate

Given that there has been very little research conducted into the impact of hearing loss on television viewing, there was no previous data on which a sample size calculation could be made. The range of sample size from the studies included in the review (Chapter 2) was six to 4266 with a median of 63. These studies were a mixture of study designs. A target sample size of up to 50 couples (100 participants) therefore seemed reasonable for the current study. Given that there are no previous studies for a sample size to be calculated, it was decided to have a sample size above the median of sample size of the included studies in Chapter 2.

5.1.6. Duration of study

Participant recruitment commenced in December and recruitment closed in April 2017.

5.1.7. Recruitment

5.1.7.1 The Nottingham BRC (hearing) participant database

The primary method of recruitment was via the BRC (hearing) participant database. The sampling strategy that was used was convenience sampling. Members of the database that were potentially eligible (such as documented hearing aid users) for participation in the study were contacted via email or post. The PIS was emailed/posted to members of the database. This ensured all participants had at least 24 hours to read and consider the study information. Those participants who expressed an interest in taking part were screened via telephone or email to determine eligibility.

5.1.7.2 Social Media

The study was also advertised via the team's social media forums such as the Facebook and Twitter websites, and the research site's website. VV also spoke about recruitment for the study during an interview on BBC Radio Nottingham.

5.1.8. Inclusion and Exclusion Criteria

Participants who were eligible to take part were hearing aid users as well as their spouse or partner. The specific inclusion criteria was:

5.1.8.1 Inclusion criteria: Hearing aid users

1. Ability to give informed consent
2. Hearing aid user (monaural or binaural)
3. First language is English or has a good understanding of English (TV clips comprised of English words and sentences)
4. Ability to view television clips on a television screen (wearing glasses is okay)
5. Aged ≥18 years (no upper age limit)

6. Mild-to-severe hearing loss (average hearing threshold 20-95 dB HL across frequencies 0.25-4kHz (BSA, 2011). There was no restriction on the type of hearing loss. That is, participants were eligible if they had a sensorineural, conductive or mixed hearing loss. The audiogram configuration for a sensorineural hearing loss was where there was no difference in air-conduction and bone-conduction thresholds at any given frequency (≤5 dB). The audiogram configuration for a conductive hearing loss was where there was a ≥15 dB air-bone gap at three or more consecutive frequencies. The audiogram for a mixed hearing loss was where there was an air-bone gap at two consecutive frequencies.

5.1.8.2 Spouse/Partner

1. Ability to give informed consent
2. Is the spouse or partner of a hearing aid user
3. First language is English or has a good understanding of English (TV clips consists of English words and sentences)
4. Able to view TV clips on a screen (wearing glasses is okay)

5.1.8.3 Exclusion criteria

1. Inability to communicate using spoken language
2. Participants who did not have a spouse/partner

5.1.9. Participant Screening

Participants who expressed an interest in taking part in the study (by email, telephone or return of the postal reply slip) were screened for eligibility. There were some participants who expressed an interest but were not eligible to take part. The breakdown of participant interest in the study is summarised in Table 5.1. Those that met eligibility were booked in for the test session.

Table 5.1 Breakdown of participant recruitment

Participants contacted	**n**
BRC database: Emailed	Approx. 800
BRC database: Postal	Approx. 100
Participants recruited	
BRC database	39
Press release/radio	2
Other	1
Participants screened	
Eligible couples	44
Did not have a spouse/partner	9
Both partners are hearing aid user(s)	2
Other	3
Eligible participants	
Participants booked	46
Participants who did not attend	2
Participant who attended alone	2

Participants on the BRC database were emailed in batches of 100 to allow for participant interest to be managed adequately. The primary reasons for participants not meeting the requirements for inclusion at the screening stage were due to participants not having a spouse or partner, or cases where both partners in couple were hearing aid users. In total, 46 couples passed the screening stage and were booked in for a test session. Of these, two couples cancelled their session due to illness and the other two couples were not included in the study as the hearing aid user in each couple attended without their partner. Thus, the final sample that was analysed was 42 couples (84 participants).

5.1.10. Participation incentives

All consented participants were offered an inconvenience allowance of £10 each and travel expenses up to £15 were reimbursed per couple.

5.2. MATERIALS

5.2.1. Television Clips

All participants were presented with a series of 12 clips from six different TV programmes (Table 5.2). The duration of each clip was 1.5 minutes. The TV clips were taken from British TV programmes and were presented via a 28-inch LG LED television Model: 28MT48DF. The in-built speakers of the television were used to present the audio of the clips.

5.2.1.1 Selection of TV Clips

It was important that the clips used for this study varied in terms of their visual and acoustical content to represent the difference listening situations depicted in the "Listening" subdomains of in the domains of hearing loss framework in Chapter 2 .

In total six different TV programmes were selected, comprising different TV genres: a documentary, soap, drama, lifestyle, chat show and weather forecast programme.

The TV clips were edited in Windows Movie Maker and shortened to a duration of 1.5 minutes each. An introductory frame containing the clip name (e.g. Clip 1 – Weather forecast) was created for each clip as well as a frame at the end of the clip with a multiple choice question. The final clips were presented as windows media player files. Unsurprisingly, the clips all varied in terms of their visual and spectral content. The overall spectra for the *Weather forecast* (Clip 1a), *Wildlife documentary* (Clip 4a), and the *Live comedy* (Clip 5a) is shown in Figure 5.1, Figure 5.2, and Figure 5.3 respectively. These figures demonstrate the diversity of the frequency and temporal characteristics of the clips. The overall spectra for the remaining clips is in Appendix 8.3.

5.2.2. Domains of Hearing Loss Survey

Hearing aid user and communication partner participants were asked to complete the domains ranking exercise. Details of the surveys created by VV are outlined in Chapter 3.

Table 5.2 Summary of television clips presented to all participants

TV Programme	Clip Part A	Clip Part B	Number of speakers	Competing sound	Visual speaker	Number of scenes	Gender of speaker(s)	"Listening" subdomain
Weather forecast	1a	1b	1	Quiet	Speaker is always visible	1	Female	Listening in quiet environments
Cooking show	2a	2b	4	Competing speaker & background noise	Speaker is sometimes visible	1	Male/female	Listening to speech in group of talkers
Soap/drama	3a	3b	6	Competing speaker and background noise	Speaker is mostly visible	3	Male/female	Listening in public places
Wildlife documentary	4a	4b	1	Background noise	Speaker is not visible	1	Male	Listening to speech (unfamiliar speakers)
Daytime talk show	5a	5b	3	Competing speaker	Speaker is mostly visible	1	Male/female	Listening to speech (speech in general)
Live comedy	6a	6b	1	Background laughter	Speaker is mostly visible	1	Male	Listening in a noisy environment

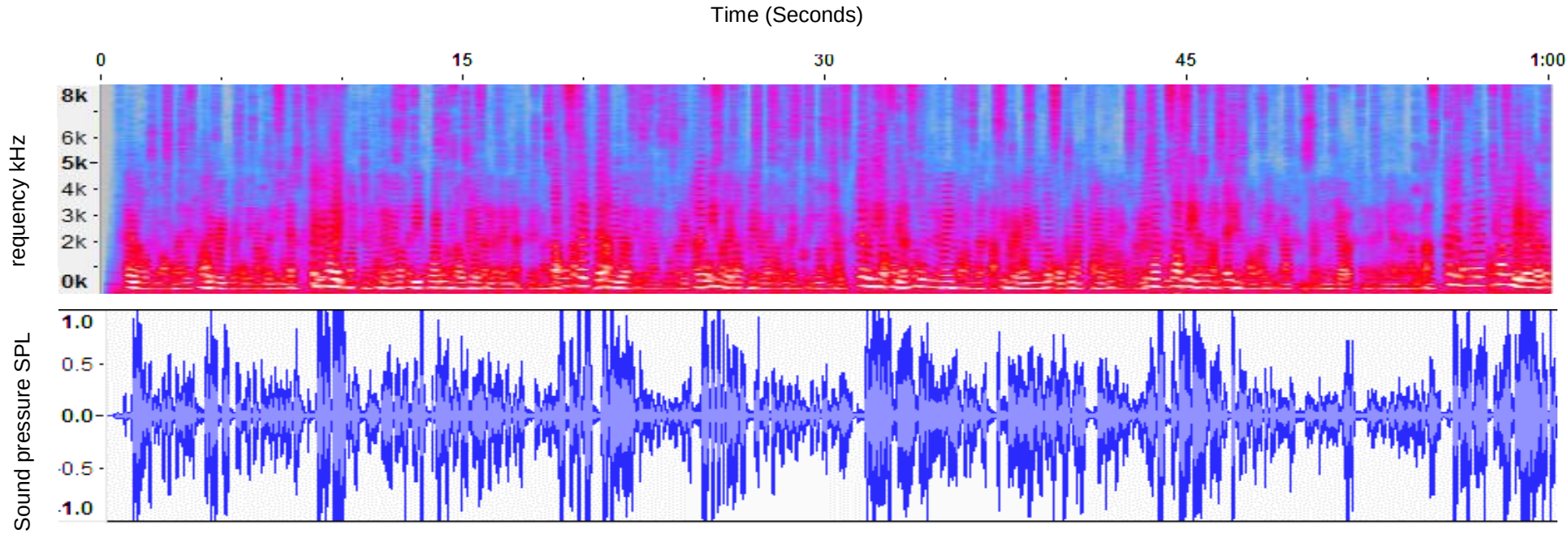


Figure 5.1 Frequency spectra for Weather forecast (clip 1a).

Taken from first minute of clip. Second graph shows waveform of same interval of clip

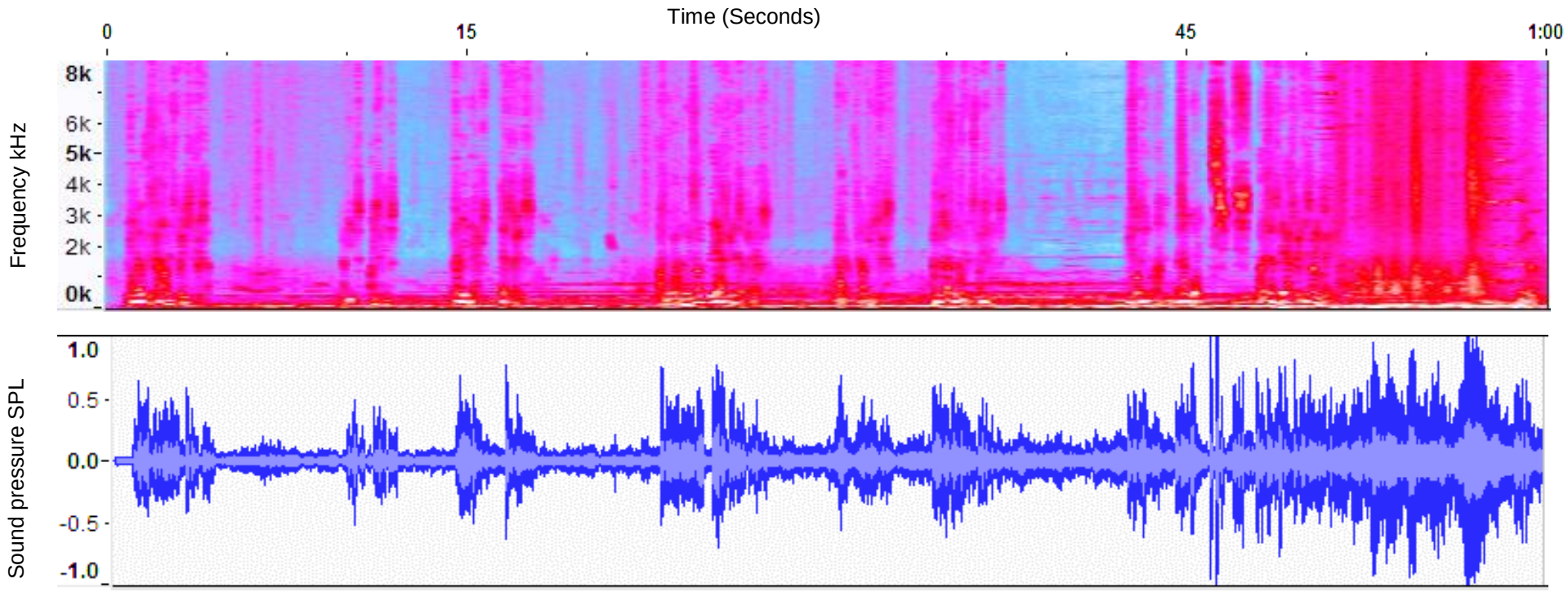


Figure 5.2 Frequency spectra for wildlife documentary (clip 4a).

Taken from first minute of clip. Second graph shows waveform of same interval of clip

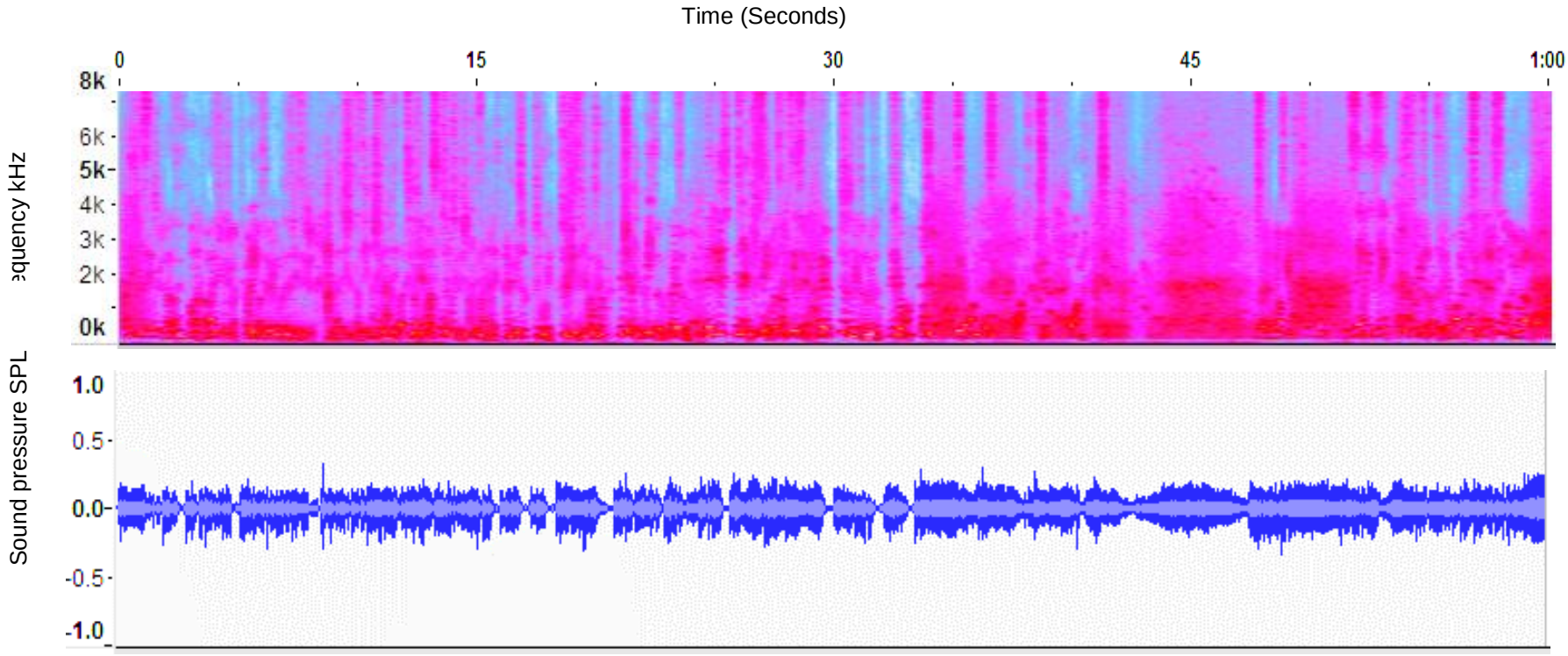


Figure 5.3 Frequency spectra for Live Comedy (Clip 5a).

Taken from first minute of clip. Second graph shows waveform of same interval of clip

The spectrogram is a spectro-temporal representation of the sound of the TV clips. These figures were created in the programme Audacity using the sound wave files (.wav) of the TV clips. The time scale of the spectrogram is the same as that of the waveform below each spectrogram in the figures. The red parts of the spectrogram represent higher energy densities, the lighter (pale/blue areas) represent lower energy densities. For the weather forecast clip (Figure 5.1), the energy density is relatively constant throughout the clip. For the wildlife documentary (Figure 5.2) the highest energy density for that clip is contained around the last 15 seconds of the clip. Both waveforms are complex and variable because they reflect the variety of vowels and consonants in the speech, as well as the dynamic nature of speech articulation. The sound pressure level of the weather forecast is relatively constant throughout as the clip contains one speaker only. The amplitude of the sound pressure for the wildlife documentary on the other hand rises dramatically in the last 45 seconds of the clip. This corresponds to the switch from the background music to the main audio of the clip. Throughout this waveform, there are brief moments of quieter intervals, which reflects moments when the male narrator stops speaking and there is some background noise/music. For the live comedy clip (Figure 5.3), the sound pressure level is low, but steady throughout the clip. This clip contains a high frequency energy density throughout the clip as shown by the spectrogram.

5.2.3. Television Viewing Experience Surveys

All participants completed a survey that tapped into their general TV viewing habits. Two surveys were developed that tapped into general television viewing habits. The first survey was targeted at hearing aid users and the second was developed for their partners. Both surveys were developed to explore (1) Demographic information from participants, (2) Self-reported hearing aid usage,

(3) Self-reported television viewing, and (4) Television viewing difficulty. The second survey was targeted at spouse/partners (non-hearing aid users). This survey was developed to explore (1) Demographic information from participants and (2) Perception of spouse/partner's hearing difficulty whilst watching television. Full details of the survey development are available in Chapter 6.

The surveys were piloted in two stages. First, the survey was piloted by lay members from PPI steering group for ease of language understanding. Second, the surveys were piloted by hearing aid users to assure functionality and user-friendliness.

5.3. EQUIPMENT SET-UP

5.3.1. Sound booth

Pure-tone audiometry was conducted with the participant seated in a sound-proofed booth. The tester performed audiometry from an observation room.

5.3.2. Test room

The television in the test room was connected to a laptop in the observation room via a HDMI cable in a split-screen set-up. This enabled VV to present the clips from the observation room. An armchair for participants was situated directly opposite the television on the other side of the room at a distance of 2.0m (Figure 5.4). The sound level meter was located next to the armchair at a height of 0.9m. The sound level meter was also connected to the laptop in the observation room.

A sound level meter (Brüel & Kjaer Type: 2250-S hand-held analyser) was situated next to the participant on a tripod.

5.3.3. Observation room

The clips were presented from the TV via the laptop. The participant and the TV could be seen by VV through a window in between the two rooms. The sound level meter interface was also displayed on the laptop so that VV was able to control the sound level meter remotely. A microphone was situated above the participant in the test room to enable communication between VV and the participant. There was also a microphone in the observation room connected to the television should VV need to communicate with the participant. The set-up in the test room and observation room is depicted in Figure 5.5. The study set-up in the test room remained consistent throughout the testing phase of the study. To ensure that the equipment lay-out such as the sound level meter and television remained in the same place, the floor was marked to guide the positioning of the equipment.



Figure 5.4 Photo of test room set up

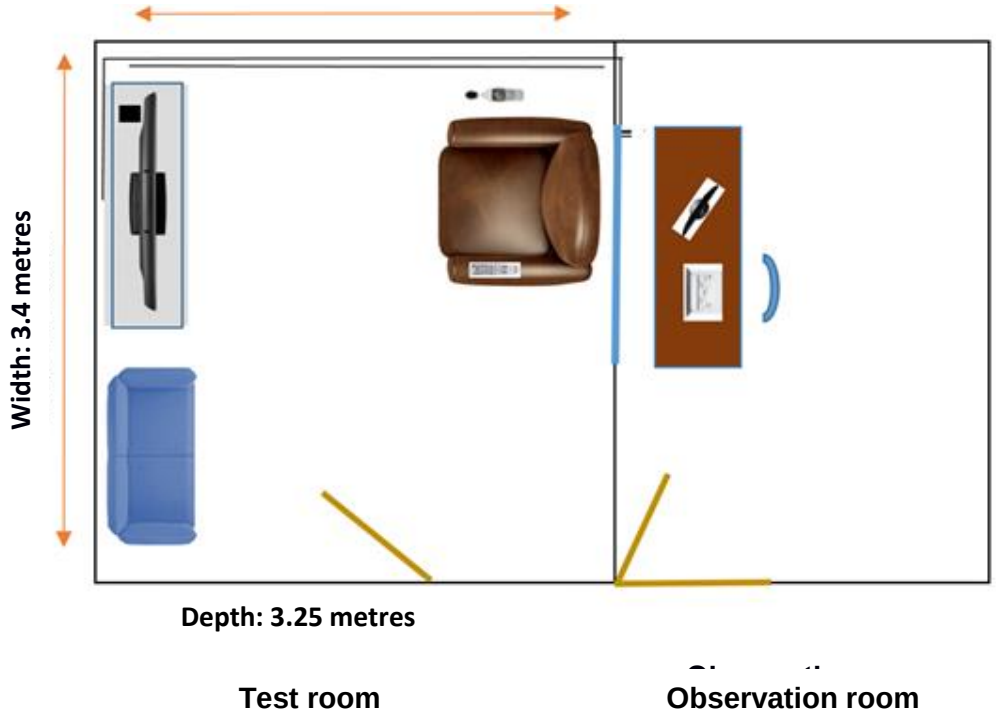


Figure 5.5 Diagram of study set-up in test room and observation room (to scale)

5.3.4. Calibration

Daily calibration was performed on the audiometer according to stage A checks as stated in the BSA procedure (BSA, 2011a).

Calibration was also conducted daily on the sound level meter. A transducer was connected to the sound level meter and a tone of 90 dB SPL was transmitted through it to ensure the sound level meter measured the correct sound level.

There was a mismatch in transducer type used to measure the sound level and the transducer selected in the sound level meter software throughout the testing period. The transducer that was used has the same sensitivity as the transducer that should have been used but requires external polarisation. The difference therefore between the two transducers is 15 dB which is a fixed effect.

Therefore, 15 dB was added to all of the sound level meter recordings once testing was complete.

The ambient noise in the test room was measured prior to every testing session. The mean ambient noise as measured in the test room across all sessions was 35 dB (A).

5.4. PROCEDURE

All testing was completed by VV. Since a couple (2 participants) attended each session, the session was coordinated so that only one participant was tested at a time (apart from the second television viewing task that required both participants together). A summary of the session agenda is outlined in Figure 5.6. Pure-tone audiometry was conducted in a sound-proofed booth. The TV listening task was conducted in a purposely-designed test-room. During the TV task, VV presented the stimuli from the observation room (Figure 5.5).

The study regimen for every couple was as follows:

5.4.1. Informed consent

The procedures did not take place during usual care and were considered additional for the purpose of research. Therefore, informed consent was required. At the start of the session, VV briefed the couple on the purpose of the research and the itinerary for the session. The information provided reiterated what was stated in the PIS (Appendix 8.3.5). The participants were then given the opportunity to ask questions. Once any questions had been addressed the participants were asked to sign a consent form (Appendix 8.3.6) which outlined the conditions of participation in the study. The hearing aid users and partners each had a copy of the consent form to sign. The original consent form was retained in the trial master file for the study and a copy of the signed consent form was given to each participant.

5.4.2. Pure-Tone Audiometry

Full pure-tone audiometry (0.25 – 8 kHz including octave frequencies) was performed on all participants according to the standards outlined in (BSA, 2011a). Masking was performed where required. Audiometry was conducted using a Siemens Unity 2 audiometer and Sennhieser HDA200 headphones.

The hearing aid user's hearing was tested first. Prior to performing audiometry VV obtained demographic information from the hearing aid user: (i) date of birth (ii) gender. Information was also obtained regarding their hearing loss: (iii) monaural or binaural hearing aid user (iv) duration of hearing aid use (v) aetiology (if known) (vi) experience of bothersome tinnitus. Information specific to their hearing aid(s) was also obtained: (vii) brand (viii) type of mould.

Audiometric tests comprised an otoscopic examination, air-conduction, bone-conduction and masking. Masking was only conducted as specified in the BSA recommended procedures for pure-tone audiometry. Rule 1 masking was performed only where there was a difference of 40dB between air-conduction thresholds at a given frequency. Rule 2 masking was performed where there was a 10dB aid-bone gap at any given frequency.

VV also obtained demographic information from the partner (i) age (ii) gender. The same audiometric tests were performed.

5.4.3. Uncomfortable Loudness Levels

Testing was conducted according to the BSA recommended procedure for determining uncomfortable loudness levels (BSA, 2011b). The participants were informed that the sounds presented through the headphones would gradually become louder and they were instructed to press the button as soon as the sound became uncomfortably loud. It was stressed to participants that the aim of the test was not to find the loudest sound that they could tolerate, but

a test to find what level of sound they felt uncomfortable. Pure tones were presented at 60 dB HL or at the participant's hearing threshold level for that ear at that frequency, whichever was highest. The stimulus was increased by 5 dB until the participant pressed the button. The frequencies that were tested were 0.5, 1, 2 and 4 kHz.

ULLs were not conducted on participants who presented with severe-profound (≥70dB HL) air-conduction thresholds at three or more consecutive frequencies.

Once audiometry had been performed on both participants, the partner was offered a short break whilst the hearing aid user completed the television listening task with VV in the test room.

5.4.4. Hearing aid listening check

A simple hearing aid listening check was carried out on all hearing aids using a stethoclip to ensure adequate function of the hearing aid. A stethoclip was used by attaching a hearing aid to it to listen for intermittence of the hearing aid as verbal sound was transmitted through it.

5.4.5. Surveys

Whilst one participant was having their hearing tested, the other participant completed a series of short surveys. For the hearing aid users these included:

- The Television Viewing Experience Survey (person with hearing loss version)
- Domains of Hearing Loss survey (person with hearing loss version)

For partners these included:

- The Television Viewing Experience Survey (communication partner version)

- Domains of Hearing Loss survey (communication partner version)

5.4.6. Television Listening Task

The participant was seated on an armchair in front of the TV in a quiet, purposely-designed test room. Prior to commencing the television listening task, the participants were given a simple visual task to complete. A series of three short sentences appeared each appeared on the screen one at a time, and the participant was instructed to read out the sentence aloud whilst seated on the armchair. This was to ensure the participants had adequate vision to view the text that would appear on the screen later on in the task. All participants passed the vision test. If any had failed, VV would have read out the text on the screen to the participant.

The participant was presented with a series of 12 short, television clips. Hearing aid users were required to wear their hearing aid(s) for this task. Each television clip commenced at an inaudible volume (volume setting 0 on the television). Participants were instructed to increase the volume of the clip using the remote control to a volume they felt comfortable to listen to. They also had the option to decrease the volume if they thought they set the volume too loud. Once the participant had set the volume to a level they were comfortable to listen at, they were instructed to press a reference button on the remote control to confirm their volume selection. As soon as the participant had confirmed their selection, VV commenced the recording function on the sound level meter for a 30-second time period. The sound level meter measured three (A-weighted) components across the 30-second time period: the minimum sound level (LAmin), the maximum sound level (LAmax) and the mean sound level LAeq (dB SPL). The recording of interest that was noted down for each clip was the mean sound level (LAeq). Once the sound level measurement was complete, the clip continued until the end at the participant's selected volume.

At the end of each clip, a simple multiple choice question appeared on the screen. The participant was instructed to say their answer which was picked up by the microphone on the ceiling directly above the participant. This microphone was connected to the laptop in the observation room where VV was able to hear participant's responses through headphones. The purpose of the questions served as a simple recall task to encourage the participant to try to listen to the content of the clips rather than to set the television to a volume they could hear the audio. An example of the recall question includes "Michael jokes about an eye test"; the response options include "true, false or I don't know." A full list of the questions is given in Appendix 8.3.5. The participants were also instructed to say any comments they had about the volume they had just set, for example if they would have preferred to set the volume louder than what they did. VV noted down any comments made and also used this time to set the volume of the television back to zero using a second remote in the observation room.

The next TV clip was then played and the process repeated for the remaining 11 clips. Once the hearing aid user had completed the television task, they were offered a short break and their partner completed the same task in the test room. The order of presentation of the clips was randomised for each participant to minimise any order effects.

5.4.7. Television task – Hearing aid user and Partner

After the hearing aid user and their partner had both completed the television task, each couple was required to view and set the volume of an additional clip together. The clip was another segment of a television programme they had viewed in the previous task (Clip 3). One participant (either the hearing aid user or their partner/spouse) was instructed to set the volume of the clip to his or her preference, without taking into consideration the potential volume preference of their partner. Control over the remote as to who would set the volume was

randomised. Of the 42 couples therefore, forty-two hearing aid users and forty-two partners were given control of the remote. The participant who was allocated control of the remote was seated in the same armchair directly opposite the television. The other participant was seated on another chair directly next to their partner.

The participants were instructed not to speak to each other during the clip as this could influence the sound level meter measurement. Again, the clip commenced at a volume setting of zero on the television and the participant was required to increase the volume to their preference and press the reference button to log their preference. As soon as they had logged their volume preference the sound level was then recorded for a 30-second interval. The clip continued then to the end at the participant's volume setting. Once completed, VV then when back into the test room and asked the partner who did not have control of the remote as to whether they would have set the volume any differently to their partner if they had been given the opportunity.

VV also asked the couple questions regarding the television set-up at home in relation to the set up in the test room, including:

- The location of the television in relation to where the couple typically sit e.g. Forward-facing or at an angle.
- The distance of the television from where the couple are typically sat.
- The size of the room where the couple predominantly watch television in relation to the size of the test room.
- The self-reported ambient noise of the primary television room at home in relation to the test room.

Once discussion was completed the test session was drawn to a close. Participants were then offered travel and inconvenience expenses. The entire test session for each couple lasted approximately two hours.

5.5. PILOTING

The study set-up was piloted by VV. The subsequent changes as a result of piloting included:

- The duration of each of the clips was shortened from 3-minutes each to 1.5 minutes. Each of the clips was split into two 1.5 minute clips.
- The placement of the sound level meter was relocated to the side of the participant seating as oppose to behind the participant.
- The sound level recording interval was altered from the entire duration of the clip to when the participant presses the reference button on the remote to log their volume preference.

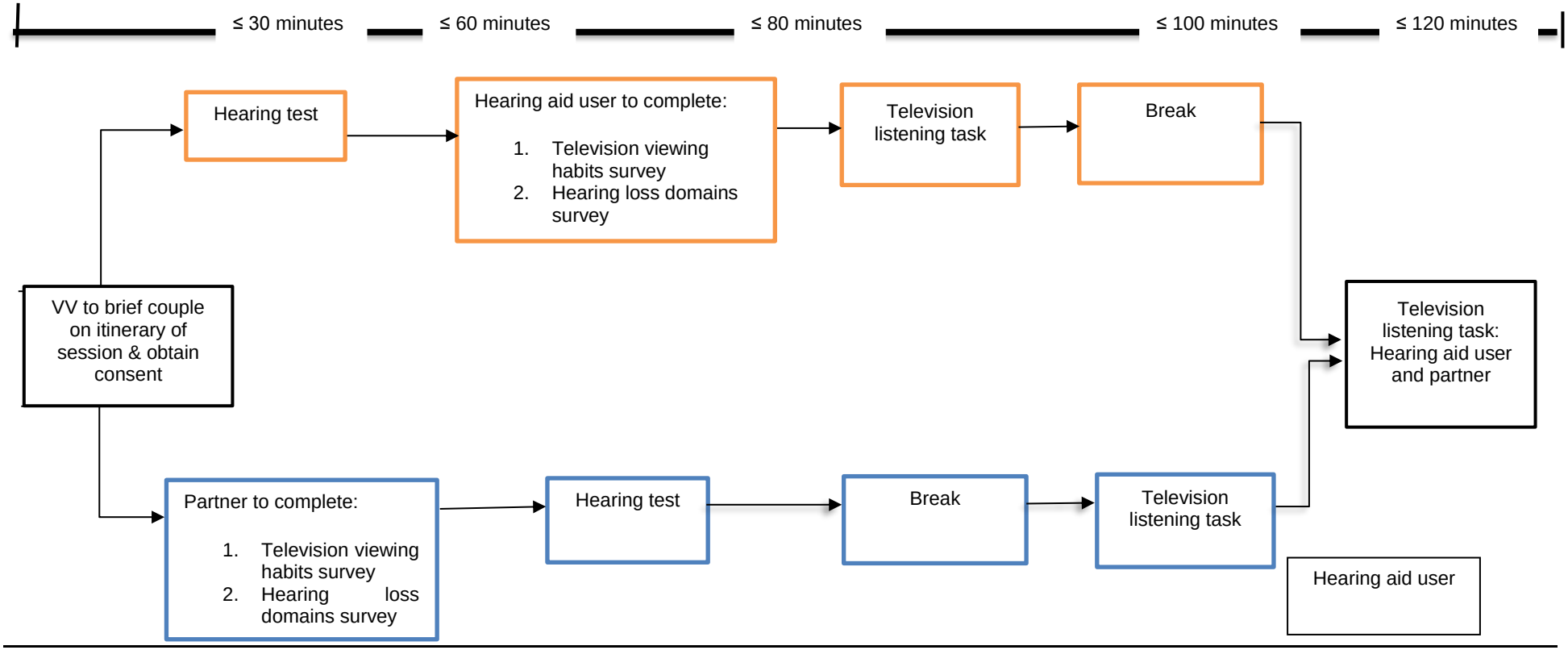


Figure 5.6 Flow diagram summarising itinerary of test session

5.6. ANALYSES

5.6.1. Primary Objective

To measure and relate the television volume set by participants across couples one of whom is a hearing aid user and the other is a partner.

5.6.1.1 Tests of normality

Parametric statistics were calculated because the mean (LAeq) sound level data from the participants were normally distributed following visual inspection of the histogram and calculation of kurtosis tests of normality:

Distribution of scores: (skewness-SE Mean)/kurtosis SE Mean.

(1.038-0.2057)/0.154 = -0.52857

Value is less than 1.96 therefore it is non-significant and is close to zero, which indicated data was likely to be normally distributed (Field, 2013).

The study design included both within-subject factors (TV clip and couple) and one between-subject factor (group). To address the primary objective therefore, analysis was conducted using mean sound level data for individual (12) clips within a general linear model.

5.6.1.2 Analysis of Covariance

Two sound level data items were missing from the dataset from two participants. Data was entered for these items based on the mean sound level for the other clips for the each participant. An analysis of covariance model was specified with a “within-subjects” factor (12 clips), and one “between-subjects” factor (two groups) and the dependant variable was mean sound level. To compare the sound level means for both groups whilst adjusting for the effects of age, PTA-average, gender and employment status, these factors were added as

covariates to the model. Age was added to the model as a covariate because hearing loss is known to decline with age (Arehart et al., 2013, Yamasoba et al., 2013, King et al., 2014). This was pertinent to the current study given the minimum age participants could take part was 18 years old and there was no upper age limit. PTA-average was added as a covariate because there was no restriction on participants' severity of hearing loss. Therefore, if a hearing aid user presented with a mild hearing loss then their preferred TV volume may have differed to someone with a moderate-severe hearing loss. Lastly, gender was added to the model as a covariate as the male gender is associated with an increasing risk of hearing loss (Cruickshanks et al., 1998, Gopinath et al., 2009, Lin et al., 2011, Nash et al., 2011). Aparício (2017) also found a significant association between gender and audiogram configuration.

5.6.2. Secondary objectives

To measure and compare the television sound level of participants across couples where one partner has set the television volume.

The dependent variable of interest was also the mean sound level data, recorded for one participant per couple. For this secondary objective, the design included one within-subject factor (42 couples) and one between-subject factor (2 groups). The TV clips were not considered a within-subject factor here since all participants randomised to have control of the remote viewed the same clip. The general linear model was also applied to this objective.

5.6.3. Exploratory Objective

To identify self-reported television viewing habits for participants with hearing loss and their spouse/partners. Dependent variables of interest here were the survey responses which were analysed using descriptive statistics.

5.7. RESULTS

In this section, the participant characteristics of those individuals who took part in this study will be described first. This includes information pertaining to demographics, hearing loss and hearing aid usage. The hearing aid user group will be described first followed by the spouse/partner group. Results pertaining to the primary objective of the study will then be explained followed by results for the secondary objective.

Forty-two couples, comprising of 42 hearing aid users and 42 non-hearing aid users took part in the study. This gave a total sample size of 84 participants. All couples lived with each other in the UK and forty couples were married. Interim-analysis was conducted during the trial. A mixed-model ANOVA conducted on 12 couples and then 35 couples showed consistent and robust findings. Recruitment therefore terminated at 42 couples.

All the couples were heterosexual which meant that there were an equal number of male and female participants (Table 5.3). The overall mean age was 67 years (SD=9.34).

Table 5.3 Demographic information of all study participants

	Hearing aid user	**Spouse/Partner**	**Overall**
Gender			
Male	20	19	42
Female	22	23	42
Age (years)			
Mean	67	67	67
SD	9.15	9.44	9.34
Range	38-86	34-80	34-86
Median	70	69	69

5.7.1. Participants

5.7.1.1 Hearing aid users

Of the 42 participants in the hearing aid user group, the number females in this group was 22 and the number of males was 20. The mean age of the participants was 66.98 years (SD=9.15) (Table 5.4).

Table 5.4 General audiological history of all study participants

	Hearing aid user	**Spouse/Partner**
Hearing loss aetiology		
Age-related	30	25
Congenital	2	0
Trauma	2	0
Infection	6	0
Unknown	2	1
Not applicable	0	16
Tinnitus		
Yes	17	2
No	25	40
Hearing loss type		
Sensorineural	30	25
Conductive	10	1
Mixed	2	0
Normal	0	16
Hearing loss configuration		
Bilateral	25	
Asymmetrical	2	
Unilateral	1	
Otoscopy		
Normal	42	42

Table 5.5 Summary of hearing aid information of hearing aid user group

Hearing aid usage	**n (years)**
Mean	10.36
SD	11.23
Range	0.1-45
Median	6.00
Hearing aid prescription	**n**
Monaural	8
Bilateral	34
Hearing aid make	**n**
Phonak nathos micro	19
Oticon spirit zest	14
Other	9
Hearing aid fitting	**n**
Open-fit	15
Skeleton mould	20
Full mould	6
In-the-ear	1
Hearing aid issue	**n**
National Health Service	41
Private	1

This group were predominately binaural hearing aid users, with a total of 34 participants wearing two hearing aids. Since all of the participants were local to Nottingham apart from one couple, the model of the hearing aids were mainly part of the Phonak and Oticon range which are typically issued by audiology services within Nottingham University Hospitals NHS Trust. One of the hearing aid users had privately issued hearing aids. The breakdown of the type and fitting of hearing aids in this sample group are given in Table 5.5. The daily usage of hearing aids was obtained by self-report from the participants. Thirty-two participants reported using their hearing aids all day (Table 5.6).

Table 5.6 Self-reported daily hearing aid usage

Daily Hearing Aid Use	n
Less than 1 hour	0
1 to 3 hours	2
2 to 5 hours	3
More than 5 hours	5
All day	32

5.7.1.2 Spouse/partners

Of the 42 participants in the non-hearing aid user group, the number of females in this group was 23 and the number of males was 19. The mean age of the participants was 67 years (SD=9.44). None of the participants in this group had ever been issued with hearing aids.

5.7.2. Audiometry

5.7.2.1 Hearing aid users

All participants in the hearing aid user group presented with a normal otoscopic examination. As expected, the most typical presentation of hearing loss was sensorineural (n=30). The number of participants with a conductive hearing loss was 10 participants. The remaining two participants in this group presented with a mixed hearing loss.

The mean pure-tone average threshold across 0.25-8kHz was (L) 53 dB HL (SD=28.8) and (R) 53 dB HL (SD=25.5). According to the hearing loss levels stated in the BSA procedures, this constitutes a moderate hearing loss. The summary of the level and type of hearing loss of participants in this group in given in Table 5.7.

Table 5.7 Summary of audiometric data for all study participants

	Hearing aid user		Spouse/partner	
Air-Conduction hearing thresholds	**L (dB HL)**	**R (dB HL)**	**L (dB HL)**	**R (dB HL)**
Mean	52.9	52.8	24.8	23.1
SD	28.8	25.5	22.4	19.8
Median	55.0	55.0	15.0	15.0
Range	0-115	0-115	-5-95	-5-100
Uncomfortable Loudness Levels	**L (dB HL)**	**R (dB HL)**	**L (dB HL)**	**R (dB HL)**
Mean	92.1	95.1	87.8	90.3
SD	11.5	12.7	12.2	12.6
Median	90.0	95.0	85.0	90.0
Range	70-115	70-115	60-115	60-115

Of the 17 hearing aid users who reported experiencing tinnitus, two participants reported that their tinnitus was bothersome.

5.7.2.2 Spouse/partners

All participants in this group self-reported normal hearing. All participants in this group presented with a normal otoscopic examination. The mean pure-tone average threshold across 0.25-8kHz in both ears was (L) 23.1 dB HL (SD=22.4) and (R) 23.1 dB HL (SD=19.8). On examination of the audiogram configuration of participants in this group, 36 presented with normal hearing thresholds in the low-mid frequency range (0.25-3kHz) and a mild hearing loss in the high frequency range (6-8kHz). The summary of the level and type of hearing loss of participants in this group in given in Table 5.4. An audiometric profile illustrating the mean hearing thresholds for each group is given in Figure 5.7.

Post-hoc t-tests of average hearing thresholds demonstrated a significant difference between groups t (38) = 2.855, p=0.001. The mean audiometric thresholds for the hearing aid user group was 53.4dB HL (SD=17.56) and for the partner group was 23.1dB HL (SD=12.94).

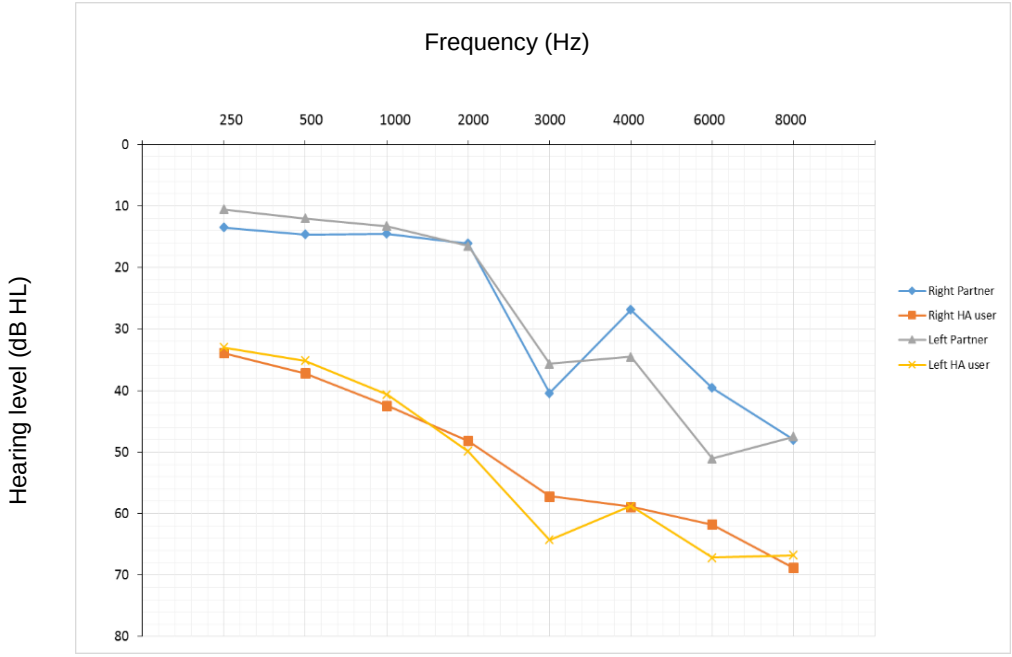


Figure 5.7 The audiometric profile of the mean air-conduction thresholds for the hearing aid user group and spouse/partner group

5.7.3. Uncomfortable loudness levels

5.7.3.1 Hearing aid user

ULLs were not measured in three participants. The hearing thresholds of two hearing aid users was deemed too severe for ULLs to be measured. Due to the self-reported severity of tinnitus of one other hearing user, it was inappropriate to subject the participant to such elevated levels of sound. The mean ULL threshold for the remaining participants in the hearing aid user group was (L) 92.1 dB HL (SD=11.5) and (R) 95.1 dB HL (SD=12.7) (Table 5.4).

5.7.3.2 Spouse/partner

ULLs were measured in all participants in the partner group. The mean ULL threshold for the remaining hearing aid user group was (L) 87.8 dB HL (SD=12.2) and (R) 90.3 dB HL (SD=12.6) (Table 5.4).

A paired t-test showed the difference in ULLs between the hearing aid users and partner not to be statistically significant: *t* (36) = 1.859, p>0.0005.

5.7.4. Television Viewing Task

5.7.4.1 Primary Objective

To measure and compare the television volume of participants across couples one of whom is a hearing aid user and the other is a partner.

The primary purpose of the ANCOVA model was to explore if there was a difference between the hearing aid users in terms of preferred TV sound level. The ANCOVA model was adjusted for the covariate groups (PTA-average, age and gender) on the mean sound level. The mean sound level for the hearing aid user group was 6.3dB more than the mean sound level for the spouse/partner group. Pairwise comparisons with a Bonferroni correction showed a significant difference in mean sound level between the hearing aid user group ($p < 0.001$) and the spouse/partner group ($p < 0.001$). Results confirmed a main effect of group (F (6,442) = 528.220, 46.88, $p<0.0001$). Preferred sound level was greater in the hearing aid user group (mean=67.7dB SPL) than in the spouse/partner group (mean=61.4dB SPL).

The difference in mean sound level between the groups for each group in depicted in Table 5.8.

Table 5.8 Sound level means set by hearing aid user and spouse/partner group for 12 clips

		Mean Sound Level (dB SPL)		
Programme	**Clip**	**Hearing aid user**	**Partner**	**Difference**
Weather forecast	1a	71.5 (7.0)	64.7 (6.1)	6.8
	1b	68.0 (5.1)	64.9 (5.3)	3.1
Daytime talk show	2a	66.2 (5.6)	59.7 (5.0)	6.5
	2b	68.0 (5.3)	61.3 (4.6)	6.6
Cooking show	3a	67.4 (4.6)	60.6 (4.6)	6.7
	3b	65.5 (4.0)	59.9 (5.6)	5.6
Wildlife documentary	4a	70.4 (4.2)	64.4 (5.1)	6.0
	4b	66.0 (4.0)	60.1 (5.3)	5.8
Live comedy	5a	69.6 (4.3)	62.5 (4.7)	7.0
	5b	67.5 (3.9)	61.1 (5.9)	6.3
Soap/drama	6a	66.8 (4.4)	59.8 (6.7)	6.9
	6b	65.0 (6.5)	58.1 (5.6)	6.8
Mean		**67.7**	**61.4**	**6.3**

An ANCOVA model with a Greenhouse-Geisser correction showed a significant main effect of clip F (6.354, 508.295) = 51.574, P <0.0005. The mean sound level of clips for both groups is shown in Table 5.8. The covariate, PTA-average was not significantly related to the clips, F (6.38, 484.88) = 0.465, p>0.0005 nor was the covariate employment status, F (6.38, 484.88) = 0.465, p>0.0005. There was no main effect observed for gender (p=.94) but there was an interaction observed between gender and clip (p=0.21). We next observed the difference between clips using pairwise comparisons (Figure 5.9).

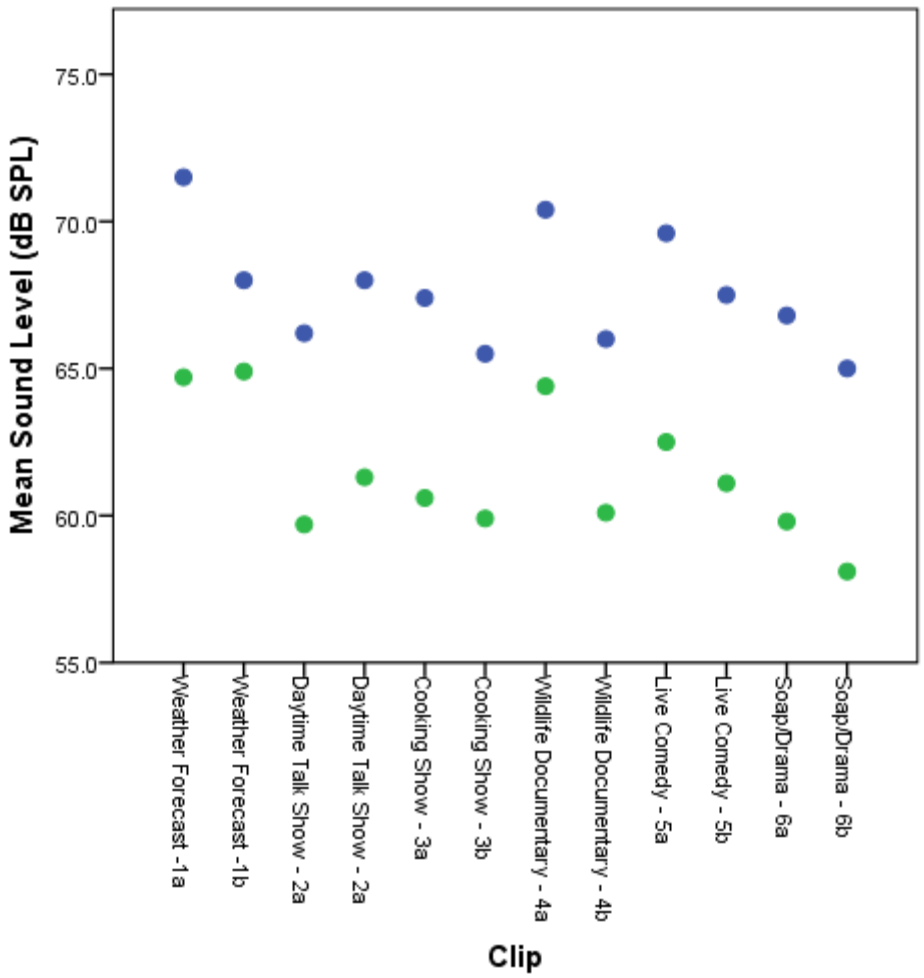


Figure 5.8 Sound level means set by hearing aid user and partner group for 12 clips

Blue dots represents means for hearing aid user group. Green dots represents means for spouse/partner group

As can be observed in Figure 5.10, the range of the sound level data per clip is much wider for the partner group. The inter-quartile range (IQR) for partners wider for the partners compared to the HA users. For clip 2a, 3a, 4a, 5a, 2b and 3b, there is no overlap in the IQR and a higher median for hearing aid users for all clips.

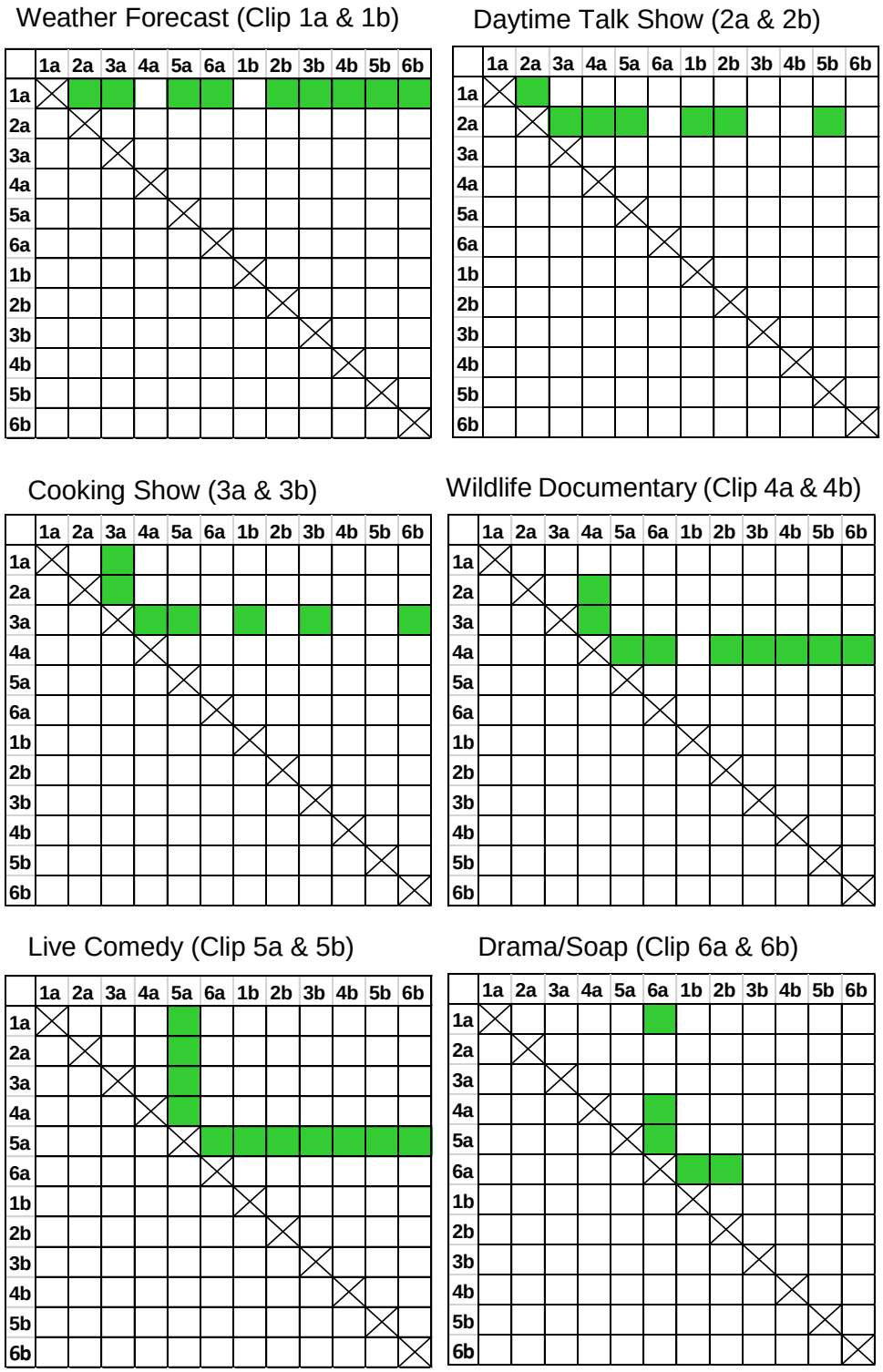


Figure 5.9 Summary of post hoc tests using the Bonferroni correction to show difference between clips.

Shaded green area represents clips that are significantly different to each other (<0.0005).

There are outliers labelled for clip 2a, 3a, 4a, 6a, 2b, 3b and 5b (Figure 5.10) that were sound level data for the one hearing aid user participant. This hearing aid user had an average sound level of 67.4db SPL for the clips which is 14.6dB SPL higher than the average sound level for the hearing aid user group. This participant presented with a bilateral moderate-severe sensorineural hearing loss with cochlea dead regions at 6 kHz an 8 kHz which may account for the louder than average volume setting. A plot of sound level by participant is given in Figure 5.11.

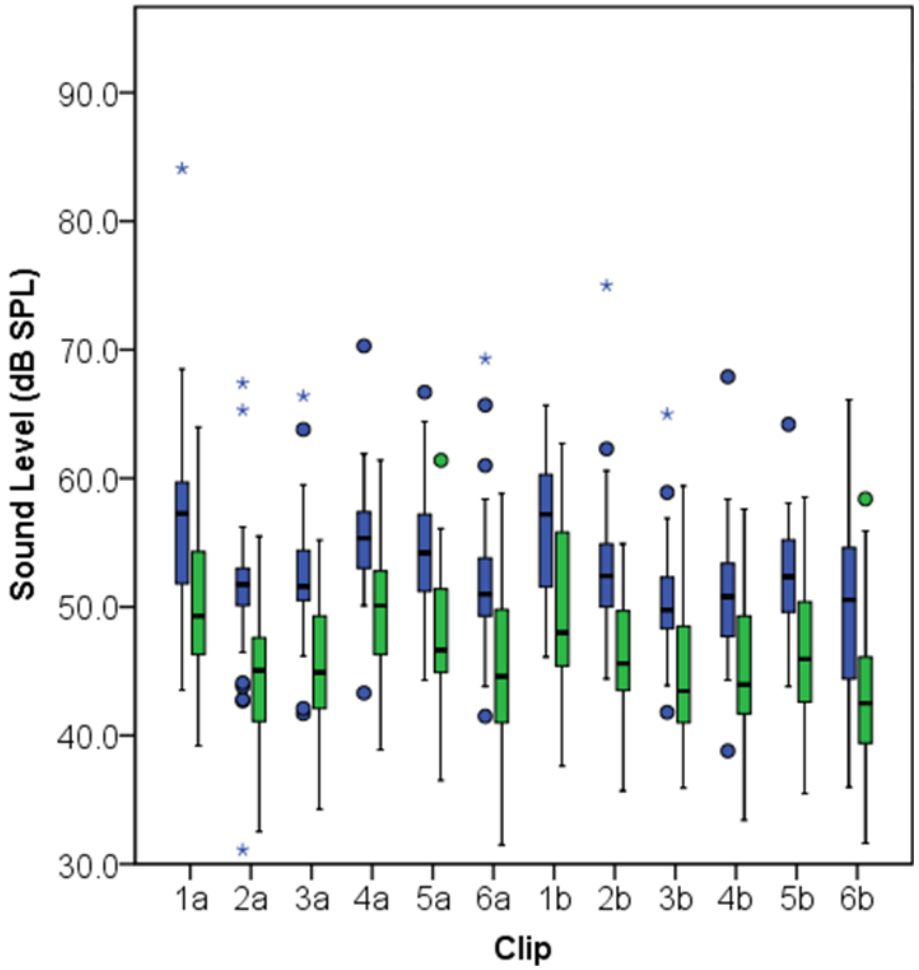


Figure 5.10 Clustered box-plot showing sound level data for both groups per clip

Blue boxes represent hearing aid users and green represents partners.

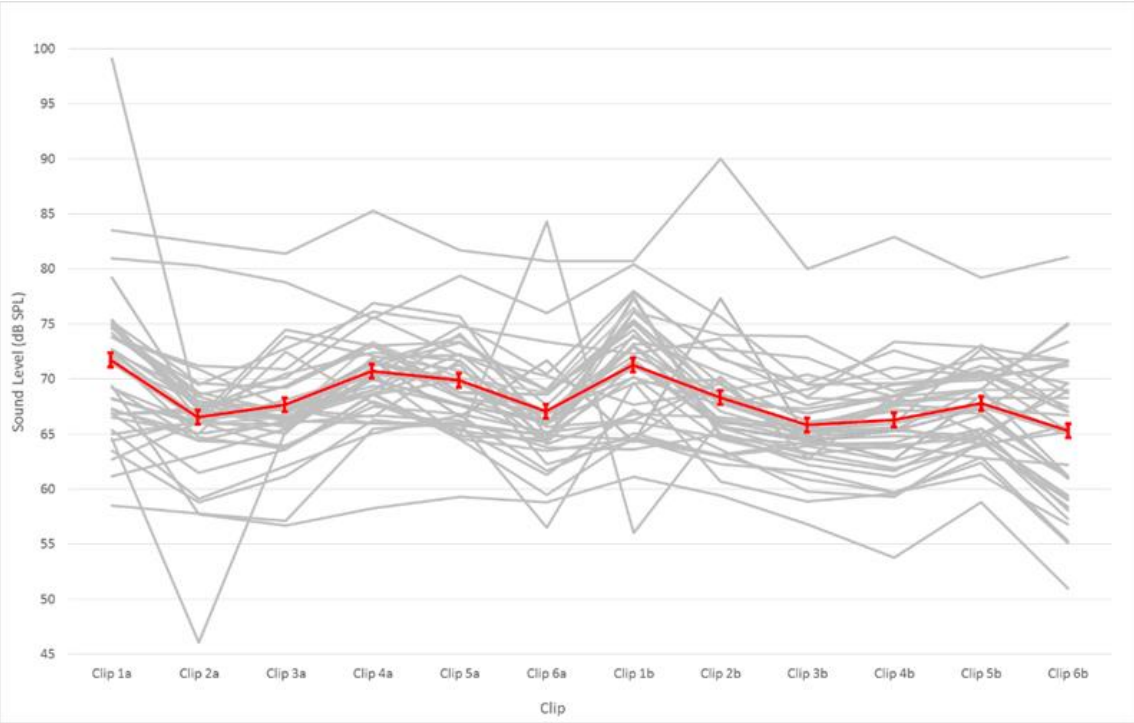


Figure 5.11 Plot of sound level per participant. The red line shows the mean sound level with standard error bars.

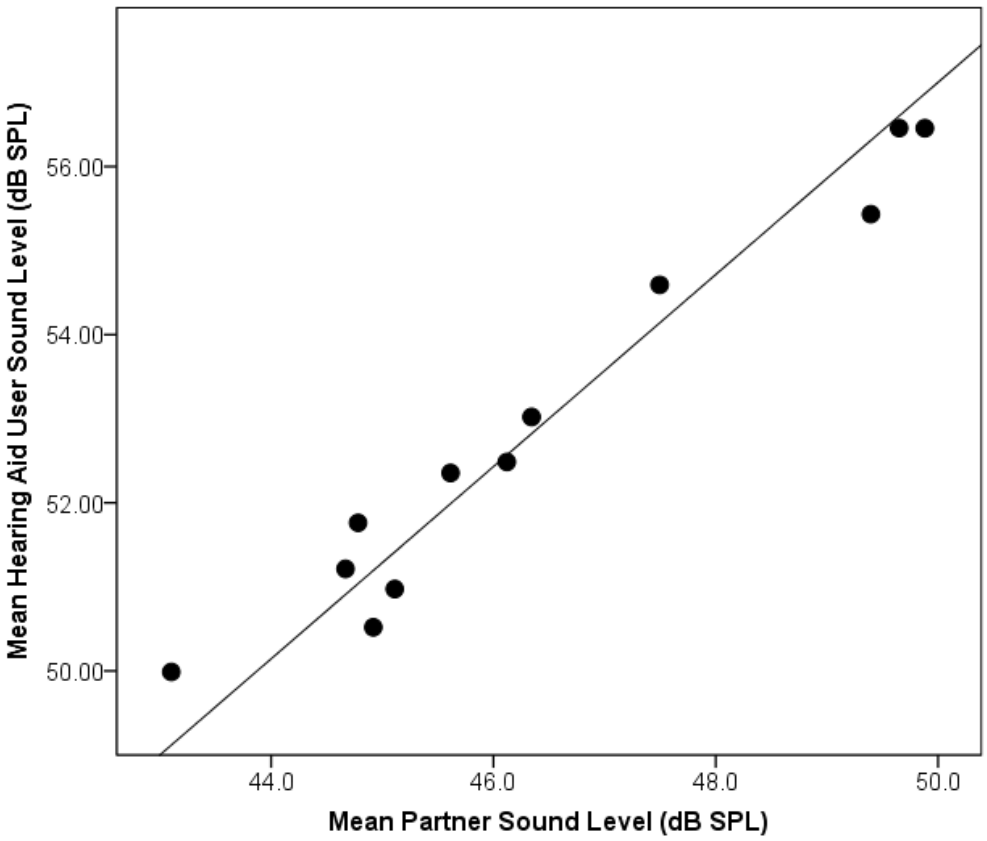


Figure 5.12 Graph depicting the monotonic relationship between the mean sound level of partners and for hearing aid users for the 12 clips.
There is a relationship between the two variables. Correlation is significant at the 0.01 level (2-tailed).

5.7.4.1 Pearson's correlation

Pearson's correlation between the average sound level in the hearing aid user group and the average sound level in the partner group across clips showed a strong positive correlation between average sound level in the hearing aid user group and the partner group, which was statistically significant, r = -0.835, n=42 p = 0.0001 (Figure 5.12). A potential limitation to the study that may have influenced this result is that the hearing aid prescription of the participants in the hearing aid group was not verified. Thus, there was no way of knowing whether hearing aid users were poorly/under-fit. If this were the case for some participants then participants may have performed differently, i.e they may have

not have had the TV volume as loud, which may have influenced the 6.3Db volume difference between the two groups.

An ANCOVA with a Greenhouse-Geisser correction showed an interaction between gender and clip (p=0.021). There was a significant difference in clip between males and females for clip 3a (p=0.038), clip 6a (p=0.017) and clip 5b (p=0.036) (Figure 5.12). There was no significant difference in the interaction between the groups and the clips (p=0.986>0.0005).

Table 5.9 Summary of mean sound levels set by participants based on gender

		Sound Level (dB SPL)	
Programme	**Clip**	**Male**	**Female**
Weather forecast	1a	69.7 (7.7)	66.3 (6.6)
	1b	68.2 (6.7)	67.6 (6.3)
Daytime talk show	2a	63.8 (6.6)	62.0 (5.8)
	2b	65.7 (6.6)	63.6 (4.8)
Cooking show	3a	65.2 (5.4)	62.0 (5.8)
	3b	63.2 (5.4)	62.2 (5.5)
Wildlife documentary	4a	58.4 (5.4)	66.4 (5.5)
	4b	63.9 (5.7)	66.4 (6.0)
Live comedy	5a	66.8 (5.5)	65.2 (5.8)
	5b	65.5 (5.5)	63.0 (5.3)
Soap/drama	6a	64.8 (7.7)	61.2 (5.7)
	6b	61.9 (6.3)	61.0 (7.5)

5.7.5. **Secondary Objective:** To measure and compare the television sound level of participants across couples where one partner has set the television volume.

For the TV clip the couples viewed together, twenty-one hearing aid users and twenty-one partners were given control of the remote. The sound level recorded for each couple is displayed in Figure 5.13.

As expected, the overall mean of sound level for the hearing aid users that had control of the remote was higher than for partners who had control. The

difference in volume preference between both groups 3.6 dB, is more than double the loudness.

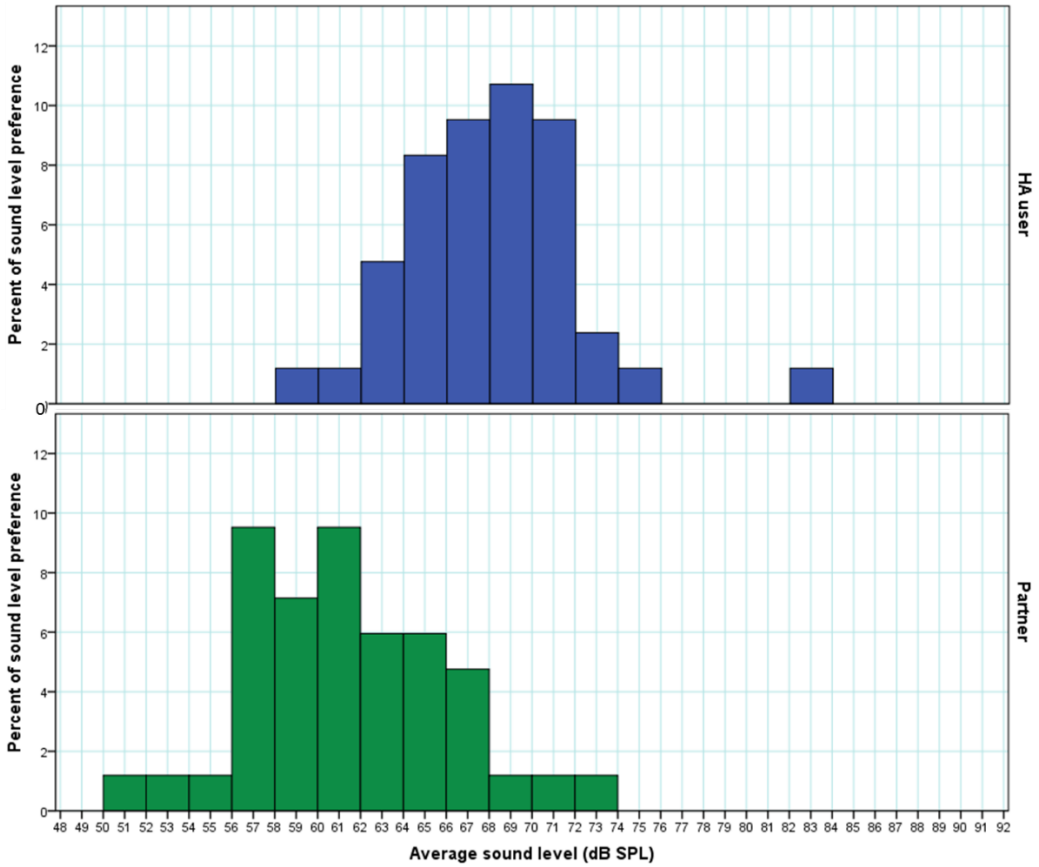


Figure 5.13 Histogram showing the frequency of preferred sound level preference among the 21 hearing aid users (blue) and 21 partners (green) that were allocated control of the remote.

Consistent with the findings for the primary objective, hearing aid users typically set the volume of the TV louder than the spouse/partner group. Whilst the graph illustrates a trend that the hearing aid users generally set the volume louder than the partner group, an independent t-test showed a non-significant effect difference in sound level between groups, t (40) = 1.665, p =.104. The overall mean of participants who set the volume in the hearing aid user group was 67.8 dB SPL and for the partner group was 64.2 dB SPL (Table 5.10).

Table 5.10 Summary of volume preferences for each group in clip viewed by both partners.

	Mean (dB HL)	SD	Range
Hearing Aid User	67.8	5.8	56-84
Spouse/Partner	64.2	7.8	50-80

The participant in each couple who was not given control of the remote was asked about their satisfaction of the volume set by their partner (Table 5.11). The 'Louder' column indicates the number of participants who would have preferred the volume louder than what their partner set. The same principle applies to 'Quieter' and 'About the same'.

Table 5.11 Outline of the self-reported volume preference of participants who did not have control of the remote

	Louder	Quieter	About the same
Hearing aid user	24 (57.2%)	3 (7.1%)	15 (35.7%)
Spouse/Partner	4 (9.5%)	25(59.5%)	13(31.0%)

There was a significant difference between hearing aid users and partners and their self-reported volume preference (χ^2 = 4.25, *df = 2, p<0.05)* such that hearing aid users were more likely to report preference for a louder volume (57%) than quieter (7%), whereas partners were more likely to report preference for a quieter volume (59%) than louder (9%). When Cramer's V was squared, it indicated that nearly 38% of the variation in the frequency counts of self-reported volume preference can be explained by group.

It was expected that more hearing aid users would have preferred to have to TV volume louder than what their partner set, given the mean hearing thresholds were higher for the hearing aid user group. For 7.1% of hearing aid users stated that they would have preferred to have had the volume quieter than

the volume their partner had set. The sound level set by two of these partners was higher than the mean sound level set by their respective hearing aid user partner. These two partners had hearing thresholds above normal (>20dB HL), and of course were unaided. This may attribute to the louder volume preference and thus the preference from the hearing aid user to have the volume quieter.

It was also expected that most partners (60%) would have preferred the TV volume quieter than what their hearing aid user partner set the volume. However, there were also some partners that stated they would have preferred the TV volume louder than what their hearing aid user partner set the volume (9.52%).

Sixty-seven percent of hearing aid users reported that they would have preferred to have set the volume louder than what their partner had set which is more than the number of non-hearing aid users reported wanting the volume louder (n=53%). Perhaps unsurprisingly, 43% of partners preferred to have the volume quieter than what the partner had set.

5.7.6. Pearson's correlation

Pearson's correlation between the average sound level set by hearing aid users for the clips viewed separately and the average sound level set by hearing aid users showed a strong positive correlation between the volume set in the two tasks, which was statistically significant r =0.720, n =21 p= 0.0001(Figure 5.14).

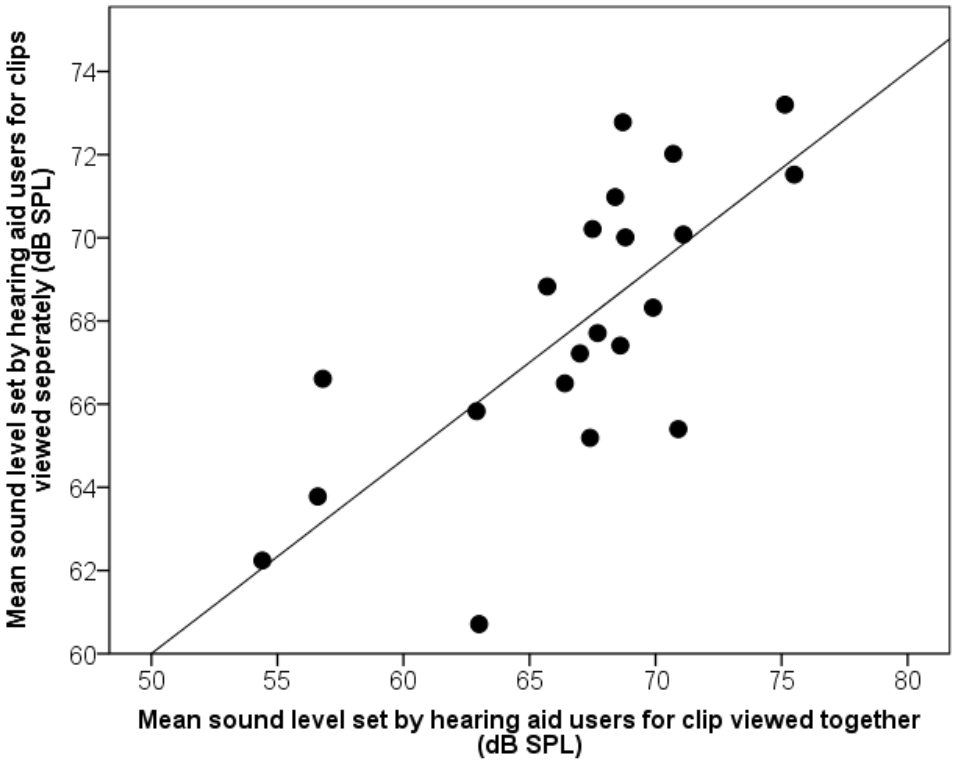


Figure 5.14 Graph showing the relationship between volume set by hearing aid users in the first and second television viewing task.

Correlation is significant at the 0.01 level (2-tailed)

Pearson's correlation between the mean volume set by partners for the clips viewed separately and the mean volume set by partners for the clip viewed as a couple did not show a significant correlation, r =0.425, n =20, p =0.062 (Figure 5.15). These results show that there were no significant differences in the volume set by partners for the first and second television task. This finding suggests that the partner group were adjusting their preferred TV volume during the joint TV task, and this adjustment in volume was a lower volume for the joint task.

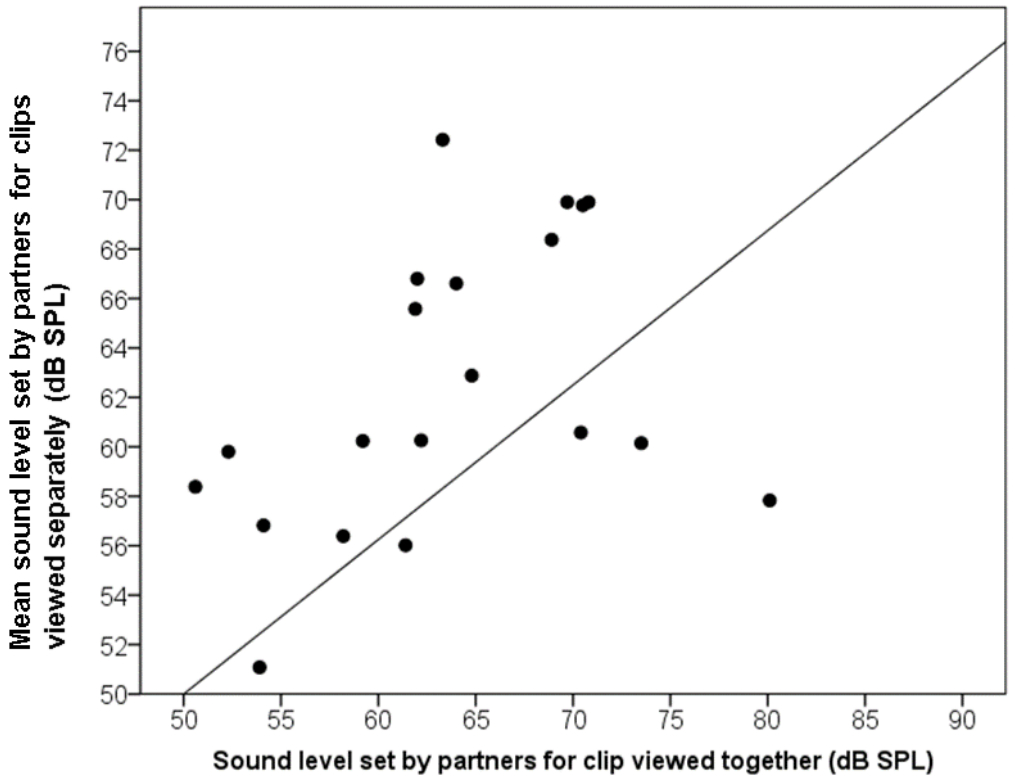


Figure 5.15 Graph showing the relationship between volume set by partners in the first and second television viewing task.

Correlation is significant at the 0.01 level (2-tailed).

5.7.7. Television Viewing Experience survey

5.7.7.1 Hearing aid user

All hearing aid users (n=42) reported that they watch TV for a period of time every day. All couples owned at least one television in their home (1=14, 2=14, 3=9, >3=5). Most couples had more than one television. Therefore, for some of the rooms where they had a TV, such as the bedroom or kitchen, the study set up was a very different arrangement. Having more than one TV also give couples the choice not watch TV alone. The average time spent watching television per day is presented in Table 5.12. The majority of couples (n=39) reported watching television together (Table 5.13).

Table 5.12 Self-reported time spent watching TV on a daily basis.

Amount of time spent watching TV per day	n
Less than 1 hour	0
1 to 2 hours	6
2 to 3 hours	11
3 to 4 hours	13
4 to 5 hours	6
More than 5 hours	14
Total	42

Table 5.13 Summary of how hearing aid users watch TV

Q: How do you typically watch television?	n
Alone	12
With spouse/partner	39
With family member	2

Twenty-one (n=52.0%) hearing aid users reported typically raising the volume of the television 'All the time' and eleven (n=11, 27.0%) reported altering the volume 'Most of the time'. Some hearing aid users reported that despite altering the volume of the television, they still struggled to understand the dialogue 'Most of the time' (n=11, 27.0%) or 'Sometimes' (n=22, 55.0%). Hearing aid users also reported to finding the dialogue of certain TV genres more difficult to follow than others.

Table 5.14 TV genres hearing aid users self-report greater difficulty understanding due to hearing loss.

Q: What TV genre do you typically have greater difficulty understanding due to your hearing loss?	n
Films	29
Soaps/Drama	21
Chat shows	13
Documentaries	12
News	8
TV adverts	1
Other	1

Of the 42 hearing aid users, 28 participants reported avoiding certain TV programmes due to the difficulty in understanding the dialogue because of their hearing loss.

Thirty-three hearing aid users reported to not using any other assistive listening devices whilst watching television aside from hearing aids. Of these, 11 (n=26%) hearing aid users felt that they could benefit from using an assistive listening device, but slightly more were unsure about the potential benefits (n=13, 31%) or felt that they would not benefit from an additional device (n=8, 19%). Interestingly, 6 (n=14%) non-hearing aid users felt that their partner would benefit from using an assistive listening device. The breakdown of the use of assistive listening devices with the television is given in Table 5.15.

Table 5.15 Summary of participants in the hearing aid user group that report using an assistive listening device for watching TV.

Use of assistive listening devices for television	**n**
Does not use an assistive listening device	33
Headset/Neck worn receiver	5
Sound Box	2
Room Amplifier	1
Total	**41**

There was some variation in response to the impact of hearing loss caused the couple to watched television in separate rooms. Most partners reported that it did not (n=27, 64%), but for (n= 8, 19%) spouse/partners this was reported as being an occasional issue.

The majority of couples (n=83%) reported to typically watching television in the living room or lounge with a relatively similar set up to the arrangement in the test room. However, most couples reported that the size of the living room at home was bigger than the test room and all couples reported that the television

at home is bigger than the television used for the study. Forty couples (n=95%) couples reported the ambient sound level in the room to being about the same as the primary television room at home. The seating preference of hearing aid users whilst watching the television is given in Table 5.16.

Table 5.16 Seating preference reported by hearing aid users whilst watching the television.

Seating preference	Number of hearing aid users
Forward-facing the TV	3
As close to the TV as possible	31
At an angle to the TV	3
Don't mind	3
Total	**40**

All hearing aid users reported to having to alter the volume of the TV to varying degrees (Table 5.18).

Table 5.17 Self-reported volume control usage among hearing aid users.

I find that I have to alter the volume of the TV	n
All the time	21
Most of the time	10
Sometimes	11
Total	**42**

Most hearing aid users stated having trouble understanding the TV dialogue in spite of modifying the volume number (Table 5.19).

Table 5.18 Self-reported difficultly of understanding TV dialogue due to hearing loss.

Even when I alter the volume of the TV, I still find that I cannot understand the dialogue	n
All the time	1
Most of the time	12
Sometimes	23
Rarely	5
Never	1
Total	**42**

Within the hearing aid user group, all participants reported to wearing their hearing aid(s) when watching television to varying degrees. Sixty-nine percent (n=27) of participants reported wearing their hearing aid(s) 'All the time' when watching television.

The majority of hearing aid users reported using subtitles whilst watching the television; 'All the time' n=9 (23%); 'Most of the time' n=4 (10%) and 'Sometimes' n=7 (18%).

Some hearing aid users reported experiences where they raise the volume of the television and others have complained that it is too loud; 'All the time' n=5 (11%), 'Most of the time' n=3 (7%) and 'Sometimes' n=16 (38%).

5.7.7.2 Spouse/Partner

Twenty-three non-hearing aid users (n=53%) felt that hearing aids at improved their hearing-impaired partner's listening of the television and twenty (n= 47%) partners felt that since having hearing aid(s), their hearing-impaired partner doesn't turn up the volume of the television as much.

Twelve partners also reported watching television alone sometimes too, but for some of these (n=6) but not due to their partner's hearing loss but rather because of difference preference in programme.

5.8. DISCUSSION

This research represents the first study to explore the impact of hearing loss on TV viewing hearing aid users and their spouse/partner. The idea for this study was derived from the comprehensive review (Chapter 2) that explored the impact of hearing loss on everyday life from the perspective of people with hearing loss and their communication partner. Difficulties with the television volume was frequently reported in both groups from several studies. This subdomain falls within the domain 'Listening' that was ranked fourth most important by hearing aid users. Therefore, the current study represents an area of research that is relevant and important to people with hearing loss and those to whom them communicate regularly with.

In 40 out of 42 couples, hearing aid users on average set the volume of the clips at 6.3 dB louder than spouse/partners. Whilst it was expected that a difference in volume preference would exist between the two groups, the extent of this difference is particularly striking, especially since hearing aid users wore their hearing aids during the television task. The potential reasons for these substantial differences in volume preferences will be discussed here.

5.8.1. Sound level of clips across volume range of TV remote control

The sound level meter measurement of the TV audio was initiated to record for 30-seconds as soon as the participant pressed the reference button on the remote control to log their volume preference. Consequently, the segment of the each clip that the sound level meter measured for 30-seconds could have

varied between participants – depending on how long they took to set the volume. To try and account for this issue, VV measured three, 30-second intervals (0:00-0:30sec, 0:30-:60sec, 0:60-0:90sec) with the sound level meter at every volume setting on the remote (0-100) for part A of the six programmes. The aim was to check how dynamic each of the clips were from start to finish to see if the content in certain parts of the clip would have given rise to a louder or quieter sound level. These sound levels were then averaged (across clips) to show the TV output at each volume setting (Figure 5.16).

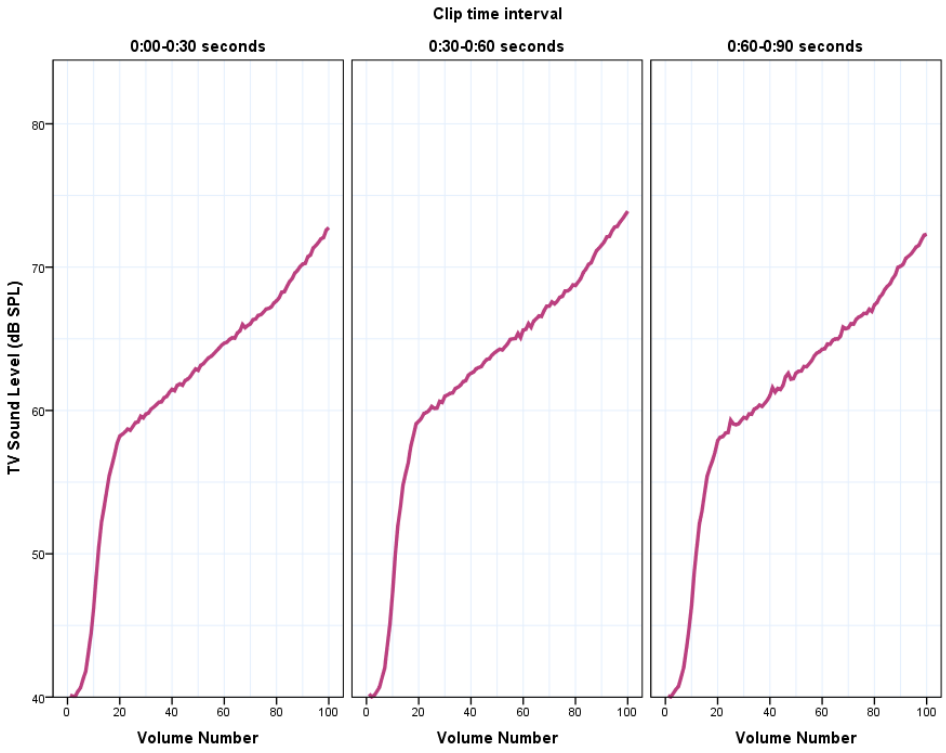


Figure 5.16. Average sound level for clips at each volume setting (1-100)

As can be seen from the graphs, each 30-second interval of the programmes was relatively similar in terms of sound level at each volume setting. The intervals of programmes that were somewhat different to each other include the wildlife documentary and the soap/drama programme. Whilst it is unknown exactly which 30-second interval was measured for the programmes, the

participants viewed and set the volume for two clips per programme. There were no significant differences in volume preference across part A and part B of the clips per group. Furthermore, the primary aim of the study was to determine the difference in preferred TV volume between hearing aid users and their partner which again remained consistent for all the programmes.

Figure 5.17 shows the average frequency spectrum of all the clips. It was calculated by downsampling the waveforms to 20 kHz, windowing the waveforms throughout to non-overlapping 800-sample Hamming windows, calculating 800-point FFTs in each window, then averaging all the FFTs. It shows that the stimuli are overall most intense around 200-300 Hz. This overall shape is similar to the long-term average speech spectrum (Byrne et al., 1994), which would be expected since all the clips are primarily speech. However, the TV loudspeakers are neither perfectly flat nor perfectly wide, and so the spectra would not be expected to match exactly.

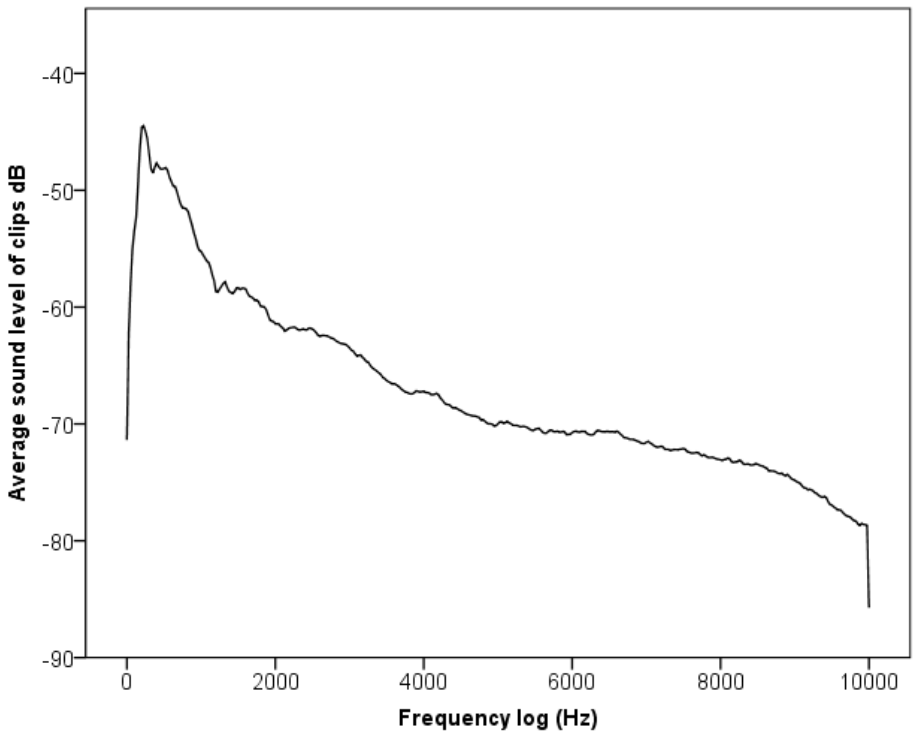


Figure 5.17 Average frequency spectrum of all the clips

Figure 5.18 shows the spectrum of the background noise of the test room. It shows the typical shape of such a spectrum, with progressively increasing intensity at the lowest frequencies, but these will be mostly inaudible given our insensitivity to such very low frequencies.

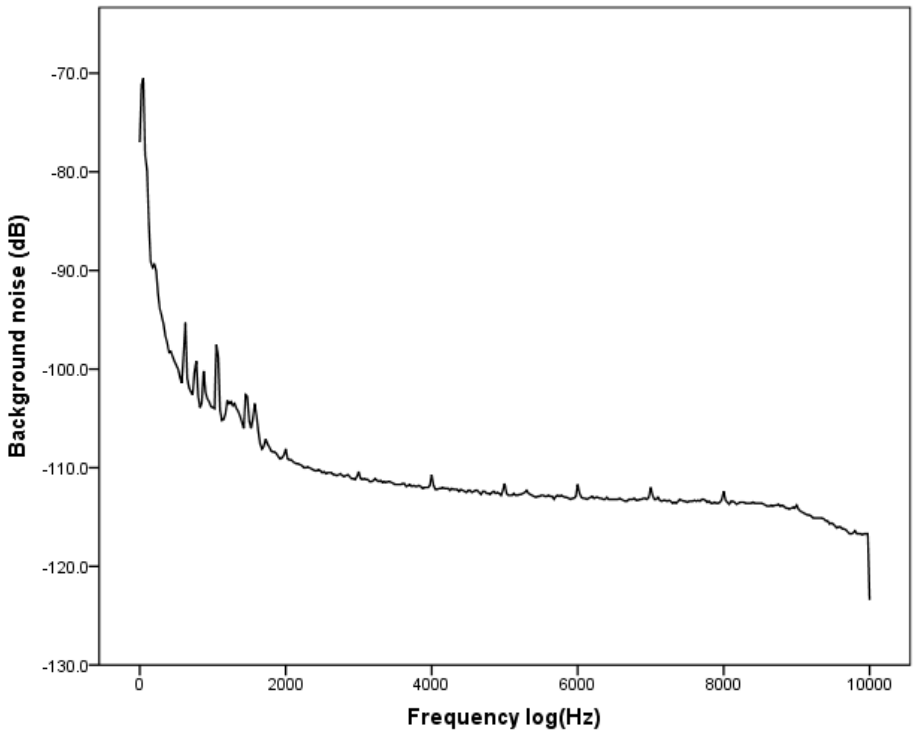


Figure 5.18 Spectrum of the background noise of the test room

5.8.2. Comparison with the literature

In 2010, BBC Vision carried out two surveys with its targeted online panel of 20, 000 viewers to identify the issues reported that caused problems with understanding TV audio content. The results revealed that about 60% of viewers had difficulty understanding speech on TV (Armstrong, 2011). The research acknowledged four key factors that can make it challenging for (normal hearing) viewers to understand the dialogue which include clarity of

speech. The primary complaints relating to this was the fast pace of speech delivery, muffled dialogue, speakers turning away from the camera and trailing off at the end of sentences.

The narrator of the wildlife documentary programme that was used in the current study was not visible to the viewer as the narrator spoke over the ambient sounds of what was being depicted in the documentary. The speech-in- noise scenario here was particularly prominent during the climax of the clip where there was reduced intelligibility. This may account for why this clip ranked second in terms of loudest volume across the programmes (Part A: 70.4 dB SPL, Part B 66.0 dB SPL). The second key factor identified by Armstrong (2011) was unfamiliar or strong accents. For consistency, all the televised stimulus consisted of British programmes comprising speakers of British accents. The remaining factors reported were in relation to background noise and background music that often drown the dialogue. The live comedy programme used in the current study also contained speech in background noise, an aspect of listening that is known to be challenging for hearing aid users. The reduced ability of hearing aid users to segregate speech sounds from background noise is well known (Lavie et al., 2014). This may account for why the difference between hearing aid users and their partners for the mean volume set for the live comedy was 7.0 dB, the largest difference between groups compared to the other programmes.

The difference in preferred listening volume between hearing aid users and their partners in the current study is likely to be due to a culmination of effects including physiological as well as perceptual changes. There has been some research in audio processing to improve intelligibility for TV sound (Armstrong, 2011). Some research has been carried out to explore improving the

intelligibility of speech on TV audio for hearing-impaired viewers. An algorithm suggested by Mush (2008) proposes that audio processing can reduce the cognitive effort required for speech discrimination and suggests algorithms to reduce listening effort and hence, improving intelligibility.

Older adults with hearing loss have been suggested to prefer louder listening levels not only because of the elevated hearing thresholds but also due to the effects of loudness recruitment decreases the sound level at which listening becomes uncomfortable (Shirley, 2013). The difference in preferred sound level between hearing aid users and their spouse/partner could therefore be due to the reduced dynamic range of hearing aid users given the severity of their hearing loss (Müsch, 2008). This has been denoted as a reduced 'window of comfortable dynamic range' (Rumsey, 2009).

These points highlight that loudness is an essential factor in speech comprehension for people with hearing loss and that signal processing alone may not be sufficient to improve comprehension, but only to reduce listening effort (Shirley and Oldfield, 2015). In addition to hearing loss however, there may be other factors that can affect television viewing among older adults. For example, the ability to process auditory signals at a rapid rate is known to decline with age due to cognitive decline (Lin et al., 2013) and this may also affect speech perception for TV listening (Gordon-Salant and Callahan, 2009). Hearing-impaired listeners may experience an increase in cognitive load due to the additional processing required to filter out (unwanted) background sound (Müsch, 2008). This may subsequently lead to less attentional resources available for higher order cognitive processing to contextualise sentences and therefore fill in any gaps caused by words not heard (Müsch, 2008, Shirley and Oldfield, 2015). An important finding from the study conducted by Gordon-

Salant and Callahan (2009) is that the speech recognition scores for the TV clips of participants did not significantly improve with the use of hearing aids compared to without.

Whitmer et al. (2015) tested the speech-to-background noise ratio through a mixing and ratings experiment using TV clips with normal and hearing-impaired listeners. For the mixing experiment, participants adjusted isolated music and effects level until they were satisfied with their balance preference. For the rating experiment, participants were given the option to rate the speech to background noise with more or less background noise. The authors found that the ratings differed between groups, but overall hearing-impaired participants and normal listeners preferred higher speech to background sound ratios, with less background sounds. Participants on average set the average speech to background noise ratio on average 12 dB higher than normal. Both groups preferred to have the average effects of the clip reduced, this was 4 dB more for the hearing impaired group than the normal hearing group.

In the current study, hearing aid users reported still struggling to understand the TV dialogue despite increasing the volume. There have been many studies that have shown listening performance with hearing aids by demonstrating improved speech recognition scores pre- and post- hearing aid fitting. Most studies that have demonstrated improved speech recognition scores using stimuli with single talker and words spoken in a pronounced style. As with most television programmes, the televised stimulus materials used in the current study used speakers that did not always face the camera when speaking. In programmes such as the cooking or soap program, the talker varied form sentence to sentence and comprised male and female speakers with varied components to their speech production.

5.8.3. Use of subtitle usage among hearing aid users

As more television programmes are closed captioned, it is unclear as to the utilisation of this facility (Lewis and Jackson, 2001). The use of subtitles to help follow the television dialogue has been reported by people with hearing loss in some qualitative studies (Wallhagen, 2010). In the current study only 33% of hearing aid users reported to using subtitles “All the time” or “Most of the time”. On the other hand, a Strelcyk et al. (2016) survey study conducted by the authors found that 67% of (183 hearing aid users) reported that they use subtitles whilst watching TV. In the study conducted by Gordon-Salant and Callahan (2009), the authors found speech recognition scores significantly improved with the used of closed-captioning, including when participants wore their hearing aids.

In the study conducted by Gordon-Salant and Callahan (2009) only 13% of participants had reported to ever using closed-captioning which is also very low, similar to the current study. Given the reported difficulty of hearing aid users whilst watching TV, these findings are relatively surprising and raises some questions as to why the usage subtitles was so low.

The low-reported usage of subtitles by participants involved in the current study could be to a number of reasons. Whilst the accessibility of subtitles of TV programmes has substantially improved over the last three decades, subtitles are not readily available for all broadcast content. There is also an on-going debate as to the efficiency of subtitles (Schröter, 2003) and in the media, particularly in regarding to timing of display in relation to the speaker (Ensor, 2011, stories, 2013). This is particularly noted for live broadcast content, where there is often a lag between the dialogue and the display (Evans, 2002). The use of subtitles does require a reasonable level of visual competency (Hefer,

2013), however, all participants in this study passed the visual test so it is unlikely due to this. Also, if the hearing aid user is watching TV with someone else, it may also not be to the preference of the other person not to have subtitles. Subtitles also present additional visual information for the hearing aid user to process in addition to the programme and audio content. Given that the rate of cognitive processing is known to decline with age (Salthouse, 2009), having subtitles might present another processing challenge for older adults who are hearing aid users. The amount of visual content might also affect the ease of listening due to the amount of cognitive processing required (McCoy et al., 2005). The low subtitle usage among hearing aid users who completed this survey could also be attributed to the greater difficulty for the hearing aid user to talk to other people whilst reading the subtitles and being too reliant on subtitles can cause a hearing-impaired person to miss what is being said by the accompanying viewer (Morgan-Jones, 1998, Scarinci et al., 2008).

5.8.4. Loudness modelling in normal hearing people and hearing impaired people

Individuals with hearing loss, particularly sensorineural hearing loss, often exhibit a difference performance than normal in several different auditory functions (Moore, 2014) compared to normally hearing adults. The first, perhaps most obvious change is that they show reduced sensitivity in detecting pure tones in quiet, which accounts for the raised absolute thresholds as determined by audiometry. Hearing loss can cause outer hair cell and/or inner hair cell dysfunction which results in a loss of active amplification on the basilar membrane in the cochlea (Robles and Ruggero, 2001). This can also mean that a loss of IHCs can may give rise to a smaller neural response than normal.

Secondly, as seen by the ULL scores of 30 hearing aid users with sensorineural hearing loss, they potentially experience an altered perception of loudness. This concept, known as recruitment is often used for diagnostic purposes. It describes the rate of growth of loudness which is typically steeper than normal and occurs over a smaller range of stimulus levels in people with hearing loss; but is perceived as the same range of subjective loudness as normal. Thus when the stimulus level is adequately high, around 90-100 dB SPL, the loudness usually approaches its 'normal' level and so the sound appears almost as loud compared to a normally hearing person. This altered perception of loudness therefore may have influenced the hearing aid user's volume preferences. Therefore, perception of the loudness of broadband stimuli is altered in people with hearing loss. For people with normal hearing, the loudness of a sound of fixed overall intensity increases with increasing bandwidth, beyond a certain bandwidth, known as the critical bandwidth for loudness (Moore, 2007). In people with hearing loss, loudness summation is significantly reduced or absent.

The hearing aid users may have also attributed the lack of clarity to the audio not being loud enough, which may have motivated their reasoning for increasing the volume As demonstrated by Whitmer et al. (2015), individuals with hearing loss prefer a higher speech to noise ratio than normal hearing individuals. Other researchers have also stated that typically, individuals with hearing loss require the speech signal to be 4 to18 dB higher than extraneous background noise in order to obtain speech recognition scores similar to normal-hearing individuals (Moore, 2012, Killion, 1997). As with hearing aids, increasing the volume of the TV amplifies all the sounds, including those unwanted, background sounds in the clip (i.e. increasing loudness does not improve the speech-to-noise ratio).

This may account as to why despite the audible volume of the TV, the hearing aid users choose to increase the volume higher because they do not notice any perceptual improvement.

5.8.5. Assistive technology for television viewing

Of the 42 hearing aid users, eight participants reported the use of assistive listening devices at home whilst watching television. In addition to assistive devices, there have been attempts to make television audio more accessible. In particular, the use of closed-captioning; subtitles and sign-language in different forms. Potential reasons for this low uptake is explained in section 6.5.4.

5.8.6. Study strengths

There were several strengths to the design of this study. The TV clips used in this study were from a wide scope of TV genres. Therefore, the clips were fairly representative in that the overall differences found across couples is not restricted to one TV genre. This meant that comparisons could be made between the volume preference and self-reported difficulty for different types of TV programmes. The clips were also from programmes that are current thus representing present-day TV. The set-up of the television test room also attempted to mimic a generic television set up at home.

Another strength of the study was that the objective of the study, the impact of hearing loss on television viewing, was explored in hearing aid users as well as their spouse/partner. With the current drive toward patient-centred care and the appreciation of the impact of hearing loss on the patient as well as those around them, the current study adopts this approach.

An additional strength of the study was that participants were asked to set the volume for each clip without their partner present. This removed any influence of having the partner with hearing loss/good hearing there whilst setting the volume. An additional strength to the study was that it was possible to record how participant's perceived their partner's volume preference after they viewed a clip together.

5.9. FUTURE DIRECTIONS

Given the lack of research within this area, there are numerous unanswered questions regarding the specific television listening difficulties of hearing aid users. The results identified by this study showed a significant difference between hearing aid users and their non-hearing aid user partner. Future research could explore the potential differences in preferred TV volume among couples who are both hearing aid users.

To investigate the influence of hearing acuity on preferred TV volume, studies could explore the preferred TV volume among people who have normal hearing.

The current study was conducted within a controlled testing environment. To make the study ecologically valid and investigate the influence of environmental factors on preferred TV volume, future research could measure the preferred TV volume of hearing aid users in their homes.

Following the statistical significance of clip demonstrated by the current study, future studies could explore the test re-test reliability of TV genre. The current study explored the self-reported difficulty of listening to different TV genres. Future research could also measure the perceived sound quality of different types of TV programmes. Such studies could also measure the TV sound level and perceived quality of sound based on the experimental set-up. This includes

the influence of speaker placement in relation to the hearing aid user whilst watching TV and also the type of audio e.g. Mono vs. stereo sound. Future research could also explore the use and benefit of subtitles and assistive listening devices for TV viewing.

CHAPTER 6. SURVEY INVESTIGATING THE IMPACT OF HEARING LOSS ON TELEVISION VIEWIING

6.1. INTRODUCTION

Difficulty watching television has been reported by individuals with hearing loss in numerous qualitative studies (Newman and Weinstein, 1986, Hetu et al., 1987, Hetu et al., 1988, Kelly and Atcherson, 2011, Stephens et al., 1990, Brooks et al., 2001, Tsuruoka et al., 2001, Miyakita et al., 2002, Hass-Slavin et al., 2005, Hidalgo et al., 2008, Scarinci et al., 2009c, McNeil et al., 2011, Wanstrom et al., 2014). These studies have explored the general impact of hearing loss on day-to-day life. They have not therefore focussed on the impact of hearing loss on TV viewing specifically. Hearing aid users report 'having to raise the volume of the TV' but this does not always remediate hearing problems. Hearing difficulties whilst watching TV have also been noted by communication partners (Hetu et al., 1988, Hetu et al., 1993, Brooks et al., 2001, Morgan et al., 2002, Stark and Hickson, 2004, Scarinci et al., 2008, Scarinci et al., 2009b, Wallhagen, 2010).

Strelcyk and colleagues (2016) conducted a media survey that explored TV listening in people with hearing loss. The authors found that 85% of 173 hearing-aid and 173 non-hearing-aid respondents considered hearing well when watching TV as 'very important' or 'extremely important'.

Chapter 5 concluded that the preferred TV volume among hearing aid users whilst watching TV is significantly louder than their spouse/partner. This finding suggests the experience of watching TV was less than optimum for the partner in situations where the partner does not have control over the remote.

Chapters 1 and 2 highlight the diversity of diagnostic and treatment-related questionnaires that have been developed for patients undergoing aural rehabilitation and research purposes. Several questionnaires have been developed that include questions about television difficulties and/or volume of the television due to hearing loss. Examples include HHIE (Ventry and Weinstein, 1982), GHABP(Gatehouse, 1999), HDHS (Hétu, 1994) and the SSQ (Gatehouse and Noble, 2004). However, these questionnaires typically only contain one or two items that tap into TV-related difficulties. The HHIE question S-15: "*Does hearing impairment cause you difficulty in watching TV or listening to the radio?"* or the SSQ question 10: "*You are listening to someone talking to you, while at the same time trying to follow the news on TV. Can you follow what both people are saying?"* are two examples. These questionnaires therefore have the potential to identify whether listening to the television is a problem for individuals with hearing loss, but are do not tap into the specific difficulties watching TV or how important this activity is to the respondent.

There have also been questionnaires that have been developed for significant others of hearing-impaired individuals (see section 1.3.2). An example of a questionnaire that contains a question relating to TV-related difficulty is the SOS-HEAR (Scarinci et al., 2012). The SOS-HEAR is a 36-item questionnaire developed to measure the level of third-party disability experienced by spouses of older people with hearing impairment (Scarinci et al., 2012). In this questionnaire, the spouse must rank according to their degree of personal relevance based on their interactions with a hearing-impaired individual. Again, this questionnaire only contains one TV-related item Question 21: *"It makes me angry when I have to tolerate the loud TV."* This question asks about angry

emotional responses without examining other aspects of the experience of watching TV with a hearing-impaired individual.

Self-reported difficulty of TV viewing as a potential indicator for hearing loss has been suggested by some researchers. A study conducted by Ranganathan et al. (2011) assessed the diagnostic utility of using television volume as a marker for hearing loss on paediatric and adult patients. This measure was compared to pure-tone audiometry. Findings showed that if the patient or family member reported watching TV with an elevated sound level, there was a 68% chance of the patient having a hearing loss or 25dB or more. Increased television volume had a sensitivity of 81% and specificity of 52% as a predictor of hearing loss. The authors suggested that self-reported television volume may be a useful screening tool for hearing loss particularly in general practice clinics. Wanstrom et al., (2014) have also shown that complaints of having to raise the volume of the television as potential indicator for hearing loss.

Thus far, there has been no research on the TV-viewing habits of hearing impaired individuals, and their communication partners. As a result, our understanding of the specific difficulties faced by people watching television and their usage of hearing aids for the TV, is rather limited. The aim of this study therefore was to explore the specific difficulties faced by hearing aid users and their communication partners whilst watching TV.

6.1.1. Primary objective

The primary objective was explore the TV viewing difficulties of hearing aid users and communication partners.

6.2. METHODS

6.2.1. Design

This was a survey design study. Hearing aid users and communication partners of hearing aid users formed the two stakeholder groups. There were two versions of the survey, one developed for each group.

6.2.2. Ethical approval

The study received favourable opinion from the University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee on 16th October 2016. Ethics reference number: F14102016.

6.2.3. Sample size and recruitment methods

6.2.3.1 Hearing aid users and communication partners

The sample size estimate for the survey and the recruitment methods are the same as those reported in Section 4.24 (Target=200).

The exact number of participants reached by the four methods are unknown, but given our knowledge of methods used in strategies 1, 2 and 4 it was certainly >1000. Given the exact number of participants approached for the Nottingham BRC and IHR database are known, the estimate of the minimum number of participants reached is 1051 and therefore response rate for these two databases was 21%.

6.2.4. Eligibility criteria

6.2.4.1 Hearing aid users and communication partners

For participants to be eligible to take part in the survey they must have been either a hearing aid user or the partner or spouse of someone with a hearing

loss. All participants were at least 18 years old with a good understanding of English.

A screening question asked the respondent to indicate their stakeholder group, which then directed the respondent to the appropriate version of the survey.

6.3. MATERIALS

6.3.1. Survey development

Generation of the 24-item survey followed a systematic approach to survey design based Kelley et al. (2003): (1) planning the content of a research tool; (2) questionnaire layout; (3) piloting and (4) covering letter.

1. *Content and layout of the survey*

According to Kelley's recommendations, the topic of interest should be carefully planned and relate clearly to the research question. Kelley et al., (2003) identified the usefulness of involving colleagues and members of the target population of interest to assure the validity of the survey content (content validity). The author also highlighted the importance of subjecting the survey to a robust process of development and testing, in order to assure the credibility of the research findings.

In the first step, VV identified general items for inclusion were grouped according three key topics: (i) day-to-day television viewing habits, (ii) television viewing difficulties, and (iii) the perceived impact of hearing loss on partner's TV-viewing habits The choice of these topics was informed by the data items used to code the 'raising the volume of the television' subdomain that appears in the DoHL-P and DoHL-CP frameworks (Chapter 2) and the focus group data (Chapter 3). The data items were also used to compile the set of questions and

response items. VV formulated several potential questions within each topic based on all the items categorised. VV focussed on identifying relevant items for inclusion in the survey, and discussed removing potentially weak or redundant items with an additional researcher (DAH). The final survey comprised 24-items. There was a progress bar on each page of the survey indicating how far along in the survey the respondent was. The first questions of the survey explored demographic information of the respondents, and hearing aid usage.

2. Questionnaire layout

Kelley et al. (2003) suggested that surveys should be clearly presented and questions should be numbered and grouped by subject. There should be instructions given for each question and headings to make the survey easy to follow. There was an online and paper version (for those recruited via the MRC IHR participant database) of the survey. The survey was created in Survey Monkey (www.surveymonkey.com). The survey administered online was split into four sections. The first section was 'Demographic information'.

For the hearing aid user version of the survey, the next part of the survey was grouped under "Day-to-day television viewing habits" (Table 6.1). This part asked questions that tapped into the general television viewing habits of the hearing aid users, such as the amount of time they watch television. The next part of the survey was "Television Viewing Difficulties". For hearing aid users, this section asked questions about the use of hearing aids and assistive listening devices for watching TV, types of programmes the hearing aid user struggles with when watching television, and use of the volume control. It also contained questions about the perceived impact of hearing loss on their

communication partner in terms of watching TV. For communication partners, it asked about the perceived impact of hearing loss on their partner e.g. whether they felt hearing aids had improved their partner's TV viewing (Table 6.2). Questions pertaining to demographic information are not reported in the tables.

Table 6.1 Hearing aid user version of the survey questions and response options (table continued on next page…)

Category	Question	Response option
Day-to-day television viewing habits	Q9. How many televisions do you have in your home?	1, 2, 3, More than 3
Day-to-day television viewing habits	Q10. Do you watch television for a period of time every day?	Yes, No
Day-to-day television viewing habits	Q11. On average, how many hours per day do you watch television at home?	Less than 1 hour, 1-2 hours, 2-3 hours, 3-4 hours, 4-5 hours, More than 5 hours
Day-to-day television viewing habits	Q12. In which room(s) is the television situated where you prefer to watch? (Please select all that apply)	Living room/lounge, Dining room, Kitchen, Bedroom, Other (please specify)
Day-to-day television viewing habits	Q13. How often do you wear you hearing aid(s) whilst watching television?	All the time, Most of the time, Sometimes, Rarely, Never
Television viewing difficulties	Q14. Do you feel your hearing aid(s) help you to listen to the television?	Yes, Not, Unsure
Day-to-day television viewing habits	Q15. Aside from hearing aid(s), do you use any assistive listening devices whilst watching television? (Please select all that apply)	I do no use assistive listening devices whilst watching television, Headset/neck-worn receiver systems, Sound box, Personal radio aids (including FM radio aids), Room amplifier (including induction 'T-Loop' system), Other
Day-to-day television viewing habits	Q16. If you do not use assistive listening devices whilst watching television, would you consider investing in any?	Yes, No, Unsure
Television viewing difficulties	Q17. Do you find the quality of the listening experience to vary across difference television programmes (i.e. do you find some programmes more difficult to hear or listen to?)	Yes, No, Unsure

Table 6.1 Hearing aid user version of the survey questions and response options (continued)

Category	Question	Response option
Television viewing difficulties	Q18. If yes, what types of television programmes do you have greater difficulty understanding because of your hearing loss? (Please select all that apply)	Gameshows, Soap/Drama, Films, News, Documentaries, TV adverts, Chat Shows, Other (please specify)
Television viewing difficulties	Q19. Since having hearing loss, do you watch television less than you used to?	Yes, No, About the same, I don't know
Television viewing difficulties	Q20. Has your hearing loss affected your enjoyment of watching television?	Yes, No, Sometimes, Unsure
Day-to-day television viewing habits	Q21. Where do you prefer to sit whilst watching television? (Please select all that apply?	As close to the television as possible, Forward-facing the television, At an angle to the television, Don't mind, Other (please specify)
Day-to-day television viewing habits, Television viewing difficulties, Perceived impact of hearing loss on partner's TV viewing habits	Q22. Please read the following statements and select one answer per row • I find that I have to alter the volume of the television • Even when I alter the volume of the television I find that I still cannot understand the dialogue • I wear my hearing aids whilst watching television • I watch television alone • I have subtitles on whilst watching television • If I raise the volume of the television, others complain that it is too loud • Since having hearing loss my partner and I watch television in separate rooms • My partner gets annoyed when I alter the volume of the television • I find female voices on TV more difficult to understand • I avoid certain programmes because I find them more difficult to follow because of my hearing loss	All the time Most of the time Sometimes Rarely Never N/A
Television viewing difficulties	Q23. While watching television, how often do you typically alter the volume using the TV remote control?	Every few minutes, At the beginning of a new programme, Only once after switching on the TV, Never
Television viewing difficulties	Q24. Do you alter the volume/settings on your hearing aid(s) when you watch television?	All the time, Most of the time, Sometimes, Rarely, Never

The question numbers correspond to the numbering system in the electronic survey, where the consent form and demographic questions formed the first part of the survey.

Table 6.2 Communication partner version of the survey questions and response options

Category	Question	Response option
Day-to-day television viewing habits	Q28. How many televisions do you have in your home?	1, 2, 3, More than 3
Day-to-day television viewing habits	Q29. In which rooms do you prefer to watch television? (Please all that apply)	Living room/lounge, Dining room, Kitchen, Bedroom, Other
Day-to-day television viewing habits	How do you normally watch television?	Alone, With my spouse/ partner, With family members, With friends, Other (please specify)
Day-to-day television viewing habits	Aside from hearing aid(s) does your partner use any assistive listening devices when watching television? (Please select all that apply)	My partner does not use assistive listening devices when watching television, Headset/ neck-worn receiver systems, Sound box, Personal radio aids (including FM radio aids), Room amplifier (including induction 'T-Loop' system), Unsure, Other (please specify)
Day-to-day television viewing habits	Q33. Do you think you partner would benefit from using an assistive listening device whilst watching television?	Yes, No, Unsure
Television viewing difficulties	Q34. Do you feel your partner raises the volume of the television too loud?	All the time, Most of the time, Sometimes, Rarely, Never
Television viewing difficulties	Q35. Do you find yourself telling your partner to turn the television volume down?	All the time, Most of the time, Sometimes, Rarely, Never
Television viewing difficulties	Q36. Do you feel you have to compromise with your partner over the television volume	All the time, Most of the time, Sometimes, Rarely, Never
Television viewing difficulties	Q37. Since your partner was issued with hearing aids, do you feel this has improved his/her listening of the television?	Yes, No, Unsure
Television viewing difficulties	Q38. Do you feel your partner doesn't turn up the volume of the television as much since having hearing aids?	Yes, No, Unsure
Television viewing difficulties	Q39. Please read the following statements and select the option that is most relevant to you • I get annoyed when my partner raises the volume of the television • We have arguments because of the television volume • I have to turn the volume of the television down • I encourage my spouse/partner to use subtitles/closed-captioning • -Since my partner's hearing loss, we watch television in separate rooms	All the time Most of the time Sometimes Rarely Never

The question numbers correspond to the numbering system in the electronic survey, where the consent form and demographic questions formed the first part of the survey.

3. Interview questions

Kelley et al. (2003) suggested having a clear, well thought out set of questions that can be either open or closed format. In this survey all of the questions were closed format. Most of the questions had multiple choice response options.

4. Piloting

Kelley et al. (2003) also recommended pilot testing the survey on a small sample of the target population to explore their understanding of the questions and instructions. In this study, the aim was to assess the construct validity and the ease of use and ensure the language understandable. There were 25 questions in the pilot version of the hearing aid user version of the survey and 20 questions in the communication partner.

For piloting of both surveys, four hearing aid users selected from a PPI steering group from the Nottingham BRC. All participants responded with positive feedback overall. The relevance of one question was queried and it was decided to be removed. The final survey contained 24-multiple choice questions in the hearing aid user version and 20-multiple choice questions in the communication partner version.

5. Covering letter

The final recommendation that Kelley et al. (2003) gave was to provide sufficient information about the organisation hosting the study, the contact details of the researcher, and the study. This information was given in the PIS.

6.4. RESULTS

In total 344 (hearing aid users and communication partners) consented to participate. However, 15 respondents withdrew. Completed surveys were obtained from 307 hearing aid users and 22 communication partners. Even though the target was 150-200, the survey was advertised to close on a particular date on the Action on Hearing Loss blog, and therefore could not be closed prior to this date, so this is why the completed number of surveys exceeds the target. Each dissemination strategy was employed consecutively, which allowed for monitoring the approximate number and source of survey responses (Table 6.3)

Table 6.3 Breakdown of respondent by recruitment route

Recruitment route	**n**
Action on Hearing Loss blog	Approx.175
MRC IHR Database	43
NIHR Nottingham BRC	Approx. 100
Unknown	22
Total responses analysed	**344**

The response rate was worked estimated using number of participants contacted from those who completed from the total number of participants contacted via the (Nottingham BRC and MRC IHR) databases was 600. The number of completed surveys from participants from these databases was 143. This gives an estimated response rate of 23%. Therefore the estimated response rate of 20-30% was met.

The following sections will describe results for the hearing aid user respondents: (i) demographic information (ii) day-to-day television viewing habits (iii) television viewing difficulties. The next section will cover the results for the communication version of the survey: (i) demographic information (ii) day-to-

day television viewing habits (ii) impact of partner's hearing loss on television viewing.

6.4.1. Hearing aid users

The majority of hearing aid user respondents had been wearing hearing aid(s) for more than 12 years (Table 6.4).

Table 6.4 Approximate duration of time since hearing aid(s) issue

Duration of Hearing Aid Use	n	%
< 3 months	4	1
3 to 6 months	16	5
7 to 11 months	10	4
1 to 3 years	45	15
4 to 7 years	65	21
8 to 11 years	43	14
> 12 years	120	39
Unsure	4	1
Total	**307**	**100**

6.4.1.1 Demographic information

143 men took part in the survey and 164 women participated in the survey. Seven respondents did not answer the demographic questions. Of the 300 who did, 195 were retired, 38 were in part-time employment, 52 were in full-time employment, and 15 specified other. The mean age of participants in this group was 65.9 years (range: 28-94 years).

6.4.1.2 Hearing aid usage

The majority of participants reported typically wearing their hearing aids all day (n=231, 75.2%) and were experienced hearing aid users (>12 years n=120) (Table 6.5).

Table 6.5 Self-reported daily use of hearing aid(s)

Self-reported daily use of hearing aid(s)	n
Don't wear them	18 (5.8%)
Less than 1 hour	12 (3.9%
1 to 2 hours	16 (6.2%)
2-3 hours	3 (0.7%)
3 to 5 hours	27 (8.7%)
All day	231 (75.2%)
Total	307

Most hearing aid users reported that they felt hearing aid(s) had helped them to listen to the TV (68.2%). The remaining respondents felt that hearing aid(s) had not improved TV listening (22.8%), or were unsure (8.8%). About two-thirds respondents wearing their hearing aids 'All of the time' (n=60.3%) when watching TV (Figure 6.2).

6.4.1.3 Television viewing habits

114 respondents (37.1%) reported to having one TV at home, 103 respondents (33.5%) reported having two TV at home, 61 (19.8%) reported having three TV at home and 26 hearing aid users (8.4%) reported having more than three televisions. The majority of respondents reported to typically watching TV everyday (n=92%), most commonly between 2 to 4 hours (Figure 6.1).

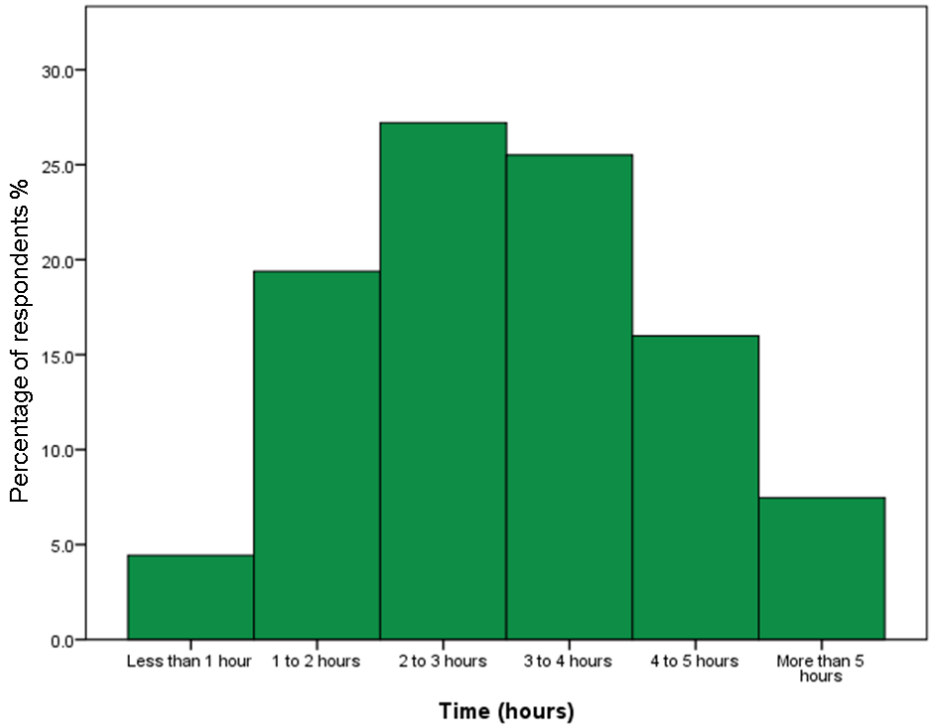


Figure 6.1 Q11 On average, how many hours per day do you watch TV per day?

6.4.1.4 Television listening difficulties

Results from this survey study found that most hearing aid users reported difficulty listening to the TV (88%), and this degree difficulty varies according to the type of TV programme (n=296, 92.0%). The survey results show that even when individuals wear their hearing aid(s) to watch TV, they still struggle to follow the dialogue.

When asked if hearing loss affected the respondent's enjoyment of watching TV, (n=144, 50.8%) reported 'Yes' and (n= 107, 37.8%) reported 'Sometimes'. A much smaller proportion of hearing aid users did not feel hearing loss had affected their enjoyment of watching television (11.3%). However, some respondents also reported that since having hearing loss, they watch less TV than they used to (26.9%).

In response to the statement, ‘Even if I alter the volume of the TV I still cannot understand the dialogue’ 55.6% responded with ‘sometimes’, 24.1% responded ‘most of the time’ and 12.2% responded with ‘all the time’.

In response to the statement, ‘If I raise the volume of the TV loud, others complain it is too loud’ (n=57, 62%) of respondents indicated this occurs ‘Sometimes’, ‘Most of the time’, or ‘All the time’.

About two-thirds respondents wearing their hearing aids ‘All of the time’ (n=60.3%) when watching TV (Figure 6.2).

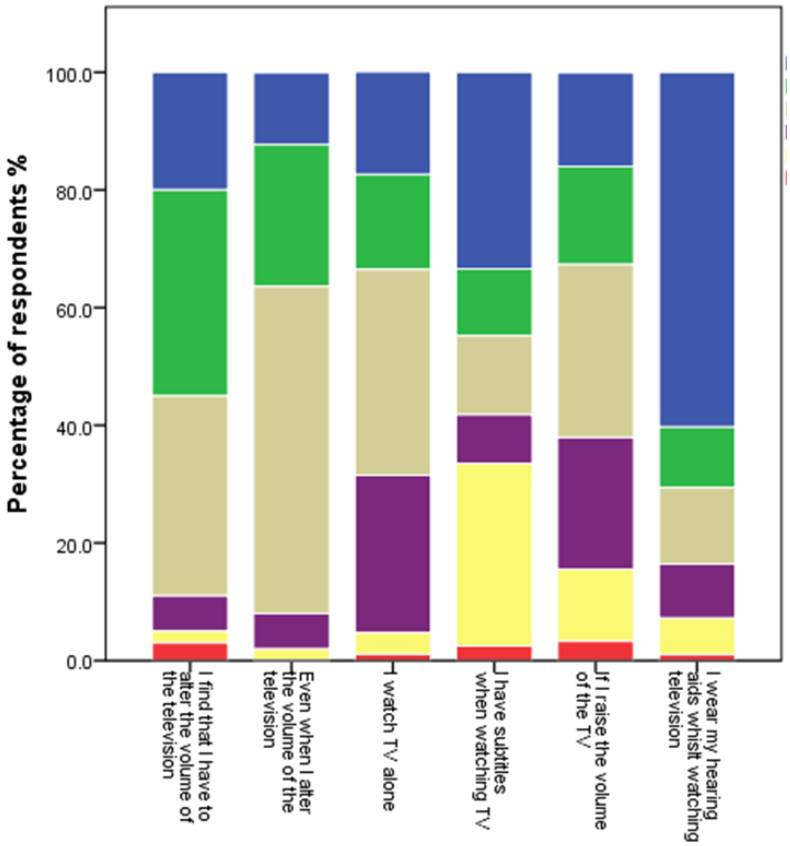


Figure 6.2 Q22 Responses to survey statements that explore TV difficulties of hearing aid users

Blue represents the response ‘All the time’, green: ‘Most of the time’, beige: ‘Sometimes’, purple: ‘Rarely’, yellow: ‘Never’ and red: ‘NA’

The quality of the listening experience was often reported to vary across TV programmes (n=269, 92.4%). The TV genres that hearing aid users reported having the most difficulty with were drama/soaps (44.5%), and films (22.7%) (Table 6.6).

Table 6.6 Self-reported difficulty based on TV genre.

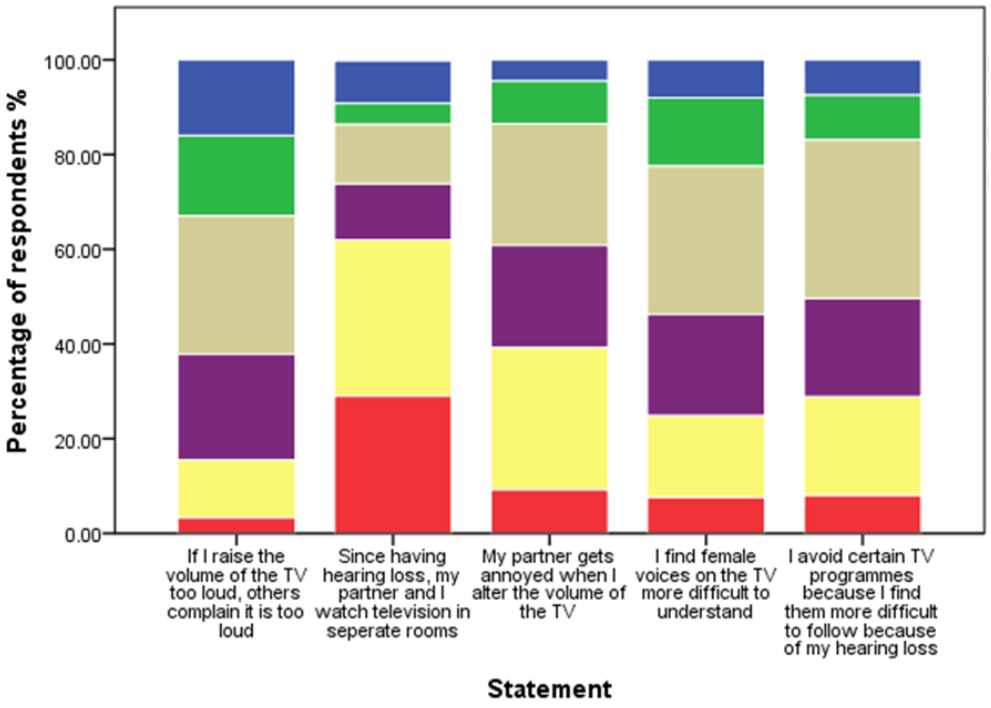
Q18: What types of TV programmes do you have greater difficulty understanding because of your hearing loss?	n	%
Soap/Drama	171	44.5
Films	139	22.7
Documentaries	72	11.8
Chat shows	67	10.8
News	57	9.9
Gameshows	52	8.9
TV adverts	41	6.9

Respondents were allowed to select more than one option. All 307 hearing aid users answered this question.

With respect to the impact of hearing loss, the majority said that when they raise the TV volume, that others complain that it is too loud 'all the time – sometimes' (n=152, 62%). On a positive note, some partners indicated that the impact of their hearing difficulties with the TV had not resulted in having to watch in a separate room to their communication partner (n=141, 45%). However, some mentioned that the loud volume has caused annoyance to their communication partner (n=39, 13.5%).

Some hearing aid users reported to struggling to follow female voices on the TV 'All the time' (n=23, 7.45%) or 'Most of the time' (n=29. 9.4%). Half of the respondents (n= 153, 49%) avoided certain TV programmes because they had difficulty following the dialogue.

Figure 6.3. Q22 Responses to survey statements that explore TV difficulties of hearing aid users



Blue represents the response 'All the time', green: 'Most of the time', beige: 'Sometimes', purple: 'Rarely', yellow: 'Never' and red: 'NA'

Most hearing aid users indicated that do not use any such device (n=192, 62.3%). The most frequently reported use of an assistive listening device for the TV was a room amplifier used by (n=17, 11.0%) of respondents. Other devices included a sound box (n=11, 4%), personal radio aids (n=5, 1.6%), wireless headphones (n=6, 2%), roger pen (n=3, 1%) ad extension speakers (n=3, 1%). Some respondents indicated that they had tried an assistive listening device in the past but did not receive any benefit from the device (n=4, 1.3%). The remaining respondents indicated the use of 'other' assistive listening devices (n=30, 9.73%).

In the survey we also asked respondents who did not use any assistive listening devices as to whether they would consider investing in any. The most

respondents answered ‘Yes’ or ‘Unsure’ (n=150, 62.2%) but there was also a considerable number of participants who indicated have not consider investing in any assistive listening devices for the TV.

6.4.2. Communication partners

6.4.2.1 Demographic information

Twenty respondents completed the partner version of the survey. Of these, 13 respondents were female, six were male and one preferred not to disclose their gender. Of those, ten respondents were retired, eight were in full-time employment, and two were in part-time employment. The mean age of respondents was 68.5 years (range: 55-69 years).

The majority of communication partner respondents reported having two TVs in their home (n=21). The remaining one respondent reported having one TV. The use of subtitles was varied among respondents, but with most communication partners reporting use of subtitles ‘Never’ or ‘Rarely’ (n=19).

The majority of respondents reported typically watching TV with their spouse/partner (75%). Fewer reported watching TV alone (15%) or with a family member (10%). In the current study, hearing aid users and communication partners reported watching TV typically between two and four hours a day (n=155).

When asked if they thought their hearing aid user spouse/partner would benefit from using an assistive listening device for watching TV (aside from hearing aids), the majority of respondents reported that they were ‘unsure’.

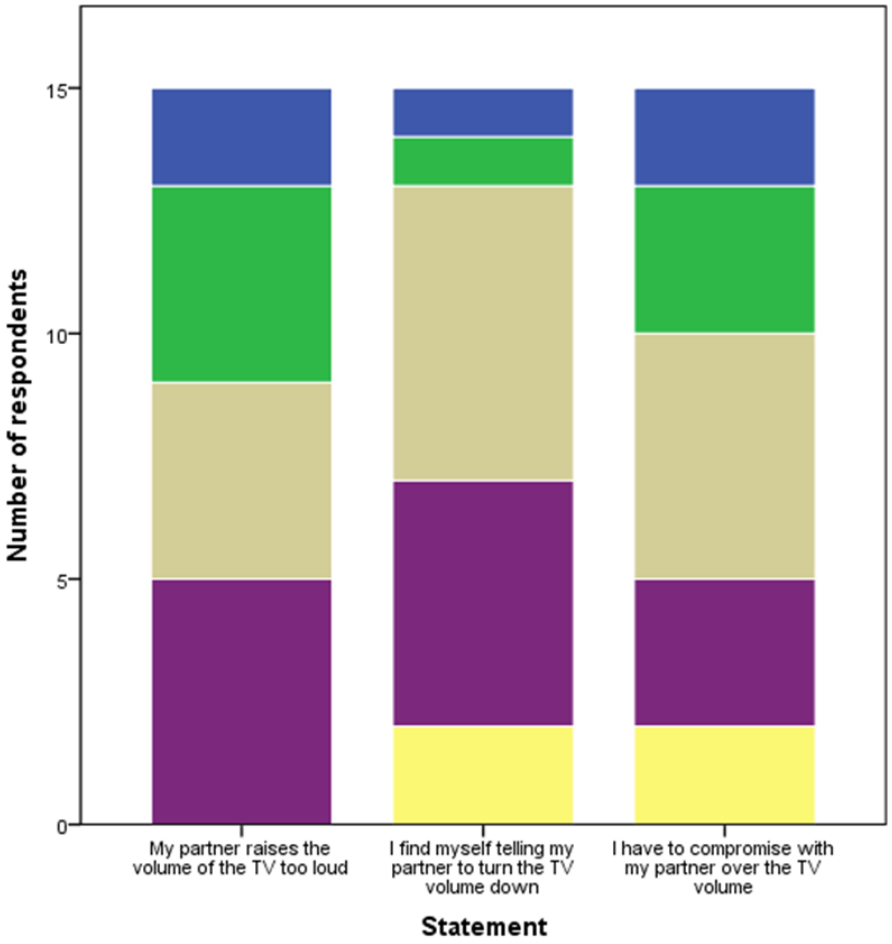
Table 6.7 Perception of hearing aid benefit from communication partner's perspective

Survey question	Q37: Since your partner was issued with hearing aids, do you feel this has improved his/her listening of the television?		Q38: Do you feel your partner doesn't turn up the volume of the television as much since having hearing aids?	
Response	**n**	**%**	**n**	**%**
Yes	5	22.7	5	22.7
No	11	50.0	11	50.0
Unsure	6	27.3	6	27.3

Whereas most hearing aid users had stated that wearing hearing aids had improved their listening of the TV, most of the communication partners felt that this was not the case. Eleven partners answered 'No' as to whether they felt hearing aids had improved their hearing-impaired partner's listening of the TV (Table 6.7). Furthermore, half of the partner respondents felt that the level their hearing aid user partner turns up the volume hasn't lessened since wearing hearing aids.

There were mixed reports about how frequently their partner raises the TV volume. Most partners reported that this occurred 'Sometimes' (29.4%) (Figure 6.4), other partners reported this to be; 'Most of the time' (23.6%) and 'All the time' (17.64%). The majority of partners reported typically having to tell their partner to lower the TV volume 'Sometimes' (41.1%).

Figure 6.4 Communication partner's perspective of hearing aid user's usage of volume control for TV

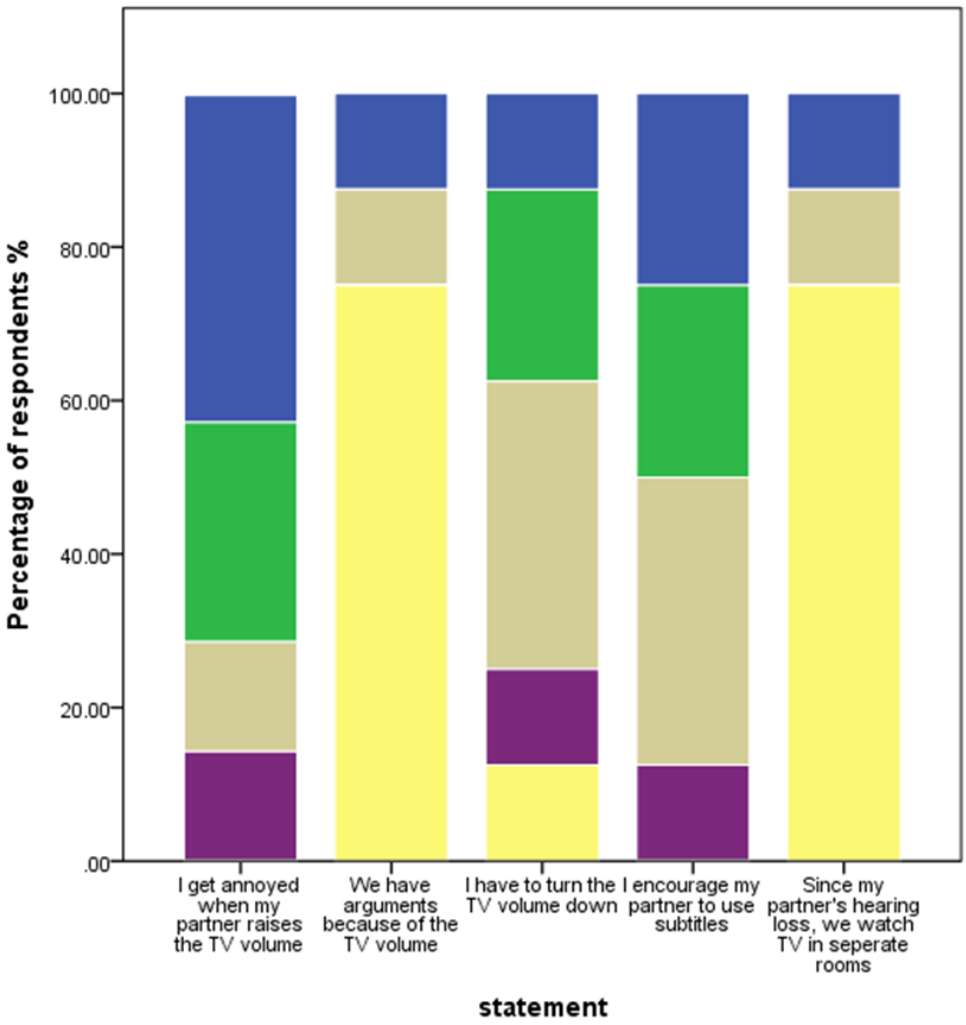


Blue represents answer response 'All the time', green: 'Most of the time', beige: 'Sometimes', purple: 'Rarely' and yellow: 'Never'.

Some communication partners stated that they get annoyed 'All the time' or 'Most of the time' when their partner raises the volume of the TV (n=6) (Figure 6.4). The number of respondents who completed this question was 16.Most communication partners found that they typically have to tell their hearing-impaired partner to turn down the TV volume 'Most of the time' (n=6) of 'Rarely' (n=5).

However, this tended not to lead to arguments (12.5%). Most partners admitted to encouraging their partner to use subtitles ‘All the time’ (25%); ‘Most of the time’ (25%) and ‘Sometimes’ (37.5%) (Figure 6.5). This suggests some level of accommodation to the hearing aid user’s needs from the partner, a domain found in the Chapter 2 and is reported by several studies.

Figure 6.5 Survey statement that taps into impact of hearing loss on (non-hearing aid user) communication partner



Blue represents answer response ‘All the time’, green: ‘Most of the time’, beige: ‘Sometimes’, purple: ‘Rarely’ and yellow: ‘Never’.

Forty percent of partners did not feel that they have to compromise with their hearing aid user partner over the TV volume. Given that the age demographic

of the partner group was similar to the hearing aid user demographic, it is likely that this group has some level of hearing loss themselves. This may provide some rationale as to why the reported annoyance over the TV volume is so varied.

6.5. DISCUSSION

The primary objective of the current study was to explore the TV viewing difficulties experienced by hearing aid users and communication partners. The results of this study demonstrate the specific difficulties associated with TV listening from the perspective of hearing aid users and their partner. Hearing aid users who participated in the survey reported wearing their hearing aid(s) whilst watching TV but with varied levels of benefit. Whilst most respondents reported they felt hearing aids had improve their TV listening, this contradicted to the partner's view. The majority of hearing aid users reported that despite having to raise the TV volume, they still struggled to understand the dialogue. Difficulties experienced appeared to vary according to the type of TV programme.

6.5.1. Hearing aids alone are not a solution

The results indicate that despite hearing-impaired individuals wearing their hearing aid(s) whilst watching TV, they still require to increase the volume. This also appears to be a considerable issue for their communication partners who complain of having to ask them to turn the volume down to meet their preference. In relation to TV viewing difficulties specifically, the TV volume being too loud is the primary and most frequently reported complaint from the perspective of communication partners (Chapter 2). It is well reported that the perceived level of hearing aid benefit among people who have hearing loss is

mixed (Dawes et al., 2014b). Hearing aids alone cannot optimise listening (Boothroyd, 2007), there are many factors that can influence the accuracy and ease of listening. Specifically, in regards to TV viewing, the signal-to-noise ratio of certain types of programmes such as live shows or sports coverage can make listening to the dialogue or commentary challenging (Rui et al., 2000). Poor signal-to-noise ratios are also known to a greater challenge for individuals with hearing loss to process and listen to (Sarampalis et al., 2009, Zekveld et al., 2011).

In the current survey study, the majority of hearing aid users reported turning up the TV volume but without improving speech intelligibility. Whilst there have not been any studies that have explored the speech intelligibility of hearing aid users whilst watching TV specifically, a frequent complaint among hearing aid users is that hearing aids makes sounds louder does not improve clarity (Kochkin and Rogin, 2000, Gatehouse et al., 2003). This observation could be applied to hearing aids users whilst watching TV, where the hearing aid user still has to increase the volume of the TV but this doesn't necessarily improve perception of the dialogue. TV programmes often feature real life situations, such as group conversation, and conversation in noise. These types of situations are already known to be particularly challenging real-life listening situations for individuals with hearing loss. Therefore the frequently reported listening complaints by individual such as those "Listening" domains in Chapter 2 may be applicable to watching television which emulate the subdomains "Listening in a group of talkers" or "Listening in noisy environments". For example, in the focus groups reported in Chapter 3, some hearing aid users made specific reference to their television difficulties; *"There always seems to me to be much louder music than there is speech" [Male 2].* This particular quote

suggests in speech perception in scenes where there is competing background sounds.

Sixty-eight percent of hearing aid users reported they felt hearing aids have improved TV-listening compared to without hearing aids, but still experience the same TV-difficulties aided. However, there seems to be a disparity between the level of benefit that hearing aid users feel they get from wearing hearing aids whilst watching TV compared to the level of benefit perceived by their partner as 47% communication partners felt that their hearing aid user partner still raises the volume of the TV as much compared to pre-provision of hearing aids. In the survey study conducted by Strelyk and colleagues, the authors found a disparity in TV loudness satisfaction in their survey study of 173 hearing aid users and 173 people with hearing. The majority of respondents indicated they were 'very satisfied' with the TV loudness when they set the volume themselves (56% non-hearing aid users; 58% hearing aid users). However, only 30% of hearing aid users and 32% of non-hearing aid users stated they were 'very satisfied' when someone else sets the TV loudness (Strelcyk et al., 2016). These results show the disparity in an individual with hearing loss' TV volume preference compared to someone else who doesn't have hearing loss. This shows that in most couples where one partner has hearing loss, satisfaction of the TV volume can only be met for the one partner who has set the volume to their preference. This volume preference may therefore at the detriment of the other partner's enjoyment of watching TV.

In the survey study conducted by Strelcyk et al. (2016), the authors also found that most respondents stated that they change the volume of the TV 'every few minutes' (19%), 'before/after commercials' (31%) or 'at the beginning of a new programme' (29%) (Stelyk et al., 2016). The authors report the most common

reasons for altering the TV volume include decreasing the volume during TV adverts, increasing the quieter parts to hear the dialogue better, adjusting volume for loudness differences between programmes and also to decrease the volume where the sound is too loud.

In the focus group (Chapter 3), some hearing aid users reported that sometimes the TV background sounds/music is too loud, forcing the individual to reduce the TV volume. Not all of the reported reasoning in the literature is attributed to having to have the TV set at a loud volume. Some authors reported interview responses of participant's describing the loss of spontaneity in conversation whilst watching TV to be a factor in the reduction in overall enjoyment of watching TV (Morgan-Jones, 1998, Scarinci et al., 2008).

The range of self-reported difficulty with certain TV genres suggests that the content is more acoustically challenging in some programmes compared to others (Kurz and Mikulasek, 2004). This is observed in the current study where hearing aid users reported 'Soaps' (44.5%) and 'Films' (22.7%) is more difficult to follow. These types of programmes often switch between speakers and settings throughout. The acoustics of these programmes therefore can be incredibly dynamic, especially in films where there often background noise that can drown the dialogue (Bonsignori, 2009, Fuchs and Oetting, 2014). The dialogue of gameshows were also reported as being difficult (8.9%). These shows are often live, and even if pre-recorded, usually contain multiple speakers and filmed within a large studio with an audience. Spatial separation in a multi-talker situations such as those depicted in these types of programmes where there can be lots of people talking is known to be significantly reduced by both hearing loss and reverberation (Marrone et al., 2008). This could be another factor that makes TV listening challenging even for someone who has

normal hearing. TV adverts were reported relatively lower in terms of difficulty for hearing aid users (6.9%). This could be due to the relatively quick nature of adverts that often have visual cues to aid the message of the advert as well as a clear speaker to convey the message. There is also evidence to suggest that the volume of TV adverts tend to have multiple types of sound stimuli, that is also louder to entice the viewer (Schwartz, 1974).

6.5.2. Listening scenarios that are difficult in real life are also difficult on TV

A lot of the difficulties pertaining to TV listening, align with real-life listening complaints synthesised in Chapter 2. Eighty-nine percent of hearing aid user reported to having to increase the volume of the TV. An important finding is that the degree of difficulty varies across different types of programmes which relates to listening difficulties in real life scenarios and listening environments. The subdomains “Listening to speech in a group”, “Listening to speech in noisy environments” and “Listening to speech in public places” for example maybe be closely applicable to situations depicted in drama, movie and live show genres. These subdomains are less likely to be applicable to content in genres such as weather forecasts and some types of documentaries which typically do not feature background noise or multiple speakers. Another example in the current study relating to the “Listening” domain is that some hearing aid users reported finding female voices on the TV more challenging to follow (53.8%). Struggling to understand female voices among those with hearing loss, particularly high-frequency hearing loss has been reported in some qualitative studies.

6.5.3. Low reliance on subtitles

Some qualitative studies have reported the use of subtitles to follow the dialogue (Wallhagen, 2010). In the current study only 33% of hearing aid users

reported to using subtitles “All the time”. This finding differs to that found in the survey study (Strelcyk et al., 2016) where 67% of respondents reported that they use subtitles whilst watching TV to varying degrees. The low-reported usage of subtitles in the current study could be to a number of reasons. There is currently an on-going debate as to the efficiently of subtitles (Schröter, 2003) and in the media, particularly in regarding to timing of display in relation to the speaker (Ensor, 2011, stories, 2013). This is particularly true for live shows, where there is often a lag between the dialogue and the display (Evans, 2002). Another reason for the relatively low percentage could be due to literacy and/or visual competency of the viewer (Hefer, 2013). Given that the rate of cognitive processes are known to decline with age (Salthouse, 2009), having subtitles in addition to the visual content of a TV programme and the audio content might present another processing challenge for older adults who are hearing aid users. The amount of visual content might also affect the ease of listening due to the amount of cognitive processing required (McCoy et al., 2005), and it may distract the viewer from the audio content. The low subtitle usage among hearing aid users who completed this survey could also be attributed to the greater difficulty for the hearing aid user to talk to other people whilst reading the subtitles and being too reliant on subtitles, can cause a hearing-impaired person to miss what is being said by the significant other (Morgan-Jones, 1998, Scarinci et al., 2008).

6.5.4. Low reliance on assistive listening devices

The results of the current survey suggest that hearing aids alone cannot alleviate the difficulties faced by hearing aid users whilst watching TV. The benefit of using assistive listening devices for watching TV, remains unclear. The majority of hearing aid users in the current survey reported to not using an

assistive listening device (62.3%), and most were unsure as to whether their hearing aid user partner would benefit from using one (62.2%). The findings for this question are consistent with those found the survey study conducted by Strelyk et al. (2016), where most of hearing loss respondents stated that they use the in-built speakers only of the TV to hear the audio, as opposed to any additional devices.

Despite recent range and continual expansion of assistive listening devices, it is unclear as to how accessible these devices are. Assistive listening devices such as some types of loop systems and FM systems have been developed specifically for the listening to the television (Connevans catalogue, 2015). However, as reported in Chapter 4, adult aural rehabilitations plans on the NHS typically comprise of a hearing aid fitting only (AoHL, 2015). The question as to how much information patients receive about assistive listening devices. A study conducted by Harkins and Tucker (2007) surveyed the uptake of assistive listening devices in a population of hearing aid users and found that the largest number of assistive listening device users was the one in which a receiver is typically provided rather than purchased. This study suggests hearing aid users view the cost of owning devices to be a barrier to use.

6.5.5. Television viewing difficulties: Communication partners

In the current study, a large majority of communication partners (n=85%) felt that their partner raised the volume of the television too loud. This is a perspective that has been reported several times in the qualitative literature. Feelings of frustration or annoyance among communication partners in response to the loud volume of the TV has been reported by partners in some studies (Hetu et al., 1988, Stark and Hickson, 2004, Scarinci et al., 2008). Scarinci et al. (2008) conducted in-depth interviews with the spouses of hearing

aid users and reported that participants complained that the volume of the TV is often too loud. Participants made reference to the impact of retirement and attributed life-style changes to their ability to cope with the television volume because retirement often mean relocating from a larger family home to a smaller home, often with only one TV.

Brooks and colleagues conducted semi-structured interviews of the communication partners of patients diagnosed with hearing loss to explore what effect the provision of hearing aids to their partners had had on them (Brooks et al., 2001). The authors found that participants with hearing loss and communication partners experienced some degree of difficulty and emotional upset in television viewing before the provision of hearing aids. Results showed that both groups were less distressed with the television viewing situation after the provision of hearing aids. The authors suggest that exactly who has the greatest difficulty with the television depends on who has control of the television remote. In the current study, 42% of communication partners reported to still getting annoyed over the TV volume, even when their hearing-impaired partner was wearing their hearing aid(s). McNeil and colleagues sought to investigate hearing-impaired patient's partners' perceptions of functional improvement following bone-anchored hearing aid fitting using the HHIA-Screening. The authors highlight that partners indicated the greatest impact of BAHA fitting was in relation to the television/radio situation (McNeil et al., 2011). However, in the current study only five communication partners felt that that hearing aid(s) had improved their partner's TV listening.

6.5.6. Strengths and limitations

To our knowledge, this study is the first to explore the range of difficulties related to television viewing among hearing aid users, *and* communication partners.

This study taps the specific hearing-related difficulties of watching TV, as well as how this varies across different TV genres. The study highlights the difficulties people with hearing loss have with TV which is an integral recreational activity for many people but current hearing loss interventions do not seek to address. It also explores methods hearing aid users use to remediate some of these difficulties e.g. use of subtitles. Various dissemination strategies for the survey were also adopted and thus respondents to survey represented a diverse range of hearing aid users. The study provides several novel insights. For example, the perceived level of benefit of hearing aids for TV watching from the perspective of hearing aid users was greater than that of their communication partner. Hearing aid users and communication partners typically reported only being satisfied with the TV volume on occasions where it is set to individual preference. This study, together with Chapter 5, also identify the low uptake of assistive listening devices (including the use of subtitles) among hearing aid users.

There was one limitation to the current study which may have affected the reliability of the results. The recruitment methods were targeted at hearing aid users and so this may have led to the relatively low numbers of communication partners who completed the survey. Therefore, it was particularly difficult to tap into this population. Unless partners or spouses visited the Action on Hearing Loss website directly, or were followers of the Nottingham BRC social media website were informed of the survey by their hearing aid user partner, then the likelihood of the survey reaching these people would have been very small. Having less communication partner respondents could make their results difficult to generalise to this population.

CHAPTER 7. SUMMARY AND DISCUSSION

7.1. SUMMARY OF KEY FINDINGS

The primary aim of this doctoral research was to identify domains of hearing loss that are reported by people with hearing loss and communication partners as being a problem for them. This objective was addressed with five consecutive studies (Table 7.1) using a mixed-methods approach.

Study one was a meta-ethnographic synthesis of the research evidence for the implications of hearing loss on individuals with hearing loss and communication partners. The number of studies included in the review was 78. This comprised 49 studies that explored the impact of hearing loss on those diagnosed only, 11 studies that explored the impact of hearing loss on communication partners, and 18 studies that explored both perspectives. Of these, the number of included studies that employed qualitative methods was 34 and there were 44 quantitative studies. Two frameworks representing domains of hearing loss were developed from the extracted data from the included studies: a “person with hearing loss” (DoHL-P) and a “communication partner” (DoHL-CP) version. DoHL-P represents the implications of hearing loss on themselves. DoHL-CP depicts the implications of the hearing loss on the communication partner of the hearing impaired individual. Both frameworks present with the same hierarchical structure with high order supra-domains and lower level domains and subdomains. The supra-domains span “Auditory”, which describes domains relating to the perception of sound and speech. In “Auditory” there are 14 domains: *Hearing, Listening, Communicating and Speaking.* The total number of subdomains across this domains is 81. The supra-domain “Social” comprises domains relating to the impact of hearing loss on social and

recreational activities. This supra-domain contains six domains: *Interventions, Social Life, Isolation, Occupational and Relationships.* The final supra-domain is “Self” which refers to self-perception and personality. “Self” contains five domains: *Role of Communication Partner, Emotions, Effort and fatigue, Identity and Stigma.*

Study two evaluated the face-validity of the frameworks. The frameworks were reviewed by 13 stakeholders: five hearing aid users, five communication partners and three hearing healthcare professionals. As a result of these focus groups, two subdomains were added to DoHL-P. The subdomain “Sound localisation” was added under *Hearing* and the subdomain “Listening to speech (unfamiliar speakers)” was added under *Listening.* There was some modifications to the terminology of pre-existing domains and subdomains. The domain *Speech production* was modified to *Speaking* and its subdomain “Speech production” was modified to “Speaking with a loud voice”. The subdomains within the domain *Occupational* (“Restrictions at work” and “Reduced job prospects”) were modified “Opportunities at work” and “Abilities to perform duties at work”.

Table 7.1 Overview of studies reported in this doctoral thesis, and key findings

Primary objective	Study design	Participants	Analysis	Key findings
Study 1: To collect and synthesise generic and hearing-specific complaints in everyday life that are reported by people with hearing loss, and by communication partners	Comprehensive review	Research evidence where adult with hearing loss and/or communication partners are the populations of interest	Meta-ethnography (inductive)	Domains of hearing loss frameworks (DoHL-P and DoHL-CP)
Study 2: To explore comments made by hearing aid users and communication partners on the domains of hearing loss frameworks, with respect to their own personal experience of understanding the construct	Focus groupx3	13 participants: five hearing aid users, five communication partners and three audiologists	Thematic analysis (deductive)	Two additional subdomains consolidated into frameworks : 'Sound localisation' and 'Listening to speech (unfamiliar speakers)'
Study 3: To identify those domains relating to the most important patient- and communication partner aspects of hearing loss	Online/paper questionnaire-survey	255 respondents: 207 hearing aid users and 48 communication partners	Ranking analysis and thematic analysis (deductive)	Top ranked domain across both frameworks: 'Communicating'
Study 4: To measure and relate the television volume set by participants across couples one of whom is a hearing aid user and the other is a partner	Prospective case-control	84 participants: 42 hearing aid users and 42 partners	General linear model	Difference in TV volume preference between hearing aid users is 6.3 dB
Study 5: To report on those TV viewing difficulties of hearing aid users and communication partners	Online/paper questionnaire-survey	329 respondents: 307 hearing aid users and 22 communication partners	Descriptive statics	Hearing loss has negatively affected enjoyment of TV viewing. Use of subtitles and assistive listening devices among hearing aid users is low

The aim of study four was for the same stakeholder groups (people with hearing loss and communication partners) to then rank the domains of hearing loss frameworks according to what is most important to them. Overall, 255 people who took part in the domains rankings survey; 207 hearing aid users and 48 communication partners. The top three ranked domains for DoHL-P was *Communicating, Hearing* and *Listening.* The domains ranked lowest were *Identity* and *Speaking*. The respondents submitted a total of 41 responses to the open questions: “Do you feel there are any aspects of your life that is affected by hearing loss that is not represented in the list?” (person with hearing loss version) and “Do you feel there are any aspects of your life that are affected by communicating with a person who has hearing loss that are not represented in the list?” (communication partner version). Of those, 33 responses could be mapped onto the frameworks at subdomain level. The remaining eight responses were either classed as miscellaneous responses or tinnitus-related and thus were not within the scope of the research question. Hence, there were no modifications to the frameworks as a result of this survey. The final version of each frameworks is presented in Table 3.6, Table 3.7 and Table 3.8 presented separately for the Auditory, Social and Self supra-domains respectively.

Eighty-four participants comprising 42 hearing aid users and 42 partners took part in the fourth study, which explored the preferred TV volume of hearing aid users and their spouse/partner. The mean TV volume of the 12 clips for hearing aid users was 68 dB SPL and 61 dB SPL for the spouse/partner group. The difference in mean TV volume for the 12 clips therefore was 6.3 dB. The volume set by hearing aid users for the clip viewed together was 3 dB louder than the volume set by the spouse/partner group.

The aim of the fifth and final study of the PhD explored the general television habits and the associated difficulties of watching TV for people who have hearing aids and their communication partners. In total, 329 took part in the television viewing experience survey; 307 hearing aid users and 22 communication partners. Most hearing aid users reported wearing their hearing aid(s) whilst watching TV (n=75%). The majority of respondents felt that their hearing loss had affected their overall enjoyment of watching TV. Most hearing aid users (68%) felt that their hearing aid(s) had helped them listening to the television whereas most communication partners felt that hearing aids had not improved their hearing-impaired partner's ability to listen to the TV (n=35%) or were unsure (n=24%). The TV genres reported most difficult to listen to due to hearing loss was soap/drama and film. Aside from hearing aids, most hearing aid users stated that they do no use any other assistive listening devices to watch TV.

7.2. GENERAL DISCUSSION

7.2.1. Comparison of findings of domains ranking survey with findings from the comprehensive literature review

The domain 'Communicating' represents a key aspect of life affected by hearing loss that is reported many times in the literature on hearing aid users (Magilvy, 1985, Hetu et al., 1987, Hétu et al., 1993, Hallam and Brooks, 1996, Gething, 2000, Morgan-Jones, 2001, Tsuruoka et al., 2001, Hass-Slavin et al., 2005, Hidalgo et al., 2008, Wallhagen, 2010, Kelly and Atcherson, 2011, Jonsson and Hedelin, 2012, Ekberg et al., 2014). The process of communicating requires at least two people, which means that any impairment to listening and participating in conversation is likely to impact on the other participant. This may account for the considerable reporting of this domain in

the person with hearing loss and communication partner literature, as well as being ranked number one by both stakeholder groups.

Despite the domain 'Interventions' being ranked 10th, those associated domains that were ranked relatively important to patients were complaints of hearing loss that can't necessarily be alleviated by hearing aids alone, such as "Emotions" (state the rank) and "Relationships" (state the rank). The fact that the interventions domain was ranked so low also raises the question as to how important hearing aid users consider their hearing aid(s) to be, or whether they felt their hearing aids were performing well but accepted the transfer of benefit to other aspects of life was not possible. This also suggests some uncertainty as to the purpose of patient's help seeking for their hearing loss, and whether these help-seeking efforts are indeed always with the expectation of being issued with hearing aids. It has been shown that not all patients attending audiological assessments describe their reason for attending the appointment as the expectation of getting hearing aids (Claesen and Pryce, 2012, Ng and Loke, 2015). This could provide some explanation as to why hearing aid usage is so low among those who own them (Action on Hearing Loss, 2011). A recent systematic review conducted by Ng and Loke (2015) identified a number of non-audiological determinants affecting the adoption and use of hearing aids, including self-perceived hearing problems, expectation and support from significant others. The determinants listed are all examples of factors that perhaps typical audiological assessment appointment may not capture since the focus of these appointments is typically on the audiological determinants of hearing aid uptake and use, such as audiometry (Cox et al., 2005, Boothroyd, 2007). The authors highlight the need to explore the influence of significant others in auditory rehabilitation.

7.2.2. Comparison of domains survey findings with focus group

The primary difference between the focus group study and the domains ranking, is that the focus group participants were asked only to share their experience of the domains, rather than to rank the domains in order of importance.

In the domain ranking survey study, all domains were ranked by respondents, indicating the relevance of the domains to the respondent's day-to-day lives. Whilst the purpose of the survey was for respondents to rank domains most important to them, it does not necessarily mean that domains ranked as not so important should be ignored or discarded. The domain ranked least important in day-to-day life was 'Speaking'. In Chapter 1, there were 16 extracted complaints from the included studies pertaining to this domain. In Chapter 3, all of the hearing aid users in the focus group could relate to this subdomain. Unlike the focus groups, there may have been some potential for respondents of the survey to misunderstand, or not fully grasp the meaning of the domain, despite the fact that the definitions of each domain provided in the survey. In the focus groups, there were opportunities for participants to ask questions, and for the facilitator to elaborate on the definition of each domain. Giving definitions of the domains to greater detail in the survey would have made the survey lengthier and text-heavy which may have put some respondents off from completion of the survey

One of the most highly discussed domains in the communication partner focus group was "Communicating". All the participants within this focus group could relate to all the corresponding subdomains. This compares with the survey study where the domain 'Communicating' was the highest ranked. A lot of the extracted complaints from the included studies relating to communicating and the focus group discussions were in relation to communicating in different environments and/or in social settings. However, there were also a

considerable number of complaints from hearing aid users relating to communicating with their communication partner specifically. This difficulty in communication reported by both perspectives also emphasises one of the gaps in current aural rehabilitation plans which tend to involve counselling patients on how to optimise listening with their hearing aids to the exclusion of their partners (Boothroyd, 2007, Abrams and Chisolm, 2013, Grenness et al., 2014a, Habanec and Kelly-Campbell, 2015). It could be that communication partners typically have higher expectations of hearing aids and communicate in a way that is not optimal for someone who wears hearing aids (Barker et al., 2017). It may also be that hearing aid users have higher expectations of their hearing aids or deem some communicative experiences, such as conversing on the telephone or watching television with their partner, more important than others.

Given the limitations of hearing aids, it is perhaps impossible to improve every listening and communicative experience for people with hearing loss. However, if there are particular situations that more frequent or more important to a patient with hearing loss then these are potentially targets for rehabilitation (Yorgason et al., 2010, Abrams and Chisolm, 2013, Manchaiah et al., 2013a). This is a component of rehabilitation that has been suggested by several researchers, and one that aligns with the current impetus toward patient-centred care and identifying the individual needs of patients (Mead and Bower, 2000, Grenness et al., 2014a).

7.2.3. Comparison of domains of hearing loss framework to Brief ICF Core Set for Hearing Loss

DoHL-P was compared to the Brief ICF Core Set for hearing loss. This project has integrated patient and professional perspectives to create a comprehensive list of categories relevant to adults' hearing loss (Danermark et al., 2013). The ICF was developed to provide an assessment of an individual's functioning with

hearing loss. This emphasis on the person with hearing loss themselves means that the comparison to the domains of hearing loss and where there is conceptual overlap. The domains in DoHL-P were conceptually mapped to the 27 domains of the Brief ICF Core Set using the descriptive labels of each domain and the ICF definitions to assist in interpretation where differences were simply due to terminology (e.g. 'occupational impacts' versus 'remunerative employment').

The Brief ICF Core Set for hearing loss has 27 domains within four category labels: body functions, body structures, participation, and environmental factors. 'Body functions' describes the physiological functioning of the body, 'Activities' refer to "the execution of a task" and 'participation' refers to "involvement in life situations" (Granberg et al., 2014a). 'Environmental factors' comprises the environmental factors such as the physical and social environment in which people live their lives (Granberg et al., 2014a).

Where possible, the domains from our framework were conceptually mapped onto the domains within the Brief ICF Core Set categories. Eight domains from DoHL-P clearly mapped onto those of the Brief ICF Core Set for Hearing Loss, while six further domains appeared to be unique to DoHL-P. These were "Isolation", "Social life", "Effort and fatigue", "Stigma", "Identity" and "Role of communication partner". With respect to "identity", the Brief ICF Core Set does contain the domain 'Societal attitudes' that is defined as "…beliefs held by a social group about other individuals…" but this represents a different concept than the one identified in the comprehensive review of hearing loss domains which was concerned specifically with the way hearing loss negatively changed the person's perception of themselves. Social life was the domain with the highest number of data items across the literature included in our review. Therefore some of the patient-reported implications are *not* represented within

the Brief ICF Core Set for Hearing Loss. While the ICF framework was designed to be widely disseminated across the field of audiology (Granberg et al., 2014a), it exclusively focuses on the person with the health condition and excludes aspects relating to the communication partner. If the ICF framework solely was used to guide clinical practice (such as by framing the patient assessment appointment) then it would risk diminishing the value of implementing family-centred care principles in audiological practice.

As highlighted in Chapter 2, the psychosocial implications of hearing loss on those diagnosed with hearing loss have recently been underpinned by an established theoretical framework, the self-regulatory model. Some of the psychosocial experiences of hearing loss reported by Heffernan et al. (2016) were conceptually mapped onto the self-regulatory model. For example, identity and stigma were mapped onto 'cognitive representations of hearing loss'. The negative emotions that emerged from the author's interviews with hearing impaired people such as frustration, embarrassment and loneliness ('Isolation' in domains framework) were mapped onto 'emotional representations of hearing loss'. A theme that also emerged from the interviews was coping responses. This was not a response to hearing loss that was within scope of the comprehensive review and thus does not appear in either framework. The author identified two forms of coping. The first, 'disengaged coping' comprises of two primary forms, 'withdrawal from situations' which refers to avoiding challenging situations. The second form of disengaged coping, 'withdrawal within situations' refers to being involved in challenging situations but being a passive presence. The second form of coping 'engaged coping' refers to an individual continuing to carry on with their daily life, despite having hearing loss.

7.2.4. Patient-centred care in adult aural rehabilitation

Over the last few years, there is been an increasing acknowledgment for a paradigm shift in healthcare to patient-centred care (also known as client-centred care). As mentioned throughout this thesis, the drive for a patient-centred approach to aural rehabilitation has been highlighted by researchers over recent years. The concept of patient-centred care focuses on the experiences of the person living with hearing loss. Clinicians are often faced with the challenge of having to listen to perspectives of the patient's difficulties as well as the perspectives of family members (Manchaiah et al., 2012). There currently is little evidence that these perspectives are taken into account during rehabilitation in routine clinical practice. For a patient-centred care approach, these insights should be treated as additional expertise to the appointment rather than detraction from the patient. Of course, the focus and consideration of these perspectives should still maintain the interest of the patient and their rehabilitation plan. This paradigm shift toward a patient-centred approach is further ahead particularly in health conditions in paediatric populations. In the context of paediatrics, the term commonly used for this concept is 'family-centred care', where the needs of the child patient is placed in the context of their family. Such approaches are now considered best practice in paediatrics. Mackean et al. (2005) described key elements of family-centred care in paediatrics. Some of these elements could be applicable to a model of patient-centred care for adult aural rehabilitation. These include acknowledging the uniqueness and diversity of patients and their families. This diversity has already been shown in the range of complaints represented in the domains of hearing loss frameworks, as well as the heterogeneity in importance of these domains, within person with hearing loss and communication partner-perspectives as well as across perspectives. Another element stated by Mackean et al. (2005) is to recognise family as central to the patient's life and

to acknowledge that the family bring expertise to both the individual care-giving level and the systems level. This again is applicable to a patient-centred approach in aural rehabilitation, where the inclusiveness of the communication partner's input should be seen as a valuable insight into the impact of hearing loss on the patient's life.

Given the aging demographic of the UK, the number of older adults living with chronic conditions such as hearing loss is continually on the rise. Therefore, it is becoming increasingly recognised that a system of care centred in a medical model where the aim is to alleviate the listening difficulties of a patient only, is a poor fit for both audiologists and patients. In order to explore this the patient-centred care for use in clinical practice, there needs to be a dynamic model of care that incorporates the patient and the partner- perspectives to best meet these needs.

Attempts to integrate biological and social paradigms have been made by WHO with the creation of the ICF Core Sets for Hearing Loss for clinical purposes. This ICF framework certainly allows for a common language used to describe aspects of hearing loss, and acknowledges the multiple stakeholders that extend beyond the researcher, required to build a holistic framework of hearing loss. However, this framework does not consider the partner or family members of the patient.

7.2.5. Communication partners involvement adult aural rehabilitation research and clinical practice

The approach taken in all studies was to pose the same research questions to hearing-impaired people/hearing aid users and communication partners separately. In this research, the data for these questions was analysed separately and then both perspectives were combined to identify where there was convergence and where there was divergence. What is important about

these frameworks is that the person with hearing loss perspective does not contain all the domains and subdomains present in the communication partner version. This confirms that is it is not possible to gain a complete insight into a patient's experiences or difficulties with hearing loss based on their perspective alone.

Some of the key challenges faced by clinicians and researchers in outcome measurement is capturing the implications of hearing loss on a patient's day-to-day life. Finding ways to address all of these complaints in rehabilitation and measure the success of interventions undertaken to address them, is challenging. In an audiological assessment appointment in the UK, the patient will typically undergo a clinical history that taps into the otological and non-otological factors of their suspected hearing loss.

The acknowledgment of the impact of hearing loss on the communication partner of someone with hearing loss has been growing in recent years. As mentioned in Chapter 1, the WHO ICF has referred to this effect on the spouse/partner as 'third-party disability' (WHO, 2001). Whilst studies have led to an improvement in the understanding of the impact of hearing loss on the individual's family members, there are very few instruments that have been developed to measure third-party hearing disability.

The frameworks also highlight the potential significance communication partners have in the life of an individual with hearing loss. In particular, the role of communication partners in assisting their partner and minimising the burden of hearing loss. What is also apparent across the domains of DoHL-P, is that most patient-reported domain refer to experiences based on interactions with other people. Therefore, whilst the impairment of hearing loss plays in big factor

in these difficulties, a lot of these domains (such as the communicating and social subdomains) are also influenced by other people and/or places.

7.2.6. Hearing aid users prefer the TV volume 6 dB louder than spouse/partner

Due to the complaints in the qualitative data pertaining the loud volume of TV, it was anticipated that there would be a difference in volume preference between the two groups. However, the extent of this difference was an unexpected finding. Reasons for the significant difference in volume preference have been suggested to be attributed to acoustical and non-acoustical factors.

An acoustical factor that may have influenced the extent of this volume difference between the two groups could have been due to the hearing aid fit of participants in the hearing aid user group. The electroacoustics of the hearing aids, i.e a verification of whether hearing aid users were fit to target was not carried out. If there were any participants that were not fit optimally, this may have influenced their volume preference.

The comparison of how each group performed in the first and second TV task suggested that the partner group were adjusting their TV volume preference. This accounts for the smaller difference between hearing aid users and partners for the second TV task. The adjustment in volume preference suggests a modified behaviour by the partners that may be indicative of compromising their volume preference to suit their hearing aid user partner. Aside from compromising, another reason could be due to an adjustment in volume set or endured by partners whilst watching TV with their hearing aid user partner that has occurred overtime.

In terms of the non-acoustical factors, hearing-impaired listeners may experience an increase in cognitive load due to the additional processing

required to filter out background sound. The additional resources required for this process may deplete the attentional resources available for higher cognitive processing, such as the ability to contextualise sentences and fill in gaps caused by words not heard (Much 2008, Shirley and Oldfield, 2015).

This finding also confirms that hearing aids alone cannot alleviate the listening challenges faced by a hearing-impaired individual. This statement is supported by previous work by Gordon-Salant and colleagues (2009) that found that speech recognition scores for the televised clips did not significantly improve with the use of hearing aids compared to without.

The concept of listening effort in relation to speech perception with hearing aids has been proposed many times in the literature. This concept proposes that due to the degraded auditory-input, the amount of resources required to attain the same level of perception is more for hearing-impaired people compared to those with normal hearing. The difference in preferred listening volume is likely to also be attributed to the reduced frequency resolution of the cochlea due to hearing loss, which affects speech intelligibility. The lack of intelligibility may have influenced the hearing aid users to increase the volume of the TV. However, it is well known that an increase in loudness does not necessarily equate to an increase in speech clarity or intelligibility.

These differences could also be attributed to differences in speech-to-noise ratios required for people with hearing loss in order for the speech to be intelligible. For example, Whitmer et al. (2015) found that hearing impaired participants preferred higher speech to background sound ratios, with less background sounds.

The result of this study also highlight that loudness perception is a key factor in listening and speech perception for people with hearing loss. However, the

survey shows that loudness alone cannot alleviate the difficulties associated with speech perception. In the TV survey (Chapter 6), hearing aid users reported still having difficulty to understand the TV dialogue even when they had increased the volume of the TV. The fact that most hearing aid users also reported that they usually find certain TV programmes more difficult to follow compared to others also show that the contextual factors of the programme determine the perceived difficulty and therefore may influence the loudness.

This additional concentration required to listen with hearing loss was also suggested in some qualitative data reported in the literature. One of the issues reported by both hearing-impaired people and partners was a loss of spontaneity in conversation. Participants reported that they could not talk to each other whilst watching TV, either because the hearing-impaired partner would struggle to hear over the TV audio, or because the hearing-impaired person would lose thread of the TV programme and it would take additional effort and conversation to follow the TV dialogue again.

A potential limitation to the current study design is that only one volume measurement was taken per clip, as oppose an average volume over 2-3 volume measurements of the same clip. The latter method would have increased the reliability of the volume preference set by participants for each clip.

7.2.7. Challenges faced by TV Broadcasters

Typically, TV content tends to be channel-based systems, where the audio-event positions are defined in terms of the level and time relationships between the signals transmitted into the loudspeaker and mixed into one-package of channels. These packages typically consists of sound sources that are mixed. Shirley and Oldfield (2015) suggests an object-based approach to clean audio,

combined with technique to isolate sounds that are important to the contextual meaning of the programme, gives viewers the ability to control the levels of all aspects of audio such as background noise, from a TV programme. An object-based system therefore allows audio events such as speech and background noise can be separated.

When semantic or contextual cues are limited, this can further exaggerate the problem. In the case of television broadcasts, some broadcasters choose to modify the speech signals e.g. By altering the speed of speech (Shirley, 2013, Shirley and Oldfield, 2015), which can further exacerbate a hearing aid user's problem in hearing the dialogue. Other factors may include the decreased ability to inhibit irrelevant information, such as background noise (Gordon-Salant and Callahan, 2009). Gordon-Salant and Callahan (2009) has suggested this may account for interruptions in television programs, such as TV commercials, may degrade the ability of older people to follow the primary content.

The continual advance of digital TV has shown improvements to, and access to surround sound content. The uptake of this increased dynamic range by broadcasters to incorporate in programmes may in fact lead to greater difficulties in speech comprehension for some viewers who have hearing loss. A White Paper literature review conducted by the BBC (Armstrong, 2011) reported that broadcasters could provide an alternative 'clean audio' version. The creation of an additional soundtrack to each programme however, consumes further resources and does not address the most of the problems audiences have with broadcast speech. Very little research has been carried out that specifically focuses on TV audio for people with hearing loss. Complaints by viewers fed to the BBC have remained largely unpublished, but have appeared in several news releases (Shirley and Oldfield, 2015). Despite

the number of complaints however, broadcasters continue content where the audio is perceived challenging by many viewers.

There are further issues faced by broadcasters to alter the sound content so that it is potentially more intelligible. For example, the BBC White Paper (Armstrong, 2011) reports that audio signals can only be separated completely if they are orthogonal. The extent of this problem is further complicated when the signal contains several sources. Any changes to the signals, such as reverberation or distortion will result in residual noise signals which cannot be removed from the individual sources. And sufficient linear mixes to separate speech signals mixed with noise or music do not currently exist (Armstrong, 2011). These methods therefore give rise to a distorted speech signal.

In the cases of separating speech from background noise, this is more challenging. Competing background noise signals e.g. dynamic noise (other speech), can be more difficult to separate the wanted speech from the unwanted speech. Current noise reduction systems model the wanted speech signal and then attenuates or removes the unwanted speech signals. This process usually results in a speech signal where there is residual parts of background speech (where it has overlapped with wanted speech) (Armstrong, 2011).

7.3. STUDY STRENGTHS

7.3.1. Data driven methodology and triangulation

The first study of this thesis investigated the current need for patient-centred approaches to research and clinical practice by synthesising research evidence that looked at the ‘person with hearing loss in the context of their own individual lives. This focus was further strengthened by consideration of ‘third-party’ disability (communication partners). Synthesised studies included evidence that

was derived using qualitative as well as quantitative research methods over a long period of time (34 years).

A major strength in refining the domains of hearing loss frameworks is that the inductive methods undertaken in Chapter 2 were reviewed by deductive methods in Chapter 3 to be as inclusive as possible and to reduce observer bias, as well as taking a multidimensional approach to refine the frameworks. In total, five sources of information were used to develop the frameworks: research evidence pertaining to person with hearing loss- and communication partner-reported complaints of hearing loss, focus group data from hearing aid users and communication partners, and focus group data from hearing health professionals.

The use of member checking and triangulation as a quality check of the frameworks had many advantages. The triangulation approach to refining the frameworks was one that employed multiple techniques within a given method to collect and interpret the data ("within-method" triangulation). This method allowed for cross-checking with stakeholder groups to assess face-validity of the frameworks. The frameworks allowed stakeholders from the same population of interest that were of interest to included studies synthesised in the review.

The concept of scaling, which is a quantification of qualitative methods was undertaken as the final method of triangulation when stakeholder groups were asked to rank the domains of hearing loss in order of importance. Not only does it capture overlap in results by the use of multiple methods, but it also uncovers some unique variance which may have otherwise been missed by single methods. For example, whilst there was some extracted data pertaining to the subdomain 'listening to speech (unfamiliar talkers)', undisputable evidence for

this subdomain only emerged from the focus group with hearing aid users. Another advantage to the process of triangulation by the use of qualitative methods such as the focus group in study two, is that it elicits data to which other methods would be blind. For example, one of the questions asked to participants was to identify past experiences that relate to the domains depicted in the frameworks. This question allowed for participants to consider the domain in the context of their lives, and to respond with answers that were also contextual. The various approaches and research methods to the development and refinement of the frameworks generated a rich and comprehensive outlook on the impact of hearing loss on hearing-impaired individuals and their communication partner.

Furthermore, in order to identify agreement and also where the differences in perspectives to those depicted in the frameworks, the questions asked in the focus group were very explicit to identifying congruence; “Are you able to share experiences” and also differing perspectives; “Do you feel there is anything missing from the frameworks?”

The process of triangulation also allowed to unveil some unexpected results between the studies. For example, the subdomain ‘Social withdrawal’ was derived from the highest number of extracted data in the comprehensive review This subdomain and its umbrella domain ‘Social life’ were also relatable to all hearing aid users in the focus group. However, in the domains ranking survey, this domain did not appear in the top three most important ranked domains.

Thus far there has not been any research in the television viewing habits of hearing aid users, and their partner. Application of the survey developed for participants involved in study four to a wider population of interest (hearing aid users) made the methods much for robust and generalisable.

Given the broad spectrum of complaints associated with hearing loss it has been emphasised in recent years that hearing aids alone cannot augment all of the issues associated with hearing loss. As mentioned with TV and assistive listening devices, the research evidence use of any assistive listening devices among hearing loss and their benefit, is sparse. The accessibility of these devices to patients with hearing loss is unknown.

7.4. DIRECTIONS FOR FUTURE RESEARCH

7.4.1. Use of Domains of Hearing Loss Frameworks in Research

There are many ways in which the domains of hearing loss framework can be utilised for research purposes. An example of an application of the frameworks was the research described in studies four and five of the thesis. The subdomain “Raising the volume of the TV/radio” was identified as being an under researched, but important field of research. Whilst the framework and the data used to develop the subdomain identify that TV volume is a problem for couples where on partner has hearing loss, the extent of these difficulties and difference in volume in preference was unknown. Furthermore, there have not been any studies that have explored the use and potential benefits of assistive listening devices for the TV.

Another aspect of this subdomain that is also relatively under-researched is the preferred listening levels of hearing aid users and their partner whilst listening to the radio. Research into this area could identify whether the preferred listening levels differ for the radio compared to the TV, particularly since the radio consists of audio-content only.

A domain from DoHL-CP that resonated with all the participant in the focus group was ‘Role of communication partner’. The included studies that provided evidence for this domain all identified that partners often took on additional

responsibilities to accommodate or help their hearing-impaired. Future studies could explore the coping/communication strategies learned by communication partners. These studies could also explore those strategies adopted by people with hearing loss in couples and whether these strategies complement or confound each other.

Future research could also focus on how on well patients who have undergone aural rehabilitation feel that their rehabilitation has considered and addressed the domains depicted in the framework. Future research could also explore how well partners or family members who attend audiology appointments with feel the domains depicted in the DoHL-CP version of the framework are considered in at all, in their hearing impaired partner's rehabilitation. To gain further insight into the frameworks from a clinician point of view, future research could explore how many of the domains are considered and addressed during rehabilitation of a hearing-impaired patient.

The domain 'occupational' was a domain that was developed from a considerable amount of data from studies that explored the impact of hearing loss more generally (Solheim et al., 2011) or specifically on working life (Hetu et al., 1995). However, given the demographic of participants involved in the focus group and the domains ranking survey, the majority of participants had been diagnosed with hearing during retirement and therefore could not relate to this domain. Future research could explore experiences of hearing aid users who are still in employment, the difficulties they have/had due to hearing loss and if/how they have overcome these issues. With increasing focus toward assistive listening devices, future research explore the use of assistive listening devices at work to see if there are any potential benefits.

7.4.2. Understanding How to Optimise Listening Whilst Watching Television for Hearing Aid Users and their Significant Other

Given the stark difference in preferred TV volume between hearing aid users and their spouse/partner and the self-reported complaints of listening to the TV despite wearing hearing aids, it is clear therefore that steps must be taken in order to optimise the listening conditions for hearing aid users whilst watching TV, particularly since watching TV is known to be such an integral recreational activity among a lot of older people's daily life. To do this however, there remains several unanswered questions. Chapter 5 found that hearing aid users set the volume 6.3 dB of the non-hearing aid user spouse/partner. The TV volumes set by participants was very heterogeneous between each group and within each group. Therefore the disparity in volume preference between hearing aid users and non-hearing aid user couples is clear. What is unknown however, is how this compares to couples who have normal hearing and therefore the subsequent influence of hearing acuity on preferred volume.

Given the heterogeneity of hearing loss as well as the listening situations of watching TV in people's homes, there are therefore several factors that may influence the TV volume and the subsequent enjoyment of watching TV for hearing aid users and their spouse/partner. Ways to optimise this listening situations should be sought. This may result in positive self-reported outcomes from the hearing aid user as well as their spouse/partner. The current experimental set-up was fixed for all participants. The influence of factors such as TV size, speaker type and placement, distance of TV (speakers) should be explored to see the effect different arrangements have on preferred TV volume. Given the disparity between the perceived hearing aid benefit for watching TV from the hearing aid user perspective compared to the communication partner

perspective, future research could also look at the preferred TV volume of hearing-impaired individuals pre- and post- hearing aid provision.

Interestingly, the programme set at the loudest and quietest overall volume (Weather forecast and Wildlife documentary, respectively) was the same for both groups. However, this does not compare to the TV genres reported to be typically most troublesome for hearing aid users to listen to, as identified from the survey results in Chapter 6. To identify what aspects of these types of programmes hearing aid users struggle with specifically, future research could ask hearing aid users to rate the perceived sound quality of a range of different TV genres.

CHAPTER 8. APPENDICES

8.1. APPENDIX A

8.1.1. Study 1: Guidance material developed to assist with data extraction

Primary research question: "What are the domains reported by people with hearing loss and their communication partner(s) which correspond to the aspects of hearing loss that are a problem for them?"

Category	Field	Guidance
GENERAL INFORMATION	**Researcher**	Initials of researcher performing the data collection
	Publication number	This is the code number given to the record to uniquely identify the study. The first record will be numbered SR_001 each record extracted will be numbered sequentially following the preceding article.
	Author (Last name, first name)	All author's names must be stated
	Title of the study	This is the full title of the record as given by the authors.
	Type of publication	Select from: Journal article, report, conference paper, book chapter.
	Year of publication	Paper-publication data of record (not date of submission or acceptance of record)
	Country of Origin	Specify country where the study was conducted.
STUDY CHARACTERISTICS	**Study Design**	Select from: Treatment, Observational, Cross-sectional, Exploratory, Other (Please specify in free-field text (cell AN in excel spreadsheet).
	Is hearing the primary condition of interest?	Select Yes/No to indicate whether focus of record is reported-complaints is in relation to hearing loss.
	Primary method for collecting individual hearing loss complaints	Select Questionnaire, Focus Group, Interview.
	Specific questions asked	If method of obtaining complaints associated with hearing loss is an interview format, state questions asked to participants to attain information.
	Type of questions	Select from: open, closed, open and closed, not stated.
	Sample size (N analysed)	State number of participants analysed in final results (also state number of male/participants)

	Theoretical framework	If indicated, specify theoretical framework underpinning rationale of study
PARTICIPANT CHARACTERISTICS	**Mean age**	Specify mean age of participants included in study. If not stated, extract information regarding inclusive age (range) from inclusion/exclusion criteria.
	Age Range (m)	Age range of female participants
	Gender	Specify gender of participants. Select from male, female, male and female, not stated.
	Setting	Select from general public, non-clinical, occupational group, primary care service (GP practices), secondary care service (audiology/ hospital clinics), and residential care (nursing homes).
	Hearing Status	Including mean audiometric thresholds, description of hearing loss severity, etiology of hearing loss.
HEARING LOSS COMPLAINTS	**Patient domains**	This refers to the dimension of hearing loss the authors intend to measure. Provide wording given by the authors or re-phrase to appropriately reflect domain. Specify every identified domain in a new cell.
	Patient measures	This refers to the method used to obtain domains. If questionnaire, specify the name (and reference). If interview/focus group, specify the questions asked to participants if provided. Specify each measure in new cell adjacent to the domain of interest.
	Examples of patient domains	Provide quotes of the most commonly and/or most significant complaints of hearing loss stated in record. If not provided in the record, refer to results section and extract the complaints the authors identify as the most commonly occurring. If the complaints are not explicit, then the researcher conducting the data extraction must interpret and convey the information to reflect the corresponding domain.
	Perspective	Specify who complaint or domain of hearing loss is referring to. Specify whether complaint refers to “self” or refers to communication partner.
	Communication partner domains	Provide quotes of the most commonly and/or most significant complaints of hearing loss. If not provided in the record, refer to results section and extract the complaints the authors identify as the most commonly occurring. If the complaints are not explicit, then the researcher conducting the data extraction must interpret and convey the information to reflect the corresponding domain.

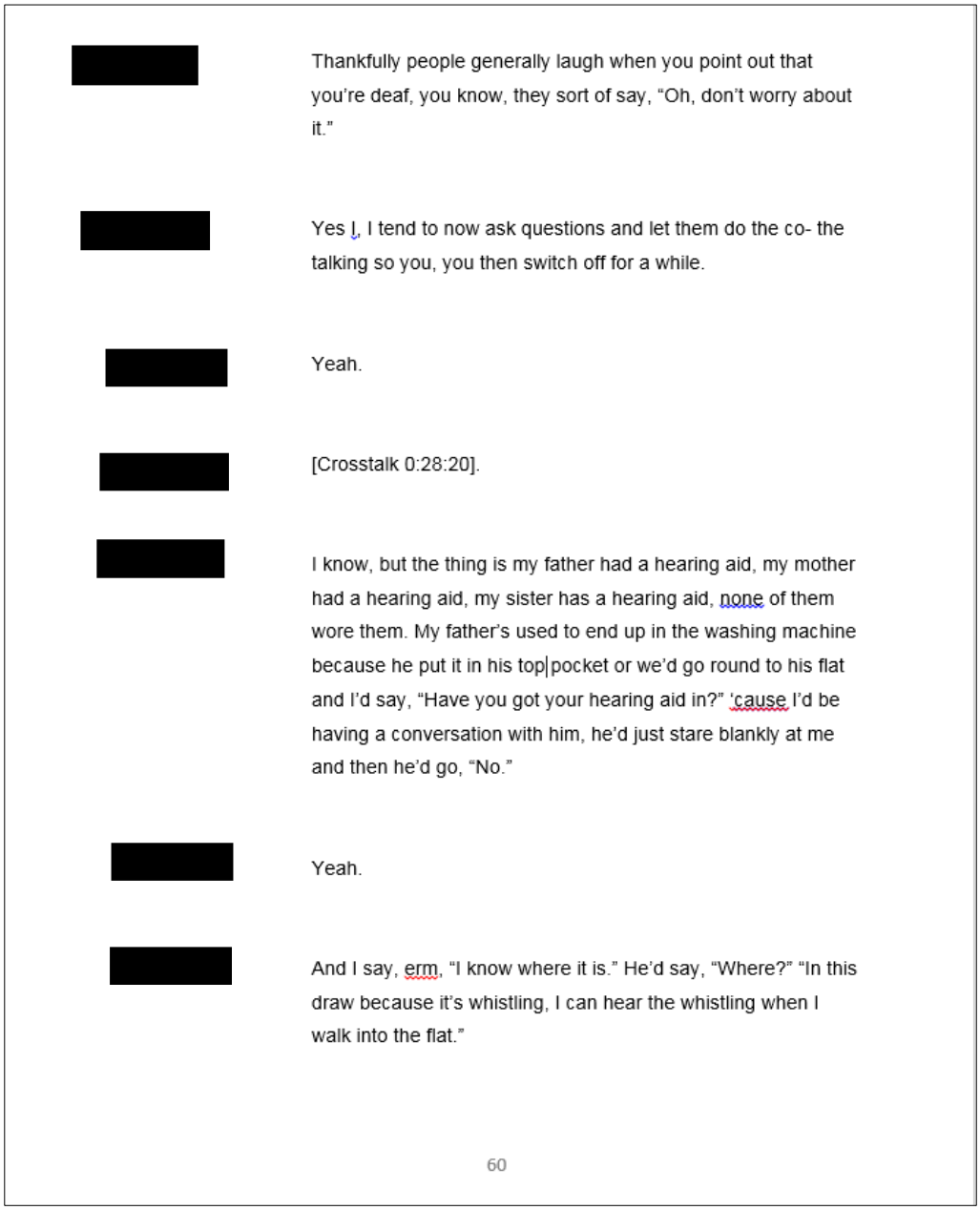
	Communication partner measures	This refers to the method used to obtain domains. If questionnaire, specify the name (and reference). If interview/focus group, specify the questions (column L) asked to participants if provided.
	Examples of communication partner domains	Provide quotes of the most commonly and/or most significant complaints of hearing loss. If not provided in the record, refer to results section and extract the complaints the authors identify as the most commonly occurring. If the complaints are not explicit, then the researcher conducting the data extraction must interpret and convey the information to reflect the corresponding domain.
	Perspective	Specify who complaint or domain of hearing loss is referring to. Specify whether complaint refers to “self” or refers to communication partner.

8.1.2. Study 1: Table of extracted data coded as miscellaneous

Domain/Complaint	Example
Environmental factors cause of difficulties	No example given
Self-rating handicap in working life	No example given
Noise at work	No example given
After a day at work, the hearing impaired person has the sensation that his ears are blocked	No example given
Travelling is difficult	No example given
Public services	Churches, banks, stores, government services, health services
Cinemas/ theatres/ chapels	No example given
Live speech	No example
One-sided speech	No example given
Temporal cues of speech	No example given
Communication is disrupted	"The communication is less personal"
Telephone marketing/sales	No example given
Meeting unfamiliar people	No example
Awareness of a hearing problem	Communication difficulties, Reactions to notification of these difficulties,
Tinnitus is very annoying	No example given
School playground duty	No example given
Public incidents	No example given
Dependence	No example given
Mobility	No example given
Maladaptive behaviour	No example given
Domestic life	No example given
Psychosocial	No example given
Learning and applying knowledge	No example given
Medical	No example given
General tasks and demands	No example given
Major life areas	No example given
Recreational providers reluctant to adapt activities to suit their needs	No example given
Medical	No example given
Activity limitation	No example given
Help-seeking	No example given
Background noise	"I am a very sensitive person when it comes to noise. I don't like noise…anywhere"
Physical or acoustical factors interfering	No example given
Background noise	No example given
Affected participation in daily life activities	No example given
Emotional withdrawal	No example given
Paranoid feelings	"I am often blamed for things that are just not my fault"
Blame	No example given
Difficulty in communicating the problem to clinician	No example given
Difficulty informing friends and co-workers about hearing loss	No example given
Decreased communicative performance	No example given

8.2. APPENDIX B

8.2.1. Hearing aid user focus group excerpt (unedited)



[redacted] Thankfully people generally laugh when you point out that you're deaf, you know, they sort of say, "Oh, don't worry about it."

[redacted] Yes I, I tend to now ask questions and let them do the co- the talking so you, you then switch off for a while.

[redacted] Yeah.

[redacted] [Crosstalk 0:28:20].

[redacted] I know, but the thing is my father had a hearing aid, my mother had a hearing aid, my sister has a hearing aid, none of them wore them. My father's used to end up in the washing machine because he put it in his top pocket or we'd go round to his flat and I'd say, "Have you got your hearing aid in?" 'cause I'd be having a conversation with him, he'd just stare blankly at me and then he'd go, "No."

[redacted] Yeah.

[redacted] And I say, erm, "I know where it is." He'd say, "Where?" "In this draw because it's whistling, I can hear the whistling when I walk into the flat."

60

[redacted] Yeah, yeah, yeah.

[redacted] But the, the trouble is, if you then do give up, and I have been in the same situation as you where you're sitting round a table, in a pub or something-

[redacted] Mhm, mhm.

[redacted] And people are having a big conversation, you can't join in because you can't actually hear.

[redacted] No.

[redacted] Even with the best will in the world and with the hearing aids I can't hear what's being said, so you tend to just sit there.

[redacted] Mhm.

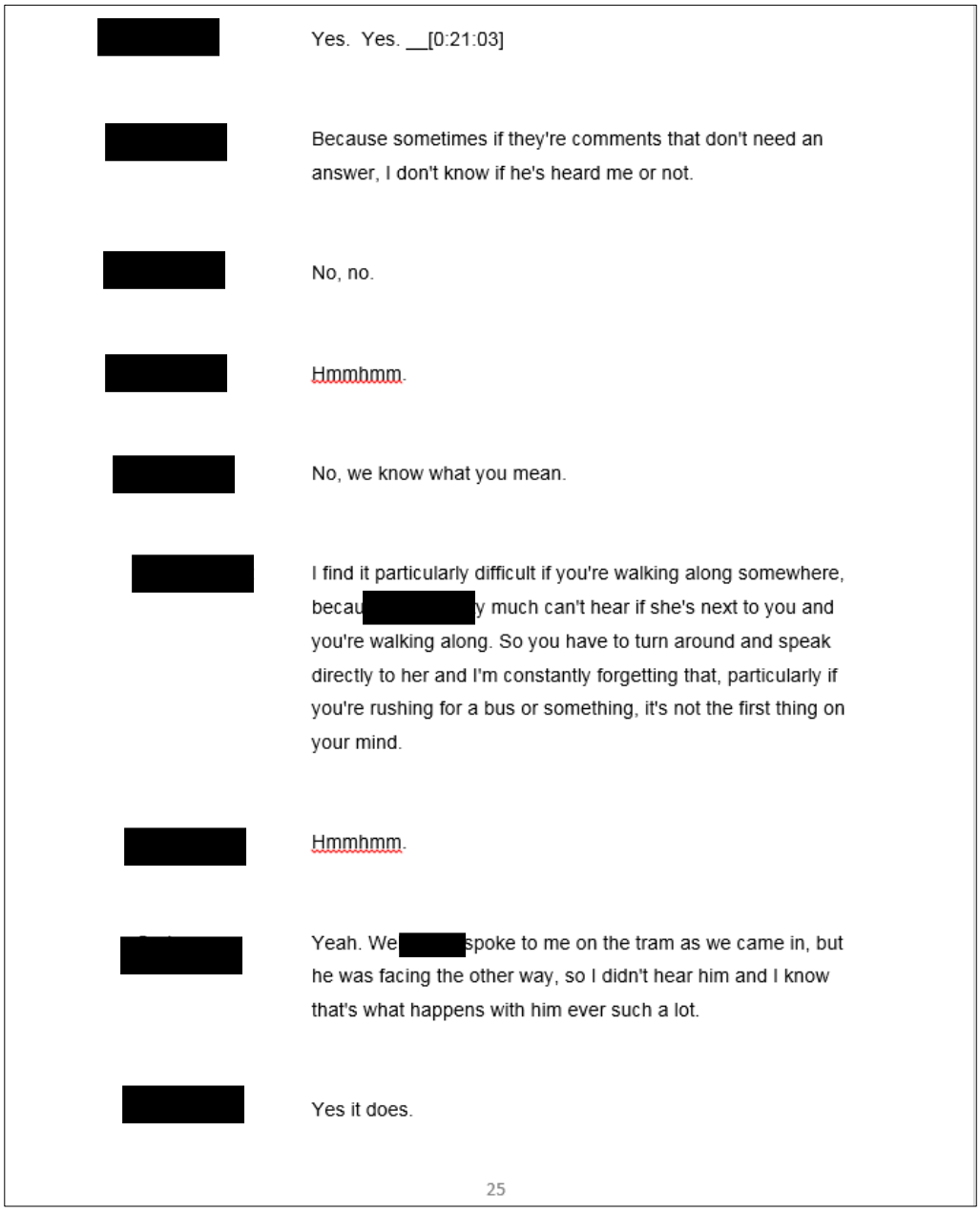
[redacted] And I think that's awful really.

[redacted] Yeah.

[redacted] Because you can't join in.

61

8.2.2. Communication partner focus group transcript excerpt (unedited)



[redacted] Yes. Yes. __[0:21:03]

[redacted] Because sometimes if they're comments that don't need an answer, I don't know if he's heard me or not.

[redacted] No, no.

[redacted] Hmmhmm.

[redacted] No, we know what you mean.

[redacted] I find it particularly difficult if you're walking along somewhere, becau[redacted]y much can't hear if she's next to you and you're walking along. So you have to turn around and speak directly to her and I'm constantly forgetting that, particularly if you're rushing for a bus or something, it's not the first thing on your mind.

[redacted] Hmmhmm.

[redacted] Yeah. We[redacted]spoke to me on the tram as we came in, but he was facing the other way, so I didn't hear him and I know that's what happens with him ever such a lot.

[redacted] Yes it does.

25

[redacted] So I have to make sure he's sort of paying attention to me before I speak to him.

[redacted] Hmmhmm. It sounds like on the whole your partners are successful hearing aid users. I'm just wondering whether any of you have any kind of thoughts or comments on some of these more, kind of, maybe negatively worded things?

[redacted] Well I don't know if you'd put stress down in that list but, erm, I find the variability of, or my perceived var- understanding of [redacted]ring loss quite stressful. Erm, we can be at home, [redacted] her hearing in, we're side by side and I can speak in a very quiet voice and Hiliary will hear every word clearly and correctly.

[redacted] Hmmhmm.

[redacted] We could be in a restaurant.

[redacted] Hmm.

[redacted] With, erm, hard floorboards and another party next to us.

[redacted] Hmm.

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8.2.3. Clinician transcript focus group excerpt (unedited)

Female 2:	If they're asking for repeats, and raising the volume of the television and the radio, they seem to, they seem to be that, their coping mechanisms as well, not necessarily…
Male:	Yeah, because the asking them to repeat, and the pleasure of listening to music, are different to, "Can you understand speech?" The, the, there's a different level in there, isn't there? There's a, in the pleasure of listening to music bit, there's a, erm, there's an emotional thing in there, as there is in asking people to repeat, because then you stop asking when you have to, you, you don't get the communication, because you stop asking, because it's embarrassing. But the rest of them, speech and communication in noise, is in the, in the one above, work, it's above, one-to-one, is that mentioned above? No, but it could be. Telephone is, group of talkers is.
Facilitator 1:	And, erm, so would it sort of, would it be a listening domain, or would it be a communication, or would it be comprehension?
Male:	Well, it depends what you want out of it, I think.
Facilitator 1:	Yeah.
Female 2:	You see I think, in, in some ways, the communication, I suppose the difficulty is, what we understand as communication, is that two-way process, is it about comprehension? Are you specifically looking for difficulties,

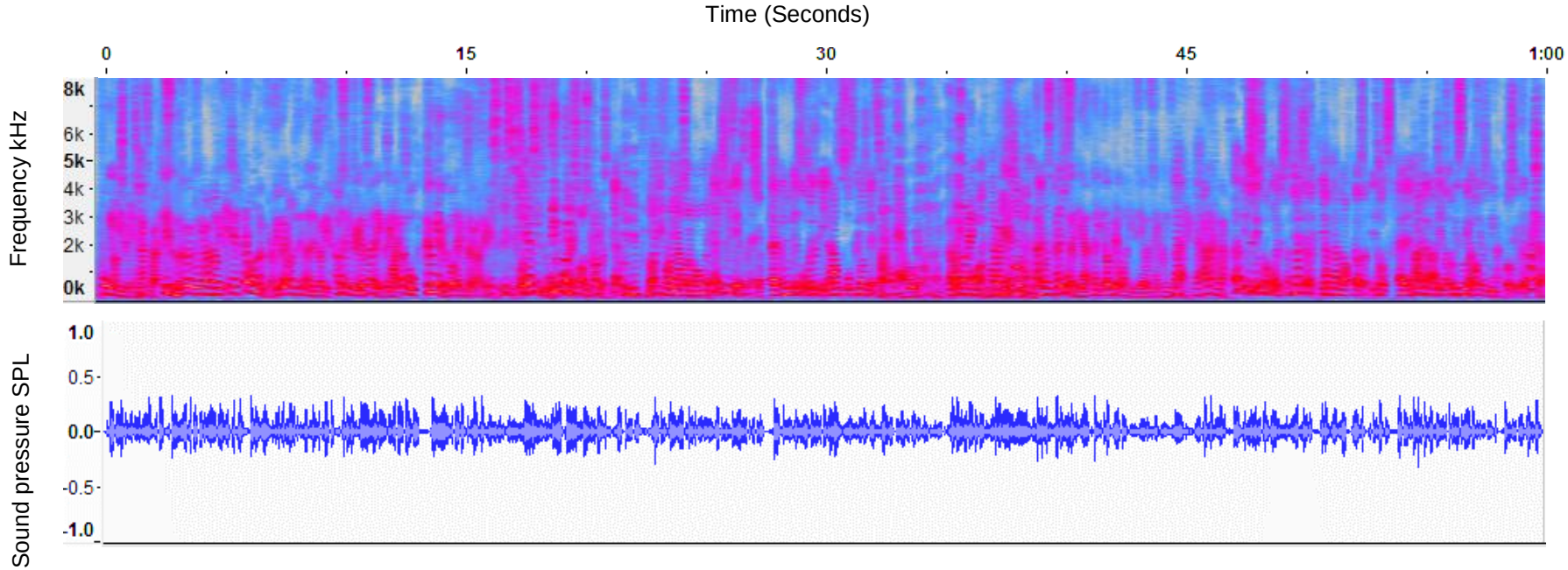
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	that people have in comprehending speech? Which says to me, that's the listening bit, whereas the communication bit is actually potentially more the impact, that that difficulty has. So I can see why you've separated them out.
Female 3:	Mmm, because you would deal with those on different levels, I'm assuming very much.
Female 2:	Yes, yes, I think you would, yeah.
Female 3:	So that's kind of how we'd need to think about combining that, is if you combine that, are you losing an element of how you would normally deal with that situation?
Female 2:	Yeah, yeah, so maybe it's not the, maybe the issue isn't that these have been separated out, and they don't need to be, but maybe it is that the listening isn't the right word.
Female 1:	Well, if they're accessing, for want of a better term, erm, you know, as I was, as I was reading through your list there, you, the way it's phrased, accessing speech in general, accessing speech at work, erm, that, that, it's just that the term listening implies some kind of, erm, active participation, in you having to glean some information from, erm, something that you're hearing. Erm, it's, it's, it's a really difficult word, because to, to us, it probably means more, than it would to the population of the people that they've, they've asked the questions on.

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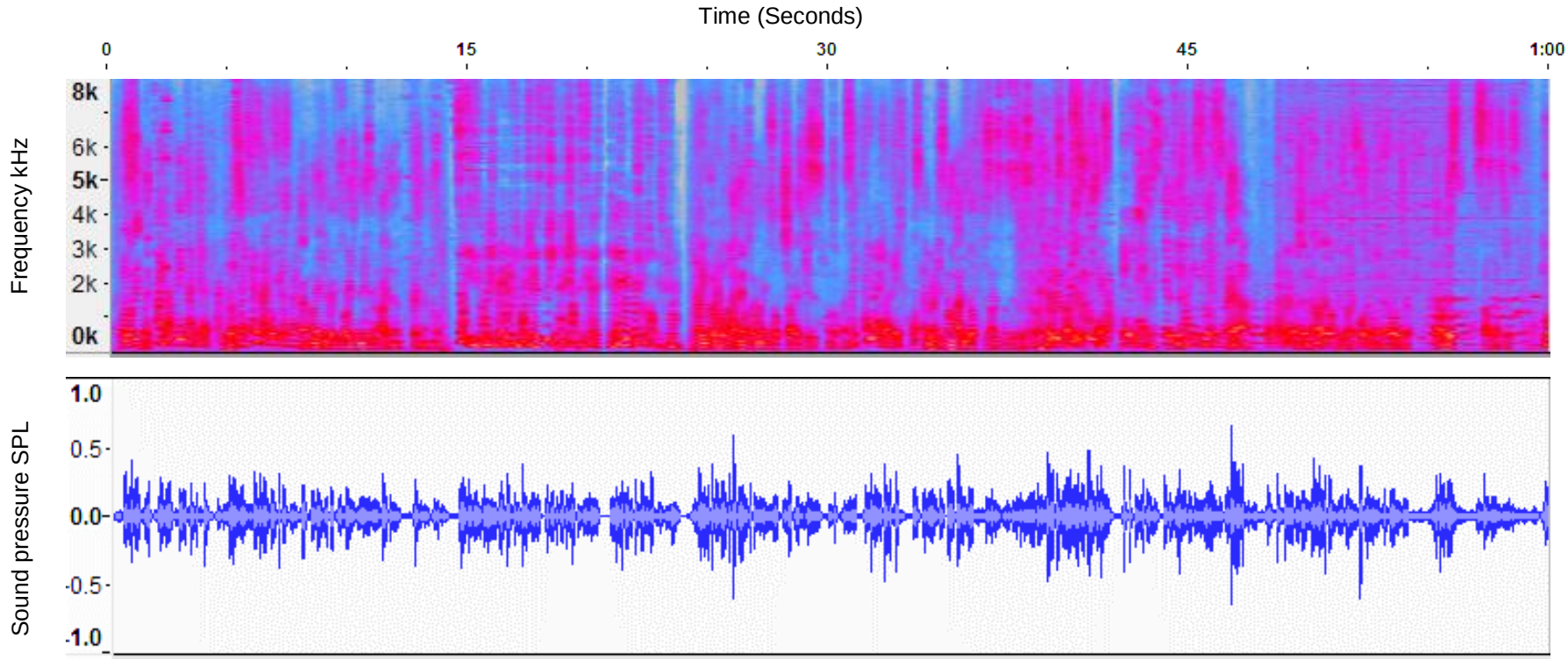
8.3. APPENDIX D

8.3.1. Frequency spectra for Daytime Interview Show (Clip 2a)



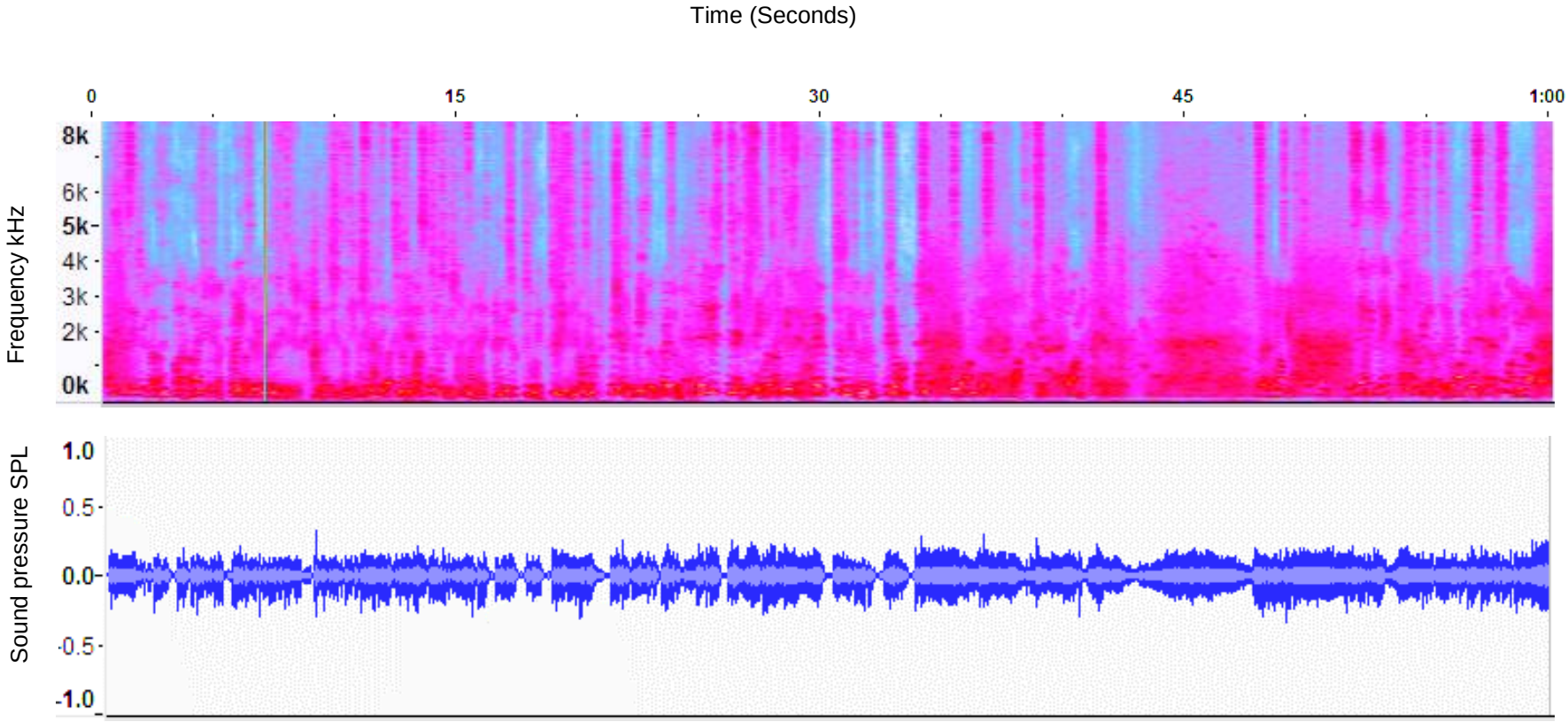
Taken from first minute of clip. Second graph shows waveform of same interval of clip

8.3.2. Frequency spectra for Cooking Show (Clip 3a)



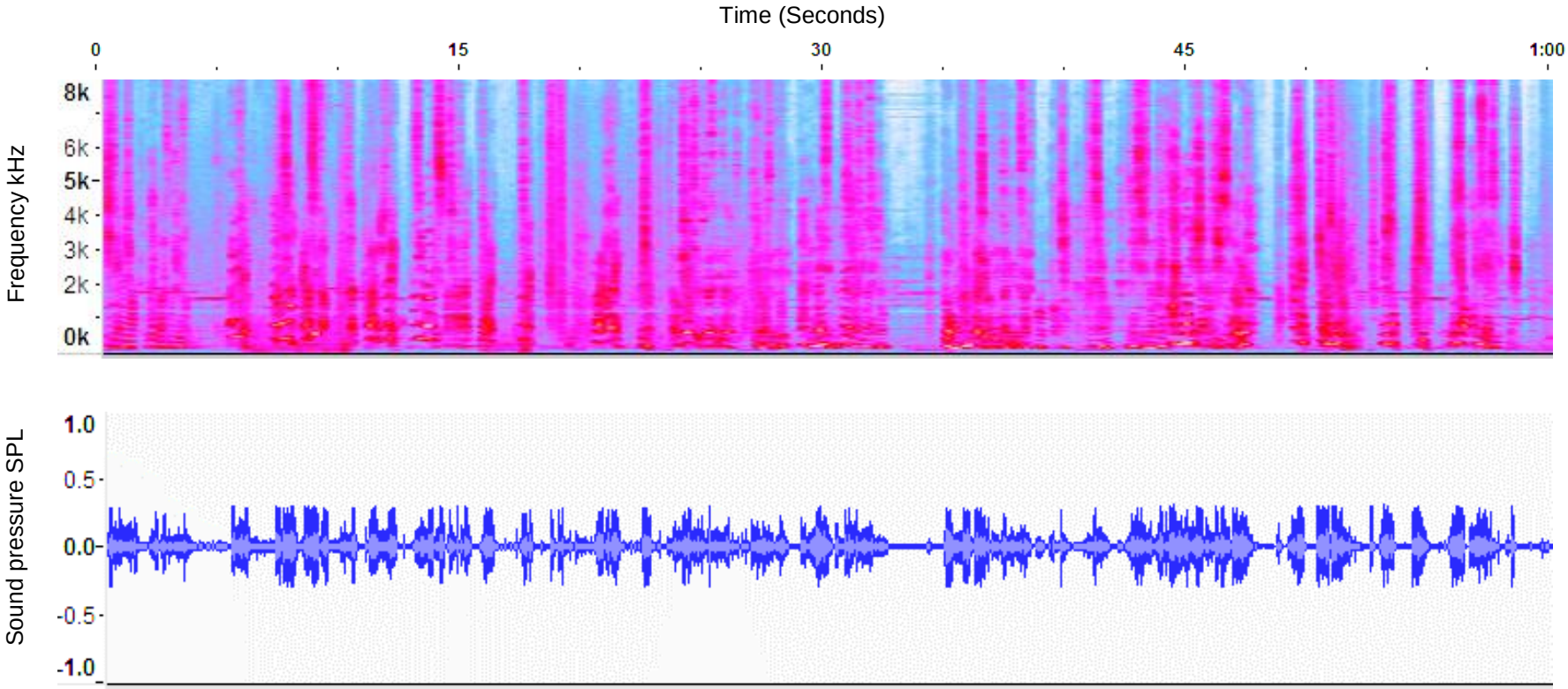
Taken from first minute of clip. Second graph shows waveform of same interval of clip

8.3.3. Frequency spectra for Cooking Show (Clip 3a)



Taken from first minute of clip. Second graph shows waveform of same interval of clip

8.3.4. Frequency spectra for Soap/Drama (Clip 6a)



Taken from first minute of clip. Second graph shows waveform of same interval of clip

8.3.5. Participant Information Sheet

Participant Information Sheet

NHS
National Institute for Health Research

The impact of hearing loss on television viewing

We invite you to take part in a research study

- Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve.
- Please take time to read the following information carefully. Discuss it with friends and relatives if you wish.
- You are free to decide whether or not to take part in this study. If you choose not to take part, this will not affect the standard of care you receive.
- Ask us if there is anything that is not clear or if you would like more information.

Important things that you need to know

- We are looking for participants who are hearing aid users and their spouse/partner.
- We want to get some insight into how hearing loss has affected the volume at which you and your spouse/partner watch television.
- We cannot promise the study will help you, but the information we get from this study will help improve our understanding about the impact that hearing loss has on television viewing experience.
- None of the tests involved in this study present any known risk or side effects.
- This study requires a visit as a couple, to the Hearing BRU for a single session for about two hours.
- **We will reimburse local travel (up to £15) and pay you £10 each for your time to complete the test session.**
- You can stop taking part in the study at any time.
- You will attend an appointment at the NIHR Nottingham Hearing Biomedical Research Unit (NHBRU), at Ropewalk House, Nottingham (city centre), NG1 5DU.

Nottingham Hearing Biomedical Research Unit



Contents

1 Why are we doing this study?
2 Why am I being asked to take part?
3 What will I need to do if I take part?
4 Will my results be kept confidential?
5 What will happen to the results?
6 Who is organising and funding the study?
7 Who has reviewed the study?
8 Who do I speak to if problems arise?
9 How to contact us
10 Where to find us

How to contact us

If you have any questions about this study, please talk to the study investigator: Miss Venessa Vas on 0115 823 2838 or email msxvv@Nottingham.ac.uk

1 Why are we doing this study?

Hearing loss is a highly common condition that affects one in six people in the UK alone. The consequences of hearing loss are wide-ranging, and often extend to partners and family members.

The aim of this study is to investigate what your preferred listening volume is whilst watching television, and what the preferred volume is for your partner's as well. We would also like to investigate if and how your television viewing has changed due to hearing loss.

What is the impact of hearing loss?

Hearing loss can have a significant impact on various aspects of an individual's life. A recently conducted study here at the BRU found that hearing loss can affect overall television viewing experience, due to having to constantly alter the volume or not being able to hear the dialogue. These difficulties have also been reported to affect a hearing aid user's partner/spouse's experience of television viewing. We would like to measure the extent of these volume changes.

2 Why am I being asked to take part?

You have been invited to take part in the study because you are a hearing aid user, or you are the partner/spouse of someone who is:

You are entitled to participate if you:

- Are a hearing aid user OR the partner/spouse of a hearing aid user
- Able to give informed consent
- First language is English or good understanding of English (video clips will consist of English words and sentences)
- Hearing aid user is aged 18 years or older (no upper age limit)
- Able to view television clips on a television screen (wearing glasses is okay)

3 What will I need to do if I take part?

You and your partner/spouse will be required to attend a single test session at NHBRU.

We would like to measure the volume at which you and your partner prefer to watch television whilst watching a series of short pre-selected television clips consisting of British documentaries, film, weather broadcasts and the news. We will ask you to watch the television clips separately and set the volume and then come together to view some more TV segments and set the preferred volume together.

You will both be required to complete a series of other listening tasks and questionnaires, including:

- A hearing test to assess hearing. If the hearing tests indicate anything of medical concern we will give you full details for you to take to your GP.
- An online survey to find out about your television viewing habits.
- A short questionnaire to assess your listening ability in different environments and to gather information regarding your daily television viewing.
- An online survey relating to the impact of hearing loss on everyday life.

The overall session is about 2 hours in total, with short breaks if required.

4 Will my results be kept confidential?

All of the information that we collect will be kept strictly confidential and will be stored at the Nottingham Hearing Biomedical Research Unit.

Any data that is stored electronically will be password protected. Data will be made anonymous using unique participant identity codes that will not include your name or address.

Only the study investigator (Miss Venessa Vas) and the chief investigator (Prof. Deborah Hall) will have access to your information. Very occasionally, regulatory authorities or ethics committees ask for access so that they can check that the study is being carried out correctly.

When we report the results, all individual test results will be anonymised.

5 What will happen to the results?

If you ask for it, we would be willing to provide you with a summary of your personal results. This may take a little while after your session, as we will need to score all of the test results and prepare the summary.

The overall results of the study will be presented at national and international conferences.

We will also publish the results in scientific journals. A copy of this can be mailed out to you in the post.

6 Organising and funding the study?

The research is organised by the Nottingham Hearing Biomedical Research Unit.

Miss Venessa Vas, a PhD student and audiologist is managing the study.

7 Who has reviewed the study?

All research in the University of Nottingham is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by :

University of Medicine and Health Sciences Research Ethics Committee

8 Who do I speak to if problems arise?

Our staff always try to conduct the research in a way that is caring and respectful.

If you have a concern about any aspect of this study, you should contact the Chief investigator e-mail: deborah.hall@nottingham.ac.uk. The full contact details of the research team are given at the end of this information sheet.

If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk.

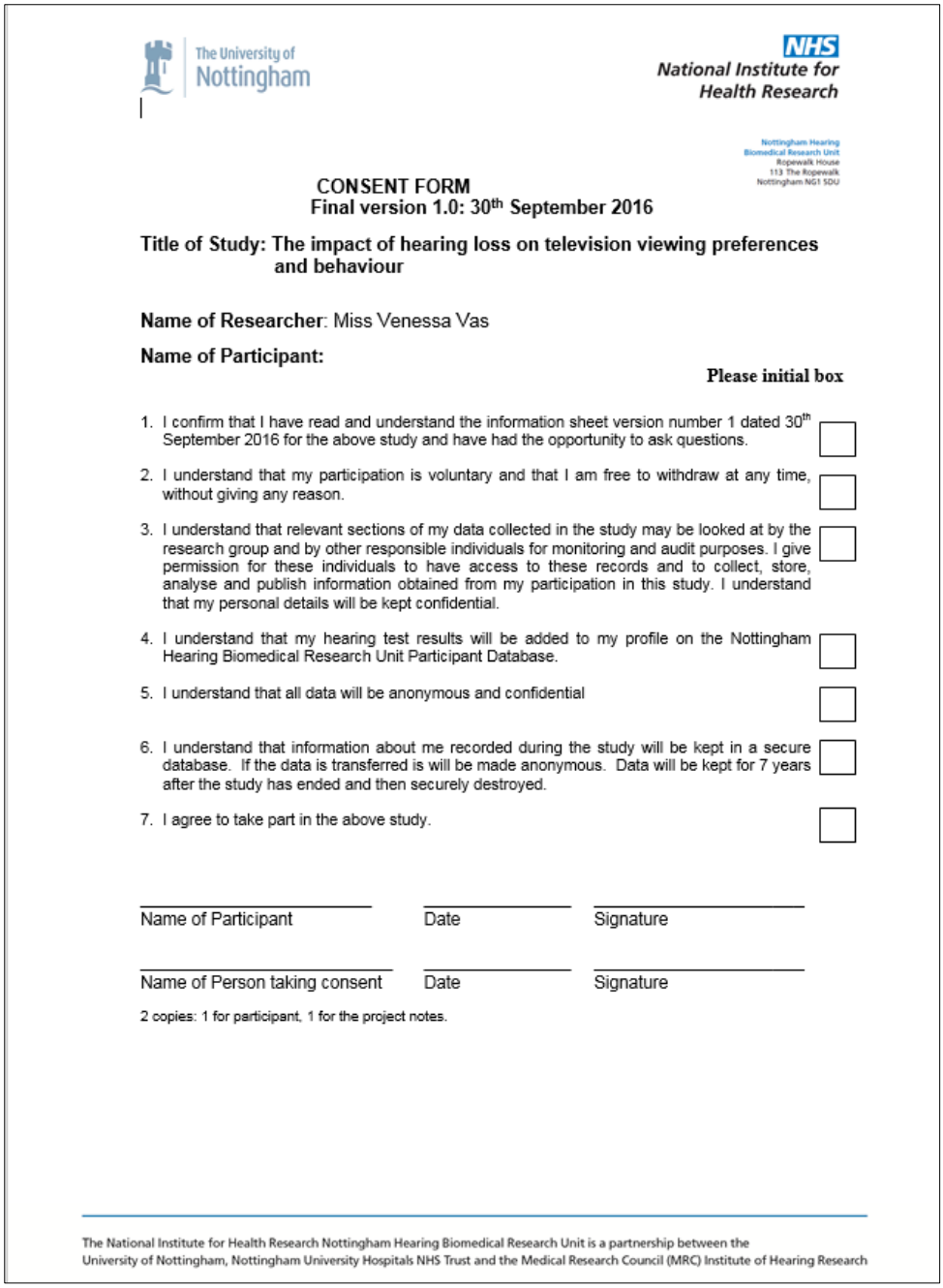
9 How to contact us

If you have questions and would like to discuss the research further, please contact Miss Venessa Vas:

Tel: 0115 823 2838
Email : msxvv@nottingham.ac.uk



8.3.6. Participant Consent form



The University of Nottingham

NHS National Institute for Health Research

Nottingham Hearing Biomedical Research Unit
Ropewalk House
113 The Ropewalk
Nottingham NG1 5DU

CONSENT FORM
Final version 1.0: 30th September 2016

Title of Study: The impact of hearing loss on television viewing preferences and behaviour

Name of Researcher: Miss Venessa Vas

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1 dated 30th September 2016 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that my hearing test results will be added to my profile on the Nottingham Hearing Biomedical Research Unit Participant Database. ☐
5. I understand that all data will be anonymous and confidential ☐
6. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

The National Institute for Health Research Nottingham Hearing Biomedical Research Unit is a partnership between the University of Nottingham, Nottingham University Hospitals NHS Trust and the Medical Research Council (MRC) Institute of Hearing Research

8.3.7. Recall questions that appeared at the end of each clip

Clip	Question	Answer option
1a	There will be a mixture of rain and sunny spells	True/False/I don't know
1b	The forecast predicts rain for the rest of the week	True/False/I don't know
2a	Nadiya talks about her new cookbook	True/False/I don't know
2b	Nadiya shows us how to make brownies	True/False/I don't know
3a	Mary likes Selasi's top	True/False/I don't know
3b	The bakers are making pastry	True/False/I don't know
4a	The Drongo bird tricks the meerkats	True/False/I don't know
4b	The Drongo bird gets the food in the end	True/False/I don't know
5a	Michael jokes about an eye test	True/False/I don't know
5b	Michael says he needs glasses	True/False/I don't know
6a	Two ladies were sitting in a café having a chat	True/False/I don't know
6b	Two ladies are arguing with each other	True/False/I don't know

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